Development of a person-centred, theory-based self-management intervention specific to young adults with chronic kidney disease.

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Summary (Abstract)

Chronic Kidney Disease (CKD) is a rapidly increasing health concern. Healthcare interventions, including self-management interventions (SMIs), can save thousands of lives between now and 2033 (Kidney Research, 2023). CKD management is complex, requiring life-long modifications, especially for young adults (YAs) who simultaneously undergo a major life transition. However, support for this vulnerable group is lacking and more research is needed to understand how CKD affects their lives in all aspects. This multi-phase study aimed to review the literature to establish key elements of the existing CKD SMIs (Phase 1) and identify gaps through the collection of quantitative and qualitative data (Phase 2), to inform the development of an appropriate SMI for YAs (aged 18-35 years old) with CKD (all stages), guided by French et al.' (2012) four-step approach (Phase 3). The literature review identified a lack of personalised, theory-based interventions and emphasised the potential of SMIs in improving self-efficacy compared to usual care. The quantitative (questionnaire study) and qualitative (semi-structured interviews) syntheses revealed a strong agreement on the unmet needs, social factors, psychological disorders, and inconsistent care experienced by YAs, based on their experience and those who look after them. The differences between the two analyses highlighted the complexity of self-managing CKD, emphasising the importance of understanding the various factors that influence it. Finally, the intervention development phase resulted in highly personalised to the unique needs of the target population, theory-based behavioural SMI enhancing YAs' participation in social activities by improving their communication and self-advocacy skills, enabling them to articulate needs, preferences, and concerns, navigate social perceptions and influences, and seek emotional support when required. This novel intervention holds promise, offering a conceptual basis for understanding how it may operate, however, its future implication and evaluation are necessary to assess its feasibility in real-world settings and capture changes over time.

Declarations and Statements

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed: Paula Krawiec [redacted] (candidate)
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STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s).

Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

Signed: Paula Krawiec [redacted] (candidate)
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STATEMENT 2

I hereby give consent for my thesis, if accepted for a research degree, to be made available for electronic sharing and for inter-library loan, and for the title and summary to be made available to outside organisations.

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Keywords

Chronic Kidney Disease; young adults; theory-based self-management interventions; person-centred care; self-efficacy

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List of Abbreviations

AIHW	Australian Institute of Health and Welfare
AKI	Acute Kidney Injury
APA	American Psychological Association
APEASE	Acceptability, Practicability, Effectiveness, Affordability, Side-Effects, and Equity
AUDIT-C	Alcohol Use Disorders Identification Test Consumption
BAP	Brief Action Planning
BCTs	Behaviour Change Techniques
BCW	Behaviour Change Wheel
BP	Blood Pressure
CCM	Chronic Care Model
CDSMP	Chronic Disease Self-Management Programme
CG	Control Group
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CKD	Chronic Kidney Disease
CKD-SMKT	Chronic Kidney Disease Self-Management Knowledge Tool
COM-B	Capability, Opportunity, Motivation-Behaviour
CVUHB	Cardiff and Vale University Health Board
eGFR	estimated Glomerular Filtration Rate
ESKD	End-Stage Kidney Disease
GRADE	Grading of Recommendations Assessment, Development and Evaluation
GSR	Government Social Research
HADS	Hospital Anxiety and Depression Scale
HAPA	Health Action Process Approach
HCP	Healthcare Professional
HD	Haemodialysis
HRQoL	Health-Related Quality of Life
IDWG	Interdialytic Weight Gain
IG	Intervention Group
IPAQ	International Physical Activity Questionnaire
IQR	Interquartile Range
KDIGO	Kidney Disease: Improving Global Outcomes
KRT	Kidney Replacement Therapy
LTC	Long-Term Condition
MCS	Mental Component Score
MDT	Multidisciplinary Team
MeSH	Medical Subject Headings
MHD	Maintenance Haemodialysis
MI	Motivational Interviewing
MoAs	Mechanisms of Action
MRC	Medical Research Council
NHS	National Health Service
PAM	Patient Activation Measure
PCC	Person-Centred Care
PCS	Physical Component Score

PD	Pre-Dialysis
PEER	Patient Experience and Evaluation in Research
PIH	Partners In Health
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QoL	Quality of Life
RCT	Randomised Controlled Trial
REA	Rapid Evidence Assessment
RoB	Risk of Bias
RRMG	Rapid Reviews Methods Group
SCDT	Self-Care Deficit Theory
SCT	Social Cognitive Theory
SEMCD	Self-Efficacy for Managing Chronic Disease
SES	Socio-Economic Status
SF 12	Short Form Health Survey-12-Items
SMART	Specific, Measurable, Achievable, Realistic, and Timely
SMI	Self-Management Intervention
SMS	Self-Management Support
SREBQ	Self-Regulation of Eating Behaviour Questionnaire
ST	Staff
TA	Thematic Analysis
TATT	Theory and Techniques Tool
TDF	Theoretical Domains Framework
TIDieR	Template for Intervention Description and Replication
TTM	Trans-Theoretical Model
UK	United Kingdom
WHO	World Health Organisation
YA	Young Adult

Chapter 1: Introduction

1.1 Introduction and Background

This thesis examines a multi-phase study involving three phases. Phase 1 involves a systematic literature review to establish the key elements of chronic kidney disease (CKD) self-management interventions (SMIs) identified in the existing literature. Phase 2 outlines the gaps in SMIs for young adults (aged 18-35 years old; collectively referred to as young adults or YAs in this thesis) living with CKD stages 1-5, which need to be addressed through the collection of quantitative (part 1, questionnaire-based study) and qualitative (part 2, semi-structured interviews) data. Finally, phase 3 involves the development of a person-centred, theory-based SMI for YAs with CKD, based on findings from phases 1 and 2. This Chapter begins with the background and introduction to the topic relevant to the present research.

Data from 2022 reported that there are 26 million individuals in England with at least one long-term condition (LTC), such as coronary heart disease, diabetes, asthma, or CKD (Stagg et al., 2022). LTCs are recognised as a health issue that cannot presently be cured, however, they can be managed through medications, lifestyle changes, and various forms of therapy. CKD remains a global concern and is rated as one of the top 10 chronic illnesses. Its increasing prevalence is expected to continue (Levin et al., 2017; World Health Organisation; WHO, 2013), varying across diverse socioeconomic clusters (Webster, Nagler, Morton, & Masson, 2017). This is partly a consequence of the growing prevalence of hypertension and diabetes in developed countries (Jager & Fraser, 2017; National Kidney Foundation, 2010; Radhakrishnan et al., 2014). Whereas, unhygienic surroundings, a high number of transferrable diseases, and poor medical care significantly contribute to the evolution of CKD in developing countries (Ayodele & Alebiosu, 2010). Data from 2019 proposed the estimated CKD prevalence as 13.4 percent globally (Lv & Zhang, 2019). CKD remains a leading cause of mortality and morbidity and it can place a significant burden on those who suffer from the disease (Almutary, Bonner, & Douglas, 2013), their families, society, and healthcare systems (Bello et al., 2017; Braun, Sood, Hogue, Lieberman, & Copley-Merriman, 2012; Wang, Vilme, Maciejewski, & Boulware, 2016; WHO, 2016).

Additionally, Neinstein and Irwin (2013) suggested that YAs (defined as individuals between their early adulthood and midlife adulthood) are worse off than adolescents or older adults on a wide range of health indicators, with those who live with CKD being predominantly vulnerable (Hamilton, Casula, Ben-Shlomo, Caskey, & Inward, 2018). For instance, kidney replacement therapies (KRTs) have largely been improving since the 1990s (Gillen et al., 2008), and currently, most YAs in the United Kingdom (UK; over 70%) on KRT have a kidney transplant. However, in comparison with both children and older adults, those YAs who receive kidney transplants are in increased jeopardy of transplant failure, also known as graft loss (Bobanga et al., 2015; van Arendonk et al., 2013). This is thought to be a result of poor adherence to immunosuppressive treatment (Ferris et al., 2015, Foster, 2015). Poor adherence to treatment (including, medication obedience, clinic visits, and regular blood monitoring) in YAs has been reported across a wide range of chronic conditions, such as rheumatologic illnesses, diabetes, and organ transplantation (Crowley, Wolfe, Lock, & McKee, 2011; Nakhla, Daneman, Paradis, & Guttemann, 2009). Treatment non-adherence is prevalent among 35-61 percent of adolescents and YAs diagnosed with CKD/ end-stage kidney disease (ESKD; Pruette et al., 2019), and it serves as a primary predictor for graft loss or mortality following paediatric renal transplantation (Gajardo et al., 2021).

Evidence suggests that transplant failure in YAs is mainly caused by non-compliance to medical treatment related to poor understanding of the treatment and outcome recognition (Akchurin, Melamed, Hashim, Kaskel, & Del Rio, 2014). This places YAs at an increased risk of mortality and morbidity (Smith & Schuman, 2005), with the mortality rate being around 30 times higher compared to healthy YAs (Saran et al., 2015). Compared to older adults with CKD, the long-term outcomes of kidney transplants in YAs are significantly worse (Rianthavorn & Ettenger, 2005). Additionally, it has been established that YAs living with chronic conditions in rural settings encounter additional challenges including access to services, suitability of care, convenience, and engagement (Robards et al., 2019).

Several studies reported that in YAs, CKD, KRT and/or transplant failure has an impact on their identity, body image, quality of life (QoL), mental health, career, social life, relationships and education (Kim & Choi, 2016; Kuh, Cooper, Hardy, Richards, & Ben-Shlomo, 2013; Lewis & Arber, 2015; Lewis & Marks, 2014; Mellerio et al., 2014; Murray, Dobbels, Lonsdale, & Harden, 2014; Neul, Minard, Currier, & Goldstein, 2013; Reid, Seymour, & Jones, 2016; Tong et al., 2013). Moreover, compared to older adults, the challenges of CKD and its treatment not only disengage YAs from their social life, but also hinder their developmental path of individualisation, independence, and maturation (Ferris, Gipson, Kimmel, & Eggers, 2006). According to Bell (2007), as a consequence of the undermined self-identity and self-perception in YAs who suffer from CKD, they typically develop psychological defences, which can be apparent as withdrawal, anger, depression, and lack of effective communication with their healthcare providers.

Those who look after YAs with CKD are also affected, as they take on the burden of the disease. Research showed that those who informally look after a friend or family member with CKD experience harmful effects on their health (Legg, Weir, Langhorne, Smith, & Stott, 2013). Caregivers of YAs with CKD experience financial stress, greater levels of psychological distress, with 30-50 percent reporting symptoms of anxiety or depression (Mahmoud, Saad, Abdelhamid, & El Hawary, 2021; Shukri, Mustofai, Yasin, & Tuan Hadi, 2020), reduced QoL (Medway et al., 2015), and consequently lower socioeconomic status (SES) (Tsai, Liu, Tsai, & Chou, 2006). Therefore, those who care for YAs with CKD should also be supported, which consequently will benefit YAs (National Health Service; NHS Kidney Care, 2013).

Furthermore, another challenging period for YAs with CKD is the transition process from paediatric services (where their parents/guardians had the main input) to adult services (where they have to start taking ownership of their condition), which is often managed poorly and as a result may have adverse health consequences (Watson et al., 2011). As established above, graft failure is a major risk in young kidney transplants and any healthcare transition (e.g., change in healthcare providers and environment) can result in a further increased risk (Garment, Lee, Harris, & Philips-Caesar, 2013; King et al., 2013; Koenig, Maguen, Daley, Cohen, & Seal, 2013). However, this transition process is unique as YAs who undergo this transition at the same time undergo a major life transition, namely the transition from childhood to adulthood. This period is known as “emerging adulthood” (Arnett, 2000), in which YAs, typically between 18 and 25 years old, become independent. It has been reported that in the UK, almost 35 percent of YAs (eight out of 20 transitioning YAs) experienced a transplant failure within three years of transitioning to adult care (Harden et al., 2012). One of the main barriers to a successful transition is linking the diverse cultures of care, including paediatric, youth, and adulthood (McDonagh & Viner, 2006).

Over a decade ago, Viner (1999) stated that YAs should not transition to adult services until they have been provided with the necessary skills to successfully function once in the adult centre. Similarly, over two decades ago, Cameron (1985) recognised the necessity for continued CKD paediatric care in adult services, and he further restated this in 2001 by highlighting that no improvement in this area had been made (Cameron, 2001). Since then, several studies on transition have been reported, however, very few have focused on CKD, and at present, there is still an evidence-based research gap. Previous research examining the shift of responsibility has primarily focused on the most common childhood/ YAs LTCs such as diabetes and asthma (Nightingale, McHugh, Kirk, & Swallow, 2019). Thus, more studies, particularly long-term follow-up research with a larger sample size, integrating paediatric and adult care with input from the multidisciplinary team (MDT), and condition-specific approaches are needed (Coyne, Hallowell, & Thompson, 2017; Forbes et al., 2014; Nightingale et al, 2019). Evidence from successful models of transition of other chronic conditions (e.g., rheumatological diseases, e.g., Tucker & Cabral, 2005; or cystic fibrosis, e.g., Bronheim et al., 2006) could be a good starting point to adapt, assess, and implement these models for YAs with CKD.

Presently, one of the successful programmes to aid the transition process for YAs with LTCs is the ready-steady-go programme proposed by Nagra and colleagues in 2015 and recently employed in the UK (Nagra, McGinnity, Davies, & Salmon, 2015). The ready-steady-go is a structured (but adjustable when required) programme that encourages involvement from YAs (as young as 11 years old) and their caregivers in the transition process at numerous key stages. The main principle of the whole programme is to empower YAs to take control of their disease and lives and to provide them with the necessary knowledge and skills to successfully manage their healthcare (in both, paediatric and adult services) with confidence. It also allows for monitoring the progress of self-management skills in YAs, and it can be personalised to their requirements, for example for individuals with developmental delay, decreased coping skills, and impaired working memory. These have been frequently recognised in individuals with later stages of CKD, on dialysis and/or after transplant (Francis, Johnson, Craig, & Wong, 2018). This programme was discussed in the current interview study and reported in Chapter 7.

Finally, many researchers agreed that as a result of emerging adulthood and continuing critical brain development in puberty, YAs require special attention from healthcare professionals (HCPs) (Chaturvedi, Jones, Walker, & Sawyer, 2009). Young adulthood is a distinct period recognised by impulsive and risk-taking behaviours and non-compliance problems, which make it difficult for both YAs and HCPs (Dobbels et al., 2010; Foster et al., 2011). Therefore, it is evident that this age group need support to self-manage their condition daily. However, there is a noticeable gap in the CKD literature concerning possible intervention strategies to support YAs (Jennette & Ferris, 2006), and more research is required to understand how CKD affects their lives in all aspects (Bailey et al., 2018).

The aim of this Chapter is first to describe the physical, social, and psychological impact of CKD and its definition and classification, incidence and prevalence, risk factors and causes, comorbidities and symptoms, management and treatment, as well as factors influencing CKD management (section 1.2). Next, the research outline, aims, questions, and objectives (section 1.3), and the significance of the current research (section 1.4) are discussed. Finally, the Chapter summary and thesis outline are provided in section 1.5.

1.2 Chronic Kidney Disease (CKD) and Its Physical, Social, and Psychological Impact

1.2.1 Understanding CKD: Definition and Classification

Over the past few years, the definition of kidney disease has changed. In 2013, the UK adaptation of the United States (US) Kidney Disease Quality Outcomes Initiative defined CKD as having five stages of renal impairment (Kidney Disease: Improving Global Outcomes; KDIGO, 2013; see Table 1.1 below for stages of CKD). CKD is typically classified by an estimated glomerular filtration rate (eGFR) that is less than 60mL/min/1.73m^3 for a period of longer than three months, with or without the occurrence of kidney impairment (Bonner, 2012; National Institute for Health and Care Excellence, 2021). CKD may also be classified by functional and structural abnormalities of the kidney, also for a period of longer than three months, as pathological abnormalities and signs of kidney impairment that may or may not reduce eGFR (KDIGO, 2013). Kidney impairment is evidenced by the continuing occurrence of haematuria, albuminuria, proteinuria, or structural abnormalities distinguished by imaging tests (Australian Institute of Health and Welfare; AIHW, 2014). CKD develops gradually and damagingly over months or years (Webster et al., 2017).

Table 1.1

Stages of Chronic Kidney Disease (CKD)

CKD stage	eGFR (mL/min/1.73m^3)	Description
1	≥90	Normal or near-normal
2	60-89	Mild
3a	45-59	Mild to moderate reduction in eGFR
3b	30-44	Moderate to severe reduction in eGFR
4	15-29	Severe reduction in renal function
5	<15	ESKD

Adapted from Kidney Health Australia (2015a). *eGFR* estimated Glomerular Filtration Rate; *ESKD* End-Stage Kidney Disease.

The five stages of renal impairment consider stages 1-3a/b as early-CKD stages and stages 4-5 as late-CKD stages (Inker et al., 2014). Stage 1 is defined as normal or near normal (eGFR higher or equal to 90mL/min/1.73m^3), and stage 2 is defined as mild (eGFR decrease between 60-89mL/min/1.73m^3) (Kidney Health Australia, 2015a). However, both stages cannot be classified as CKD without the signs of kidney impairment which include haematuria, albuminuria, proteinuria, or structural abnormalities. CKD stage 3 is subdivided into two stages: stage 3a, which is described as mild to moderate reduction in eGFR (between 45-59mL/min/1.73m^3), and stage 3b is described as moderate to severe reduction in eGFR (between 30-44mL/min/1.73m^3). CKD stage 4 is described as a severe reduction in renal function (eGFR between 15-29mL/min/1.73m^3), and the final CKD stage 5, also defined as ESKD, is identified by eGFR less than 15mL/min/1.73m^3. Commonly, in stage 5, when eGFR is lower than 10mL/min/1.73m^3 and when kidney function is unable to sustain life, KRTs are needed (Dring & Hipkiss, 2015). The symptoms that are present in addition to the underlying pathology are described in section 1.2.4.

1.2.2 Importance of Psychological Factors in CKD

CKD is a significant, progressively increasing, global public health concern, with an estimated worldwide prevalence of around 10 percent (GBD CKD Collaboration, 2020). The recent data from 2023 recognises CKD (all stages) as an important health concern in the UK, affecting approximately 7.19 million people (12.8% of the UK population aged 16 years or older), and it is projected that by 2033 this will increase to 7.61 million individuals (Kidney Research UK, 2023). In Wales, with a population of around three million, CKD affects six to eight percent of the population (approximately 200,000 individuals) (Network WRC, 2016). Almost 3000 individuals are being treated for kidney failure in Wales, and one in five people admitted to Welsh hospitals will have a serious problem with their kidneys as part of their disease (Kidney Research UK, 2017). CKD individuals are at increased risk of having a stroke, heart attack, and kidney failure which requires dialysis or a transplant, and Kidney Research UK (2023) further reported that healthcare interventions have the potential to save over 10,000 lives between now and 2033.

Additionally, Kidney Research UK also noted in a 2024 report that there are ongoing efforts to improve the understanding and treatment of CKD through various research initiatives, including evaluating the impact of new medications and studying the potential of early interventions to reduce the progression of the disease (Kidney Research UK, 2024). These efforts emphasise the need for psychological interventions as part of a comprehensive care strategy for CKD individuals and the importance of early intervention strategies, including psychological support, to prevent or slow the progression of CKD. This report advocates the need for increased focus on mental health resources tailored to the needs of young CKD patients, suggesting that integrating psychological care into standard treatment protocols may significantly improve patient outcomes.

In their systematic review, Hill et al. (2016) identified the estimated worldwide prevalence of each of CKD's stages. CKD is treatable and it can be prevented or delayed if recognised early (stages 1-2) and managed properly (Johnson et al., 2013). Data in Table 1.2 below shows that approximately 7.4 percent of this population may have the best possible patient outcomes in preventing or delaying their disease.

Table 1.2

Prevalence of Each Chronic Kidney Disease's (CKD) Stages

CKD stage	Prevalence (M)*
1	3.5%
2	3.9%
(1 and 2)	7.4%
3	7.6%
4	0.4%
5	0.1%

(M)* represents the Mean across 74 populations. Adapted from Hill et al. (2016).

While these statistics highlight the widespread nature of CKD, they do not fully capture the profound psychological impact associated with the disease, particularly among YAs. The importance of addressing psychological factors in CKD is underscored by growing evidence linking psychological distress to worse health outcomes in CKD individuals. YAs are particularly vulnerable to psychological challenges, including depression, anxiety, and reduced QoL. These mental health issues can exacerbate the progression of CKD, leading to several adverse outcomes and increased healthcare costs (Francis et al., 2024). Research indicates that the prevalence of depression among individuals with CKD is significantly higher than in the general population, with estimates ranging from 20 to 30 percent (Palmer et al., 2013). Anxiety is also common, affecting up to 5 percent of CKD patients (Gilbertson et al., 2019). These psychological conditions not only reduce QoL but are also associated with increased mortality, higher rates of hospitalisation, and poorer adherence to treatment regimens (Goh, Griva, Chia, & Luo, 2021). The stress of managing a chronic illness, coupled with the fear of disease progression and the potential need for dialysis or transplantation, can create a substantial psychological burden.

Furthermore, evidence suggests that psychological interventions, such as cognitive-behavioural therapy (CBT), stress management, and self-management programs, can be effective in reducing depression and anxiety in CKD patients, and improve adherence to medication, dietary restrictions, and other aspects of self-care, leading to better overall health outcomes (Barber, Horrocks, Cornelius, & Fletcher, 2022). For YAs, who are in a critical phase of life development, psychological support can also aid in coping with the social and emotional challenges of living with a chronic illness, thus enhancing their long-term well-being and QoL. The need for tailored psychological interventions is further supported by the unique challenges faced by YAs with CKD who are at a transitional life stage, dealing with the typical stressors of emerging adulthood, while also managing a serious chronic condition. The dual burden of CKD and its psychological impact can delay their development and overall life trajectory, making psychological interventions not only beneficial but essential.

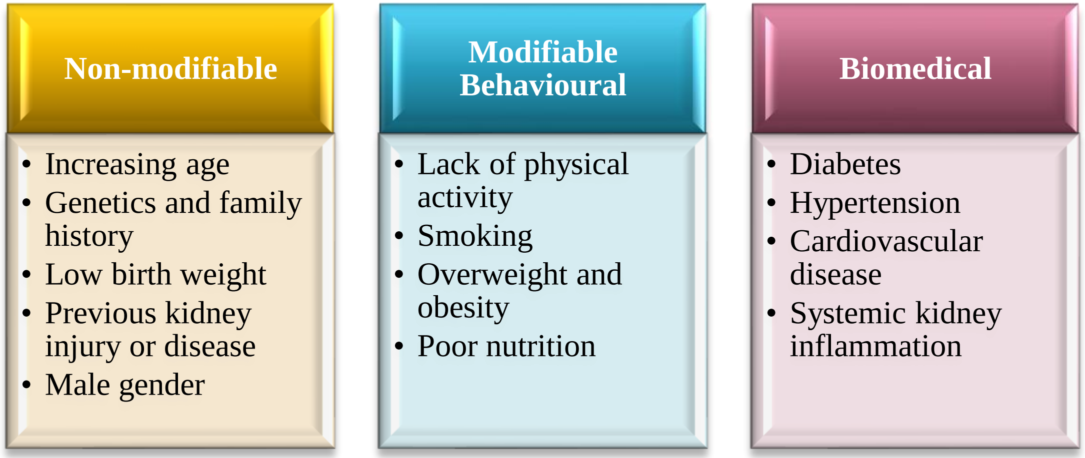
Finally, the high prevalence of CKD, together with its significant psychological burden, particularly among YAs, underscores the need for integrated psychological care as part of CKD management. The evidence points to the effectiveness of psychological interventions in improving both mental health and clinical outcomes, highlighting a critical area for healthcare improvement and research.

1.2.3 CKD Physical and Psychological Risk Factors and Causes

The development and progression of CKD are influenced by a combination of non-modifiable, modifiable behavioural, and biomedical risk factors (AIHW, 2009; 2016; see Figure 1.1). Among these, modifiable behavioural factors such as smoking, obesity, and poor management of conditions like diabetes and hypertension are crucial targets for intervention. Psychological factors play a significant role in influencing these behaviours, making psychological interventions important in mitigating the risk and progression of CKD.

Figure 1.1

Chronic Kidney Disease Risk Factors



Non-modifiable	Modifiable Behavioural	Biomedical
• Increasing age • Genetics and family history • Low birth weight • Previous kidney injury or disease • Male gender	• Lack of physical activity • Smoking • Overweight and obesity • Poor nutrition	• Diabetes • Hypertension • Cardiovascular disease • Systemic kidney inflammation

Adapted from AIHW (2009; 2016).

Psychology is important in changing modifiable behavioural factors associated with CKD. For instance, mental health challenges such as depression and anxiety can hinder a person's ability to manage their health effectively, leading to poor adherence to medical advice, unhealthy lifestyle choices, and increased disease progression. Addressing psychological factors through targeted interventions can therefore lead to significant improvements in managing these modifiable risk factors.

Globally, the primary risk factors for developing CKD include diabetes, hypertension, obesity, cardiovascular disease, and smoking. These factors are closely linked to psychological determinants, such as stress, mental health issues, and socioeconomic aspects, which can exacerbate these risks (Tomson & Bailey, 2011; Yacoub et al., 2010). For instance, research shows that smoking is not only a behavioural habit but also a coping mechanism for stress and anxiety, which are common among individuals with chronic conditions (Yacoub et al., 2010). This highlights the need for psychological support to address underlying mental health issues that contribute to risky behaviours like smoking. Similarly, obesity, which is strongly associated with CKD, often has psychological roots. Emotional eating, driven by stress or depression, can lead to weight gain and, subsequently, to the development of CKD (Eckard et al., 2013). Research indicates that psychological interventions can be effective in helping individuals manage their weight by addressing, for example, the emotional triggers of overeating, and consequently reducing the risk of CKD (Flesher et al., 2011; Lowth, 2013).

Further, socioeconomic factors, including education and income, also play a significant role in CKD risk. Lower socioeconomic status is associated with higher levels of stress and reduced access to healthcare, which can worsen CKD risk factors (Singh et al., 2013). Psychological stress related to financial insecurity and social disadvantage can further compound these risks by leading to poor health behaviours and reduced adherence to treatment regimens (Martins, Agodoa, & Norris, 2012). Nicholas, Kalantar-Zadeh, and Norris (2015) suggested that key CKD determinants, such as diabetes, obesity, hypertension, and chronic inflammation, often stem from socioeconomic deficiencies (Nicholas et al., 2015). Factors like residential segregation, discrimination, low health literacy, inadequate education, limited healthcare access, and chronic stress contribute to these conditions, leading to increased CKD development, progression to ESKD, and higher mortality rates (Lora et al., 2011; Nicholas et al., 2013; Norris & Nissenson, 2008).

Additionally, the incidence and prevalence of both hypertension and diabetes, which are key risk factors and causes of CKD, have been significantly growing in past decades contributing to the increase in CKD rates, and this high prevalence is expected to continue rising (Go et al., 2013; Guariguata et al., 2014; Hung et al., 2017). It has been projected that approximately 40 percent of individuals with diabetes will develop CKD (Evans & Taal, 2015). According to Centres for Disease Control and Prevention (2014), approximately one in five adults with hypertension, and one in three adults with diabetes have CKD. Diabetes causes functional and structural changes in the kidneys, mainly due to glomerulosclerosis (Lim, 2014), which directly increases glomerular permeability and deteriorates albuminuria (Toth-Manikowski & Atta, 2015). Whereas, high blood pressure (BP) causes damage to the kidneys’ arterial blood vessels (Huan, Cohen & Townsend, 2015). Hypertension may also be a complication of CKD because the kidneys have an important role in BP homeostasis, so when kidney function worsens, the kidneys are less able to aid in regulating BP (Thomas, Kanso &

Sedor, 2008). Psychological factors such as chronic stress and depression are known to increase the risk of developing these conditions, as they can lead to poor lifestyle choices, such as unhealthy eating, lack of exercise, and non-adherence to medication, thus psychological interventions that address stress management and emotional well-being are important in preventing the onset and progression of CKD.

Other common CKD causes are presented in Table 1.3 below adapted from the UK Renal Registry data from 2009 (Steenkamp, Castledine, Feest, & Fogarty, 2011).

Table 1.3

Percentages of Primary Renal Diagnosis, UK 2009

Primary renal diagnosis	%
Glomerulonephritis	16.0
Diabetes	14.7
Pyelonephritis	11.9
Polycystic kidney disease	9.6
Hypertension	5.7
Renal Vascular Disease	3.4
Other	14.8
Uncertain aetiology	20.6
Data not collected	3.3

Adapted from the UK Renal Registry data (Steenkamp et al., 2011).

According to the above data from 2009, glomerulonephritis is one of the most common causes of CKD in the UK (Steenkamp et al., 2011). Glomerulonephritis is the result of infections, autoimmune responses and contact with toxins and drugs (Levey & Coresh, 2012). However, it is important to note that glomerulonephritis is no longer the leading cause of CKD in developed countries. Whereas, in some Asian countries (typically low-income countries), factors such as environmental toxins and infectious diseases are the leading cause of renal impairment (Imai & Matsuo, 2008).

Furthermore, emerging evidence also highlights the role of psychological stressors in new CKD risk factors, such as those related to the COVID-19 pandemic. The outbreak of COVID-19 has significantly impacted CKD, particularly through increased rates of acute kidney injury (AKI) in hospitalised patients, which has been linked to severe stress and anxiety (Jewell et al., 2021; Lumlertgul et al., 2021; Wan et al., 2021). Those with AKI had higher admissions and required more respiratory support (Gasparini et al., 2021). Patients failing to recover kidney function faced a heightened risk of developing CKD. Psychological stress during the pandemic has also led to disruptions in routine care, resulting in poor outcomes for CKD patients (Geetha et al., 2022). Mortality rates notably increased among kidney transplant recipients and dialysis patients due to missed treatments and potential healthcare worker transmission (Corbett & Moss, 2021). Overall, the CKD population experienced substantial excess mortality, with 34,000 observed excess deaths in England from March 2020 to March 2021 (Dashtban et al., 2022). Addressing the psychological impact of the pandemic on CKD patients is therefore important in improving health outcomes.

Finally, while traditional risk factors like diabetes, hypertension, and obesity remain central to understanding CKD, the psychological factors influencing these behaviours are equally important. Effective management of CKD must include psychological interventions aimed at modifying these behavioural risks, improving treatment adherence, and ultimately enhancing patient outcomes.

1.2.4 CKD Diagnosis and the Physical and Psychological Comorbidities and Symptoms

According to Havas, Douglas, and Bonner (2018), the burden of CKD is predominantly increased in ESKD, which involves time-consuming and high-cost KRTs, such as dialysis or transplantation. Several studies have established that early referral of individuals with more severe CKD to a renal unit is related to a decreased decline in kidney function, decreased care cost associated with the following dialysis, reduced requirement for and time of hospitalisation, as well as decreased morbidity and mortality (McDonald, Excell, & Livingston, 2009). Therefore, the diagnosis of CKD in the earlier stages may slow the development of the disease and achieve optimal patient outcomes. However, recognition and diagnosis of the early CKD stages can be demanding given that people affected by the disease often do not experience the symptoms (Mathew & Corso, 2009). Thus, CKD is often undiagnosed until acute damage or loss of kidney function occurs (Mathew et al., 2010). Moreover, the common asymptomatic nature of CKD, together with low or lack of overall awareness of kidney function, makes it hard for CKD individuals to understand, manage, and take control over their disease (Bowling et al., 2017; Campbell-Crofts & Stewart, 2018; Lopez-Vargas et al., 2014; Tuot et al., 2016; Tuot & Plantinga, 2011).

CKD is associated with low health-related quality of life (HRQoL) (Pagels, Soderkvist, Medin, Hylander, & Heiwe, 2012; Zimbudzi et al., 2016), but also, individuals with CKD often suffer from associated comorbidities (e.g., cardiovascular disease, diabetes, chronic inflammation, and depression) which increase the complexity of care (Tonelli et al., 2015). Many individuals have multiple chronic conditions, known as multimorbidity (Fortin, Lapointe, Hudon, & Vanasse, 2005). Multimorbidity is related to increased healthcare costs and worse clinical outcomes, compared to the incidence of a single chronic condition or good health (Barnett et al., 2012; Fortin, Hudon, Haggerty, van den Akker, & Almirall, 2010; Lehnert et al., 2011; Perruccio, Katz, & Losina, 2012). A significant number of individuals with CKD experience symptoms of depression and anxiety, irrespective of the disease stage, and heightened anxiety symptoms can elevate the risk of developing additional comorbidities (Huang et al., 2020), further highlighting the need for psychological interventions. Hospitalisation rates in CKD individuals are 2 to 3 times higher in those with multiple comorbidities and the presence of additional commodities can further impair their ability to cope and self-manage their condition (Sulivan et al., 2021). Therefore, those individuals who suffer from CKD and associated comorbidities must be provided with ongoing care, while considering psychological factors (Brand & Pollock, 2018).

The high occurrence of related unpleasant symptoms places an increasing burden on people with CKD (all stages) with research identifying up to 30 unpleasant symptoms in CKD individuals (Almutary et al., 2013). These symptoms include dyspnoea (Janssen, Spruit, Wouters, & Schols, 2008), nausea, cramps, constipation, oedema, and dry skin (Murtagh et al., 2007), and fatigue (Bossola, Vulpio & Tazza, 2011). Individuals with later stages of CKD, on average report experiencing 13 related unpleasant symptoms (Almutary, Bonner & Douglas, 2016). According to Saini and colleagues (2006), such a burden is very similar to that in cancer. Numerous factors may lead to the incidence of these symptoms, including comorbid conditions, the disease itself, or treatment modalities. According to Dodd, Miaskowski, and Lee (2004), the presence of multiple symptoms may produce a coexisting group of symptoms that form a cluster. The research proposed that symptom clusters independently predict HRQoL (Amro, Waldum, Dammen, Miaskowski, & Os, 2014), mortality rate (Amro et al., 2015), and functional status (Herr et al., 2015). However, symptom cluster research in CKD is limited to small sample sizes (Lee & Jeon, 2015), the dialysis population (Jablonski, 2007), and examining mainly physical symptoms (Thong et al., 2009; Yu, Huang, & Tsai, 2012). Thus, more research into symptom clusters in CKD is needed as information about these associations can be important in facilitating the development of interventions, which lead to an improvement in patients' functional status, HRQoL, and survival.

1.2.5 Managing CKD: Treatment and Psychological Support

Research has suggested that regular blood tests, urinalyses, and imaging studies can recognise decreased kidney function, especially in those who are at risk of developing the disease, such as individuals with a family history, cardiovascular disease, or diabetes (Qaseem et al., 2013). Several structured programmes for kidney screening to identify any issues have been implemented globally (Bello, Nwankwo, & El Nahas, 2005). CKD is considered to be a mostly preventable disease since several of the risk factors that impact progression from CKD stages 1 and 2 to ESKD are modifiable (Johnson, 2004). Appropriate management for CKD risk factors may reduce progression to ESKD by approximately 50 percent, and in some cases, CKD may even be reversed (AIHW, 2016; Sharaf El-Din, Salem, & Abdulazim, 2016).

To reduce the impact and progression of the disease, the early stages of CKD can be managed both pharmacologically and non-pharmacologically (Walker, Marshall, & Polaschek, 2013). However, when there is a reduction in eGFR to less than 15 mL/min/1.73m^2, KRT (including haemodialysis, peritoneal dialysis, and kidney transplantation) is crucial. CKD management is determined by the severity of kidney function failure, the underlying cause of the illness, and the occurrence of associated comorbidities. The purpose of CKD management is to improve the HRQoL, prevent or delay the development of the disease to ESKD, and decrease cardiovascular risk (Nikolajenko, 2013; Turner, Bauer, Abramowitz, Melamed, & Hostetter, 2012). Individuals who suffer from CKD and other related comorbid conditions need to manage their BP, cholesterol, blood glucose levels (in those with diabetes), weight, diet, fluid intake, medication, physical activity, smoking, and alcohol consumption (Javalkar, Fenton, Cohen, & Ferris, 2014; Krane & Wanner, 2011; Melamed & Thadhani, 2012).

Pharmacological therapy for controlling BP, blood glucose and cholesterol levels forms essential interventions to slow down CKD progression and prevent cardiovascular morbidity and mortality (Norris & Nicholas, 2015). However, the effectiveness of these treatments is closely related to psychological factors, given that a person’s mental health can significantly impact their ability to adhere to medication regimens and maintain the lifestyle changes necessary for managing CKD. Whereas, non-pharmacological treatment is typically used to manage the early stages of CKD, and includes lifestyle modifications and dietary changes (Browne & Merighi, 2010). Lifestyle modifications include increased physical activity, weight reduction, smoking cessation, and reduction in alcohol consumption (Tuot et al., 2013), and these require a high level of psychological resilience and motivation. Dietary modifications involve adopting a healthy eating plan, which comprises fat and sodium reduction, and are also essential, but can be challenging for patients to sustain without psychological support to address habits and stress-related eating behaviours. Other aspects of CKD self-management comprise regulating fluid intake, controlling electrolytes, and access to cardiovascular care (Mason, Khunti, Stone, Farooqui, Carr, 2008), all of which are more effectively maintained when psychological factors such as stress, anxiety, and depression are addressed. These interventions aim to delay CKD progression and prevent the consequences of CKD (Johnson et al., 2013).

The management of CKD is complex for many individuals with the disease requiring life-long modifications and therefore it remains a continuing challenge for HCPs (Ong, Jassal, Porter, Logan, & Miller, 2013). For instance, BP control is of the greatest importance for individuals with CKD, but regular monitoring and adherence to treatment can be difficult without psychological support to sustain motivation and coping strategies. Regularly checking BP may contribute to a decrease in cardiovascular disease and it may slow the development of the disease (Judd & Calhoun, 2015). Therefore, with the increasing number of individuals who suffer from LTCs, such as CKD, it has become important for HCPs to empower and support those individuals to develop knowledge, self-confidence, and skills to manage their health (Department of Health, 2013). It has been established that SMIs, which often include psychological components, are effective in achieving these goals, highlighting the importance of addressing psychological factors in CKD management.

In the past few years, policymakers, patients with non-dialysis CKD, their caregivers and clinicians have recognised the need for optimal strategies to support individuals with CKD in managing their condition and associated comorbidities to slow down or prevent the progression to ESKD (Hemmelgarn et al., 2017). CKD research emphasises SMIs as a top priority in preventing the progression of the disease (Tong et al., 2015). According to Richard and Shea (2011), the purpose of SMI is to assist a person in improving their ability to manage their disease and related comorbidities including symptoms, treatment, and CKD-related psychosocial and physical outcomes, as well as make significant lifestyle changes. CKD self-management includes paying attention to disease requirements such as CKD knowledge, skills, and self-confidence to manage the medical aspects of the disease, as well as recognising and gaining access to resources and support in learning to live with CKD and coping with its impact on life and emotional outcomes of the disease (Eknoyan et al., 2013; Grey, Schulman-Green, Knafl, & Reynolds, 2015; Wierdsma, van Zuilen, & van der Bijl, 2011).

Research has identified several benefits of SMIs, including improvements in symptoms (Chow & Wong, 2010), HRQoL

(Moattari, Ebrahimi, Sharifi, & Rouzbeh, 2012), disease-specific and self-management knowledge, ability, behaviour (Choi & Lee, 2012; Lingerfelt & Thornton, 2011; Wang & Chiou, 2011), BP, interdialytic weight gain (IDWG; Tsay, 2003), psychological issues (Lii, Tsay & Wang, 2007), and utilisation of healthcare services (Chen et al., 2011). Further, evidence has consistently shown that structured self-management programmes can improve outcomes for individuals living with various chronic conditions. For instance, a number of positive outcomes of such programmes have been documented, including symptoms and disease management, mood, coping, adherence, self-efficacy, health-related behaviours, hospitalisation, communication with HCPs, fatigue, disability, depression, and health distress (Janson, McGrath, Covington, Cheng, & Boushey, 2009). Moreover, those individuals who took part in self-management programmes report that they found them beneficial (Kazawa & Moriyama, 2013), and those who have not yet taken part show interest and willingness to participate (Washington, Zimmerman & Browne, 2016).

Finally, recent evidence also indicates that eHealth self-management interventions (e.g., digital technologies and/or online resources) can foster healthy behaviour and enhance health outcomes for CKD patients (Shen et al., 2019). These interventions are both feasible and acceptable for individuals with CKD and their HCPs (Shen, van der Kleij, van der Boog, & Chavannes, 2024). YAs may especially benefit from these interventions given their familiarity and comfort with digital technologies. For the purpose of this thesis, the SMIs are discussed in more detail in Chapter 3 which reviews the existing literature on CKD SMIs.

1.2.6 Psychosocial Barriers and Facilitators in CKD Self-Management

In order to improve HRQoL and clinical symptoms of chronic disease, individuals need to learn to take responsibility for managing their disease (Ludman et al., 2013; Novak, Costantini, Schneider, & Beanlands, 2013). According to Lorig (2002), adequate skills, such as knowledge and confidence are required to improve a person’s ability to effectively self-manage their disease. For instance, Schwarzer’s (2014) study has established that people who have relevant confidence reach improved health outcomes.

Confidence can be defined as a perceived ability to engage in required actions, including making decisions, dealing with problems, and maintaining health to manage chronic illness (Riegel & Dickson, 2008). A person's confidence in recognising problems associated with their disease and looking for solutions is significant in developing skills to maintain their health (Lorig, 2002). Similarly, research (e.g., Bhurji, Javer, Gasevic, & Khan, 2016) has shown that having the relevant knowledge to manage one's disease is also important to improve HRQoL and reduce the impact of the illness. Unfortunately, some studies (e.g., Gallagher, Warwick, Chenoweth, Stein-Parbury, & Milton-Wildey, 2011; Song et al., 2013) have shown that many individuals who suffer from chronic diseases lack adequate knowledge about their illness, medication management and side effects, and activities required to promote their health and manage their disease.

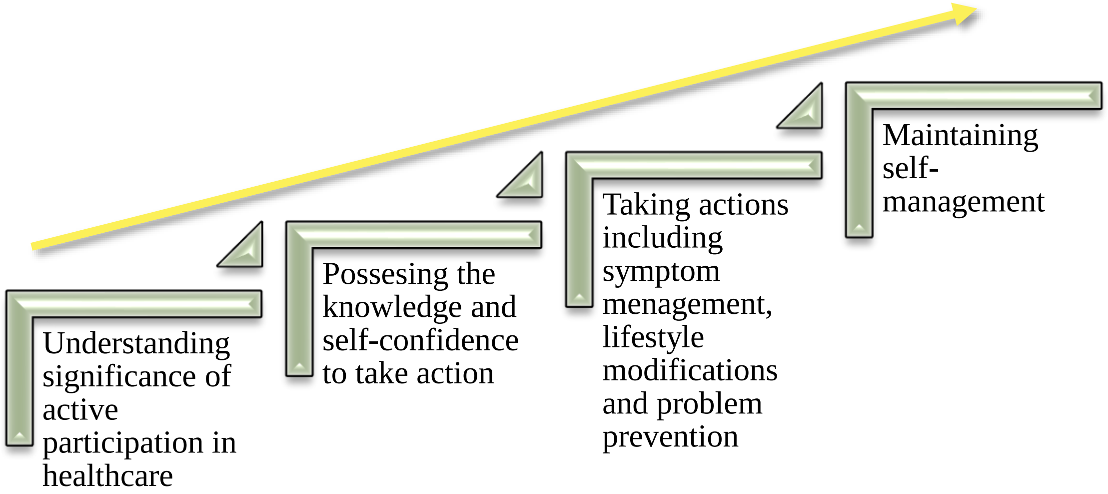
Furthermore, evidence suggests that certain individuals' characteristics, including SES, age, gender, and level of education, are likely to influence their CKD knowledge. For instance, low levels of CKD knowledge have been related to lower SES, old age, lower educational levels, and ethnicity (Hocking, Laurence, & Lorimer, 2013). Similarly, non-marital status and male gender have been related to low knowledge of the disease (Fraser et al., 2013). Moreover, previous research has shown that a person's characteristics also influence their desire for support. Particularly, it has been established that males, older participants, and lower SES are less actively engaged in their healthcare compared to females, and younger participants, with higher SES (Hibbard & Cunningham, 2008; Williams, Mohammed, Leavell, & Collins, 2010). Thus, it appears that those individuals with lower SES, who possibly already are at high risk for negative outcomes, may be less involved with their HCPs and may need more tailored support.

There is also evidence to suggest that individuals who are in the later CKD stage are willing to learn and regret that they did not understand the significance of self-management earlier in their condition (Harwood, Locking-Cusolito, Spittal, Wilson, & White, 2005). Havas, Douglas, and Bonner (2017a) examined the patients' desire for self-management support (SMS) and concluded from their study that those individuals who have been living with CKD for longer than 10 years, showed a stronger desire for SMS compared to those who have been living with CKD for the period shorter than 10 years. These findings suggest that even though CKD education is offered to patients usually later in the illness process (Morton, Moustakas, Howard, Webster, & Snelling, 2009), more research is needed to establish ways in which those individuals with earlier CKD stages can be motivated to efficiently manage their disease (Costantini et al., 2008).

In addition, CKD self-management literature reviews report that patient engagement is a significant predictor of outcomes, and it should be encouraged by HCPs (Simmons, Wolever, Bechard, & Snyderman, 2014). Several studies established that more activated individuals tend to have lower healthcare costs (Hibbard, Greene & Overton, 2013) and improved health outcomes (Greene, Hibbard, Sacks, Overton, & Parrotta, 2015; Hibbard, Mahoney, Stock, & Tusler, 2007; Shively et al., 2013). While tailoring treatment to different types of people, it is important to consider that individuals will be at diverse stages of activation concerning self-managing their condition (Hibbard, Stockard, Mahoney, & Tusler, 2004; Hibbard, Stockard, Mahoney, & Tusler, 2005). Figure 1.2 represents stages of patient activation, and the theoretical concept of patient activation is discussed further in Chapter 5.

Figure 1.2

Stages of Patient Activation



Adapted from Hibbard et al. (2004) and Hibbard et al. (2005).

Moreover, according to Devraj, Borrego, Vilay, Pailden and Horowitz (2018), CKD individuals need to be knowledgeable and health literate about self-management behaviours to effectively manage their condition. Health literacy and knowledge are closely associated, even though health knowledge, which is critical for effective health literacy, does not indicate that a person is health literate (Baker, 2006). Low health literacy has been associated with adverse health outcomes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011) and affects a significant percentage of CKD patients (23-28%; Jain & Green, 2016). However, the definition of health literacy itself is less clear (Martensson & Hensing, 2012). While narrow definitions describe health literacy as the capability of writing, reading, and numeracy in healthcare settings (often referred to as functional health literacy), wider definitions (e.g., by WHO, 1998) refer to health literacy as the social and cognitive skills that determine the motivation and capability of a person to access, understand, and use information in ways that promote and sustain good health (referred to as comprehensive health literacy). Although health knowledge has been considered an outcome of functional health literacy, the position on health knowledge varies. Researchers indicate that health knowledge serves either as an essential dimension of health literacy itself (e.g., Freedman et al., 2009), as an antecedent (e.g., von Wagner, Steptoe, Wolf, & Wardle, 2009), or as a consequence of health literacy (e.g., Speros, 2005). One can say that it denotes information, facts, and skills developed through education or experience, along with the practical and theoretical understanding of a subject associated with health and healthcare (Chin et al., 2011).

Health literacy is a significant factor in the improvement and maintenance of health (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004), and is crucial for disease self-management (Sorensen et al., 2015). Low health literacy has been related to lower CKD knowledge (Wright Nunes et al., 2011) and poor kidney function (Ricardo et al., 2014). Research in chronic diseases has shown that low health literacy is related to health outcomes, including lower QoL (Loke et al., 2012), mortality risk, and increased emergency service use (Wu et al., 2013), and consequently an increased burden on health costs worldwide (Eichler, Wieser, & Brugger, 2009). A recent systematic review noted that although the available evidence has limitations, there are consistent associations between higher health literacy and positive self-management behaviours among CKD individuals, however, the definitive links between health literacy and patient outcomes are less established and still not fully understood (Billany et al., 2023).

Low health literacy has been linked to poorer health-related behaviours, specifically self-management skills (Mbaezue et al., 2010; Naik, Street, Castillo, & Abraham, 2011). Mackey, Doody, Werner and Fullen (2016) reviewed the association between the development of self-management skills and health literacy and reported that low health literacy indicates a considerable problem in self-management skills development, which are the main resources for the treatment of chronic diseases. The researchers concluded that health literacy is a possible facilitator or barrier to better health outcomes (Mackey et al., 2016). Much of chronic disease self-management occurs outside healthcare settings. This care is often complex, for instance, medication adherence requires understanding complex dosing and scheduling details. Therefore, health literacy is vital in enabling individuals to develop appropriate self-management skills to manage their disease (Magnani et al., 2018). However, although some evidence suggests that health literacy should be considered in SMIs (Suka et al., 2015), other studies found no relationship between self-management behaviours and health literacy. Although the researchers found no effect of health literacy on asthma self-management, they reported that it may be due to chance and suggested that more research is required to confirm the association between self-management behaviours and health literacy (Londoño & Schulz, 2015).

Furthermore, it is crucial to consider the emotional impact of the disease on CKD individuals. As mentioned earlier, studies have reported that psychological disorders, particularly anxiety and depression are common in CKD patients with almost 80 percent suffering from some type of psychological disorder (Kokoszka et al., 2016). Given that anxiety and depression are related to decreased HRQoL, lessening psychological distress leads to improvement in CKD individuals’ HRQoL (Lee, Kim, Cho, & Kim, 2013). People with CKD often struggle to talk about their psychological distress (de Sousa, 2008), thus HCPs should pay more attention to their patients' psychological well-being (Brandes, Linn, Butow, & Weert, 2014). Moreover, there is evidence showing that individuals with chronic conditions desire their family to accompany them in decision-making or clinical appointments and educate their loved ones about their disease and treatment (Phillips et al., 2015a). Finally, it remains evident that factors including cognitive function, level of activation and health literacy, mental health, and education have an important part to play in how a person self-manages their disease. This in turn only adds to the relevance of conducting research in self-management within the CKD population.

1.3 Research Outline, Aims, Questions, and Objectives

The current research, in the form of a multi-phase study involving three phases, aims to explore and address the gaps in the existing CKD SMIs by reviewing the literature (phase 1) and identifying what SMIs for YAs living with CKD (stages 1-5) need to address, through the collection of qualitative and quantitative data (phase 2). Following this, based on findings from phases 1 and 2, it is aimed to develop a novel person-centred, theory-based SMI specific to YAs with CKD (phase 3). Research questions and how they were addressed in each phase can be seen in Table 1.4 below.

Table 1.4

Research Phases, Questions, Objectives, and Methods

Phases	Questions	Objectives	Methods
1	What are the key elements of CKD SMIs identified in the existing literature?	To conduct a review of the literature to establish key elements of the existing CKD SMIs	Literature review (Systematic review)
2	Among YAs living with CKD stages 1-5, what aspects of the existing CKD SMIs need improvement and what aspects may they benefit from?	To identify existing self-management behaviours among YAs with CKD and identify perceived gaps to inform a novel intervention	Collection of quantitative data (Cross-sectional approach) and qualitative data (Thematic analysis)
3	What will be the most optimal intervention for YAs (18-35 years old) with CKD?	To develop an appropriate person-centred, theory-based SMI for YAs with CKD stages 1-5	Intervention development (Systematic four-step approach)

CKD Chronic Kidney Disease; *SMI* Self-Management Intervention; *YA* Young Adult.

1.4 Significance of the Current Research

This introductory Chapter provided insight into the growing concern of CKD worldwide, a significant cause of mortality and morbidity, imposing a substantial burden on those who suffer from the disease and those who look after them. While CKD is manageable and preventable with early detection and appropriate care, it necessitates lifelong adjustments. YAs with CKD, who face heightened vulnerability compared to other age groups, and are characterised by impulsive and risk-taking behaviours and non-compliance problems, are of particular concern. The psychological impact of CKD on YAs is profound, as the disease and its treatment can lead to social disconnection, hindered development towards independence, and emotional challenges such as withdrawal, anger, depression, and communication difficulties with HCPs.

The importance of psychological factors in managing CKD cannot be overlooked. YAs transitioning to adult care must not only learn to manage their disease daily but also navigate the major life transition to adulthood. Psychological support is crucial in helping them develop the knowledge, skills, and self-confidence needed for effective disease management. HCPs play an important role in empowering YAs by addressing these psychological challenges and fostering resilience. Healthcare interventions that incorporate psychological components, particularly SMIs, have been recognised as a top priority in preventing CKD progression and improving overall well-being. Thus, based on the evidence reviewed, it is apparent that there is a pressing need to investigate how CKD affects this unique cohort in all aspects of their lives and to address these issues by providing them with comprehensive support that includes psychological care. More research is required for appropriate tailored support for YAs with CKD to assist them in lessening the burden of the disease, while considering their unique needs, associated comorbidities and symptoms, CKD-related psychosocial and physical outcomes, and risk factors influencing SMIs.

Finally, examining the key elements of the CKD SMIs identified in the existing literature (phase 1), and identifying factors that SMIs for YAs with CKD need to address (phase 2), will aid in the recognition of gaps in the current CKD literature and add to knowledge about CKD SMIs specific to YAs to address the research question about the most optimal intervention for this demographic. Findings from these two phases will aid the development of a person-centred, theory-based SMI for YAs living with CKD. This may benefit further research in improving SMIs, which in turn may benefit the individuals living with CKD, their families, society, and the healthcare system by addressing both the physical and psychological challenges of the disease.

1.5 Chapter Summary and Thesis Outline

This thesis includes 9 Chapters. This Chapter began with an introduction to the topic and background, and it described CKD, as well as outlined the research and its significance. The next Chapter offers a methodological overview of this research, presenting protocol deviations, the revised overall research design and phases, as well as detailed methodology and methods for phase 2. Chapter 3 is a systematic literature review related to this study examining key elements of the existing CKD SMIs (Phase 1). Chapter 4 offers a theoretical underpinning for this research by discussing the concepts that explain health behaviour change. Whereas, Chapter 5 adds to this by exploring the concepts used to elicit health behaviour change. It offers relevant models and frameworks (relevant to the theories described in Chapter 4) for developing health behaviour change interventions. Chapter 6 reports a Quantitative study (phase 2, part 1) and its results, whereas Chapter 7 presents a Qualitative study (phase 2, part 2) and its findings. Finally, a novel intervention is proposed in Chapter 8 (phase 3), and Chapter 9 provides the final discussion and draws the main conclusions of the current research.

Chapter 2: Methodological Overview

2.1 Introduction

The evidence discussed in this thesis sheds light on the challenges faced by individuals with chronic kidney disease (CKD). One of the key insights is that CKD patients often struggle to find practical and personalised support to manage their illness. Another observation is that they are seldom consulted about the type of support they require, and their involvement in the development of self-management interventions (SMIs) is limited. Additionally, there is a noticeable gap in the CKD literature regarding possible intervention strategies to effectively support young adults (YAs). Given that this age group requires special attention from healthcare professionals (HCPs), it is imperative that more research is conducted to understand how CKD affects their lives in all aspects.

The current study aimed to recognise how YAs (group 1) manage their health condition by gaining an understanding from their perspectives, as well as the perspectives of those who care for YAs with CKD, including their health and social care professionals (group 2; also referred to as staff; ST, or professionals in the below analyses and syntheses). Consequently, the goal of phase 2 was to identify existing self-management behaviours among YAs living with CKD and which factors the interventions might need to address, through the collection of quantitative and qualitative data from both groups of participants (refer to section 2.4.4 for a detailed description of participants). Phase 2 addressed the following broad research question: *Among YAs living with CKD stages 1 to 5, what aspects of the existing CKD SMIs need improvement and what additional aspects may they benefit from?* The research aims, objectives and hypotheses for the quantitative study and specific research questions for the qualitative study are provided in the sections below.

Finally, the findings from phase 2 will be beneficial in informing future research in the CKD SMIs field. The findings from this phase and phase 1 (literature review) will inform the development of person-centred, theory-based intervention specific for YAs living with CKD (phase 3 of this project).

This Chapter first discusses the protocol deviations, including the initial intentions and reasons for changes to the study design (section 2.2) and then it presents the revised overall research design and phases (section 2.3). Following this, detailed methodology and methods for phase 2 (part 1 - quantitative study and part 2 - qualitative study) are presented (section 2.4), followed by data analysis and synthesis in section 2.5. (beginning with part 1 questionnaire-based study, and following with part 2, semi-structured interviews). Finally, ethical considerations are provided in section 2.6 and Chapter summary in section 2.7.

Note that: in this and the following Chapters, the term “researcher” and/or “interviewer” refers to the PhD candidate, and those who were involved in the recruitment process (phase 2) are identified by their role.

2.2 Protocol Deviations

There are some deviations from the original study design as it was impossible to predict every possible change in circumstances during the research and several unforeseen and unforeseeable circumstances have occurred. The initial intentions and reasons for changes to the study design are presented in Table 2.1 below. The majority of changes were due to the advent of COVID-19 and/or subsequent disappointing recruitment rates. With the COVID outbreak, many researchers were caught off-guard as, for example, collecting data face-to-face was suddenly impossible when social distancing to avoid contracting the virus was implemented (Kuckertz et al., 2020). These restrictions made conducting health research in the laboratory and clinical setting very challenging (Mitchell et al., 2020; Padala, Jendro, & Padala, 2020a; Tolaney et al., 2020). Clinical research that involved patient samples required immediate deviations in protocols (Sathian et al., 2020). Thus, many researchers had to be flexible, creative, and innovative in assessing participants and collecting data (Liebenberg, 2020). Even though the researcher attempted to adapt the current research design to these unforeseen circumstances, some modifications and refinements to the original approach and study design had to be made. The final version of the study protocol, which was reviewed by the study supervisors and the Patient Experience and Evaluation in Research (PEER) group at Swansea University, can be located in the "Additional file 2, the study protocol, v.15" (available upon request), which includes the amendment history at the end of the document.

Table 2.1

Study Protocol Deviations

Section of protocol deviation	Deviations and rationale for changes
Participants	It was intended to recruit four different groups of participants, including YAs with CKD (stages 1-4), as well as their: parents/ guardians, caregivers, and HCPs. Although the recruitment process was the same for all groups of participants, out of all, only two showed interest in taking part in the study, particularly YAs and their HCPs. Thus, parents/ guardians and caregivers of YAs were removed from the study design. Moreover, the HCP group has been changed to "health and social care professionals" to enable gaining important perspectives of those who look after YAs with CKD (stages 1-5 after changes) including renal youth social workers.
Recruitment process	The study gatekeepers from the Kidney Wales Foundation were appointed to advertise the study and recruit participants based on their available data. Although the latter was not possible, efforts were made to advertise the study (via emails, posters, and social media) to recruit as many participants as possible. However, the recruitment rate was very poor which was mainly caused by the advent of COVID and YAs constituting a small portion of the CKD population. Recent research on participant and caregiver perspectives on clinical research during the COVID pandemic (Padala et al., 2020b) reported some reasons to decline participation, including "COVID fears", highlighting the effect that emotional factors can have on individuals' willingness to participate in the study.

Section of protocol deviation	Deviations and rationale for changes
Sample size and settings	Originally, it was aimed to recruit participants located in Wales. However, due to the abovementioned low recruitment rate, it was decided to expand the study UK-wide and to include the additional five organisations and some renal social workers to support the recruitment process by advertising the study UK-wide. Additional advertising materials were also developed to enhance the recruitment process, including advertising flyers to be distributed to participants in the clinics once COVID restrictions eased off, and an advertising video inviting participants to take part (*available upon request*). Furthermore, before the pandemic, participants were offered to take part in the study either at the Kidney Wales Foundation office in Cardiff or Swansea University Singleton Campus. However, since collecting data face-to-face was no longer an option following the COVID outbreak, the study setting had to be adapted to the current circumstances. Thus, the study settings have been changed to online only until COVID restrictions ease off. The questionnaire-based study was conducted using an online survey and interviews were conducted via Zoom.
Study design	Initially, the study was designed as RCT and it included a fourth phase that aimed to assess the feasibility, accessibility, and potential effectiveness of the proposed intervention, while phase 3 was designed not only to develop but also to implement a novel SMI for YAs with CKD. However, due to significant delays in recruitment, it was no longer possible and this research had to be re-designed by removing phase 4, and the element of implementation in phase 3. The revised study design, including the re-calculated required sample size, is presented below.
Qualitative study	Initial intentions were to conduct both focus groups and individual interviews to produce multiple perspectives on a given topic (Natasia & Rakow, 2009). Although data saturation is not about the numbers as such, but about the depth of the data (Burmeister & Aitken, 2012), it is recommended that the size of the sample in focus groups is between six and 12 participants so that the size of the sample is large enough to generate a diverse group and small enough for all participants to have the opportunity to talk and share their perspectives (Onwuegbuzie, Leech, & Collins, 2010). Given the very small sample size recruited in the current study, conducting focus groups was impossible and instead, the study focused on semi-structured individual interviews.

CKD Chronic Kidney Disease; *HCP* Healthcare Professional; *RCT* Randomised Controlled Trial; *YA* Young Adult.

2.3 Overall Research Design and Phases

Once the relevant changes to the study design were made, Phase 1 of the current study involved a systematic literature review which was conducted to establish the key elements of the CKD SMIs identified in the existing literature. Phase 2 involved the collection of quantitative data (part 1, questionnaire-based study) and qualitative data (part 2, semi-structured interviews). Phase 2 was conducted to explore experiences and identify the gaps in self-management interventions for YAs living with CKD stages 1-5. Thus, the overall study design was a mixture of quantitative and qualitative studies to inform the development of an intervention. The findings from both phases will be beneficial in informing future research in the SMIs field, particularly for YAs with CKD stages 1-5. It was aimed that incorporating the findings from this stage (phases 1 and 2), in conjunction with an understanding from the evidence, theory, stakeholders, patients and providers, will inform the development of an appropriate person-centred, theory-based SMI for YAs living with CKD stages 1-5 (phase 3). Refer to Chapter 1, Table 1.4 where the three phases involved in this research are graphically presented.

Note that, the methods and results for quantitative study were reported as per the strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies (von Elm et al., 2008; last updated on March 2, 2023; see Appendix A for STROBE checklist: cross-sectional studies). Whereas, the methodology and findings for the qualitative study were reported following consolidated criteria for reporting qualitative research (COREQ) by Tong, Sainsbury, and Craig (2007; last updated on December 6, 2023; see Appendix B for COREQ checklist).

2.4 Phase 2 - Methodology and Methods

2.4.1 Design

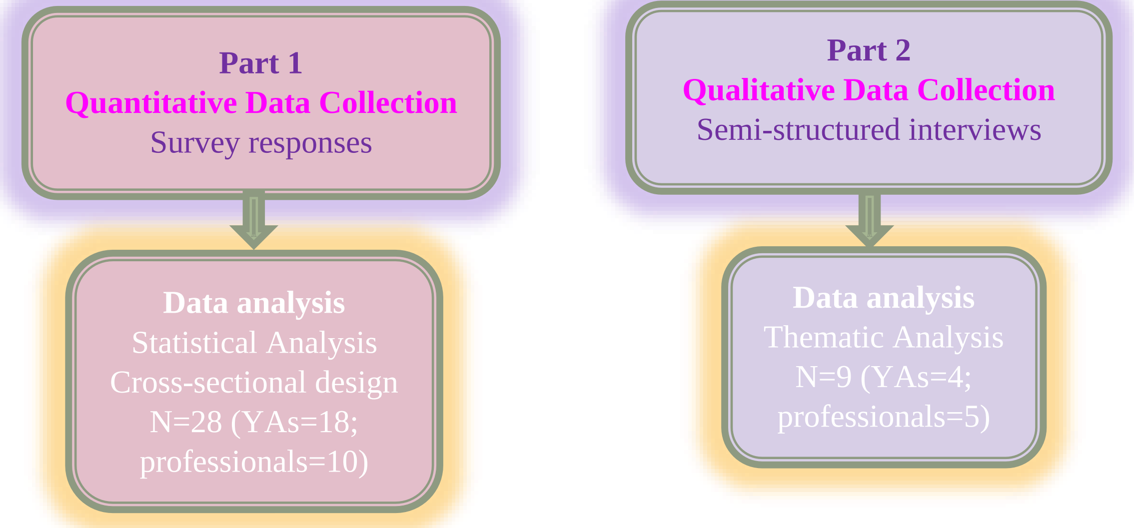
Prior to the commencement of the study, methods of the analysis, research questions, materials, and inclusion and exclusion criteria were specified in advance, and reviewed and approved by the National Health Service Research Ethics Committee (NHS REC; HRA and Health and Care Research Wales; HCRW - reference number: 19/EM/0339; see Appendix C) and the Swansea University

Patient Experience and Evaluation in Research (PEER) group advisory group. These were documented in a protocol for this phase (refer to additional file 2). In addition, before the start of the study, the researcher together with the Kidney Wales Foundation's director and advocate met with young people with CKD who attended a workshop at Swansea University. During this workshop, YAs shared their experiences and challenges of living with CKD, thus their feedback aided in developing a project proposal and in informing the aim and design of the study and appropriate materials.

Phase 2 involved a mixture of quantitative (questionnaire-based study; part 1) and qualitative (semi-structured interviews; part 2) data collection and analysis. A cross-sectional design was utilised for the quantitative study. A longitudinal design which would allow the collection of more information about CKD self-management at different points in time (LoBiondo-Wood & Haber, 2006) was considered initially but was not feasible due to time constraints, low recruitment rate, and the need for more resources (see "protocol deviations" in section 2.2). Similarly, an experimental/quasi-experimental design was also ruled out because a further understanding of the YAs population, CKD self-management, and associated variables is needed prior to developing an intervention. Thematic analysis was adopted as a method of analysis for the qualitative semi-structured interview study. A Graphical representation of the study design for phase 2 can be seen in Figure 2.1 below.

Figure 2.1

Study Design for Phase 2



YA Young Adult.

2.4.2 Settings

The participants who provided written informed consent (see Appendix D-H) to take part in the research were asked to complete a set of questionnaires followed by semi-structured individual interviews (optional). All participants were given the option to complete the questionnaires either online or via pen and paper, however, mainly due to the advent of COVID-19, all participants chose to complete an online survey. Similarly, for the semi-structured interviews, the participants were also offered the option to take part in face-to-face interviews, before COVID and after the restrictions eased off, or over the telephone or via video conference (such as Zoom). However, all interested and eligible participants chose to take part in the interviews via Zoom, thus part 2 of phase 2 also took place online. Those who were not interested in participating in the interviews overall were still able to complete the questionnaire-based study.

2.4.3 Sample Size

Studying a sample of participants with particular characteristics allows for drawing inferences about the whole population (Nayak, 2010; Suresh & Chandrashekara, 2012; Weber & Hoo, 2018). In the current research, the determination of the sample size for the quantitative study relied on statistical calculation, whereas the sample size for the qualitative study was determined based on the concept of saturation.

It is important to note that in the current research, the researcher originally calculated the sample size required for the initial study design and analysis, however, due to the poor recruitment rate identified during and post-data collection and subsequent changes in the study design, adjustments had to be made. The revised study design prompted the researcher to recalculate the sample size, prior to conducting statistical analyses. This adjustment was necessary to ensure that the sample size was appropriate for the revised study design and would provide sufficient statistical power to detect meaningful effects and draw reliable conclusions.

The researcher conducted an a priori power analysis for a revised study design, using G-power software 3.1.9.4 (Faul, Erdfelder, Lang & Buchner, 2007), to estimate the size of the sample in the questionnaire-based study for YAs (group 1). Whereas data from health and social care professionals (group 2) was exploratory, and thus did not require sample size calculation.

Finally, once all data was analysed, post-hoc (or posteriori) analyses were conducted (Kang, 2021), also using G-power software, to verify whether the achieved sample size was adequate to support the statistical results obtained. Recalculating the sample size and conducting post-hoc analyses was important to adapt to unexpected challenges, ensure the study’s statistical power, as well as acknowledge and explain any limitations or potential implications of adjusting the sample size (e.g., reducing the number of variables included in the study) and interpreting the findings accordingly.

The sample size for YAs - survey:

The main factors that affect the study sample size are α, β power, and effect size. It should be noted that we were unable to obtain the effect size for similar studies in comparable populations, and thus we based the sample size calculation on Cohen's (1988) d medium effect size. Consequently, to estimate the minimum number of YA participants required for this study, α was set as .05, power was set as .80, and the effect size was set as .15 for linear multiple regression analysis (two-tailed) with two predictors (self-efficacy and patient activation) and time since diagnosis as the covariate. This resulted in the total sample size for YAs estimated as 77. Unfortunately, the response rate in the current study was poor, resulting in 18 YAs participants who completed the survey.

The sample size for both groups of participants - interviews:

Many factors have an influence on sample sizes for qualitative research, including the research design, purpose of research, analytic approach, available resources, and characteristics of the research sample (Bryman, 2012; Malterud, Siersma, & Guassora, 2015). However, the most common guiding principle for measuring the adequacy of a goal-directed sample is saturation (Morse, 2015). To establish the size of the sample for the individual interviews, the researcher addressed the common question: "How many interviews will be enough to reach data saturation?" (Guest, Bunce, & Johnson, 2006). Saturation is said to be reached when there is enough information to replicate the study (Walker, 2012), and when further coding is no longer feasible (Guest et al., 2006). One can conduct the study in a way to reach data saturation by collecting thick (quantity) and rich (quality) data (Dibley, 2011; Gerring, 2011; Porte, 2013). Thus, the current study involved a mixture of a quantitative and qualitative collection of both, thick and rich data, and the researcher continued recruiting participants for the interviews until saturation was reached, resulting in four YAs and five professionals.

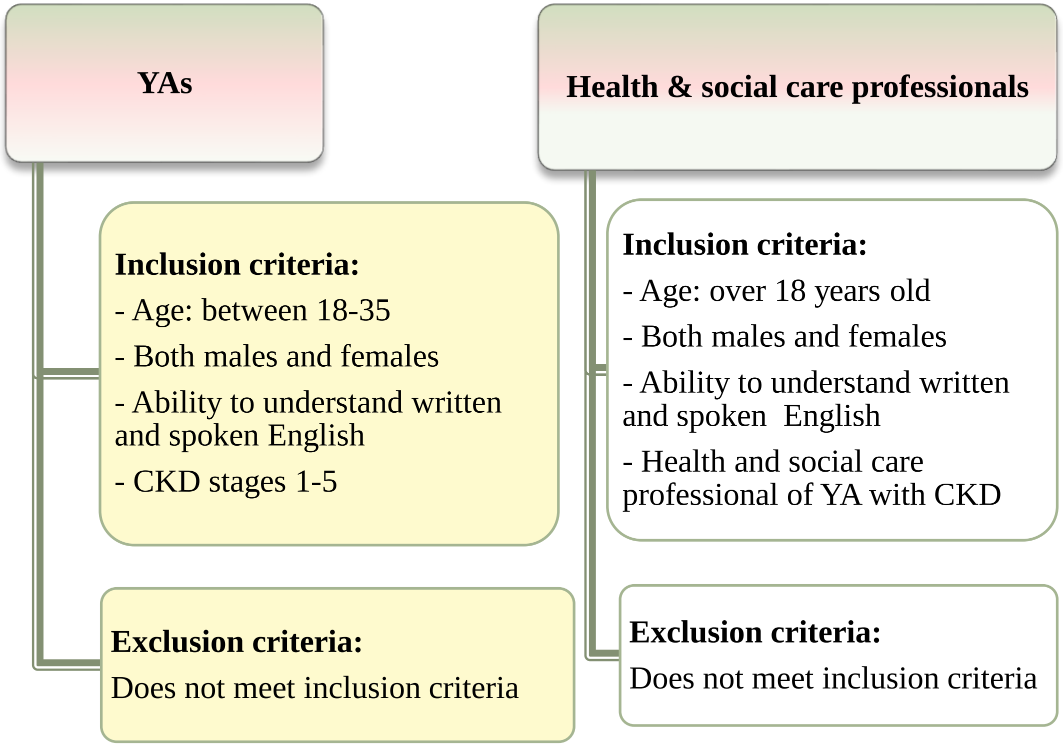
2.4.4 Participants and Eligibility Criteria

Phase 2 involved two different groups of participants, including YAs (study group 1) and health and social care professionals (study group 2). The inclusion criteria for YAs included both male and female participants, between 18-35 years of age who were diagnosed with CKD stages 1-5 and were able to understand written and spoken English. Whereas the inclusion criteria for professionals of YAs with CKD included both males and females, over 18 years old, and the ability to understand written and spoken English. Graphical representation of both groups of participants together with inclusion and exclusion criteria can be seen in Figure 2.2.

The inclusion of health and social care professionals alongside YAs in this research project was important to gain valuable insights into their viewpoints and the challenges they encounter when delivering care to YAs with CKD. It was aimed that their perspectives shed light on barriers and facilitators in current care practices, offering a broader understanding of the systemic issues that impact YA health outcomes. Their input was significant in refining intervention components to ensure they align with clinical best practices and are feasible within healthcare settings. Finally, by incorporating health and social care professionals in both quantitative and qualitative studies it was intended to enrich the research by capturing diverse viewpoints and fostering collaboration towards optimising CKD care for YAs.

Figure 2.2

Participants - Inclusion and Exclusion Criteria



CKD Chronic Kidney Disease; *YA* Young Adult.

2.4.5 Materials

The online questionnaires for this research were generated and distributed using Qualtrics software, Version 12/2020 of Qualtrics. Copyright © 2020 Qualtrics. (Qualtrics and all other Qualtrics product or service names are registered trademarks or trademarks of Qualtrics, Provo, UT, USA). Additionally, the Zoom Videoconferencing platform, which offers several features, including secure recording, transcribing, and storing of sessions, was used to collect qualitative data (Zoom Video Communications Inc., 2016). This innovative, cloud-based videoconferencing platform is commonly used as a research tool in qualitative and mixed-methods studies because of its relative security options, data management, ease of use, and cost-effectiveness (Archibald, Ambagtsheer, Casey, & Lawless, 2019).

In phase 2, the participants who provided a written consent form to take part in the research (refer to AppendicesAppendix D-H) and those who familiarised themselves with a participant information sheet (see Appendix I and Appendix J), were given a set of questionnaires, including some participant background information (YAs only). At the end of the study, the participants were provided with a debrief form (see

Appendix K). Below is a detailed description of the study instruments used for both groups of participants in the quantitative study.

Participant group 1 - YAs:

The participant background information sheet for YAs included 10 items (see Appendix L). Significant thresholds were employed to describe and present descriptive analysis and report the demographics of the sample. Particularly, participants' residence was recorded to establish geographic areas. Age was defined in years from the date the participants signed the study consent. Then, for gender, participants were categorised as males and females, and for education, they were split into four categories. Next, the participant's employment status was reported as employed or unemployed, and the household income (split into five categories and one category reporting "missing data") as well as the number of people living in the household was reported. Further, clinical characteristics included time since diagnoses (statistically analysed using an interval variable but presented in four categories in the descriptive presentation), stages of CKD split into six different levels of the disease for descriptive presentation (but two levels were used for inferential statistics: early-CKD stages: 1-3a/b, and late-CKD stages: 4-5; Inker et al., 2014), and the existence of comorbidities. It also included health-related behaviours, which reported the participants' smoking status (smokers vs. non-smokers), alcohol consumption (divided into four risk levels), diet and physical activity (with three different levels: low, medium, and high, respectively). Finally, descriptive statistics from standardised measures (see below) were reported and some of these variables were later analysed using inferential statistics (refer to Chapter 6). YAs were asked to complete a set of questionnaires related to:

1. CKD self-management - Partners In Health (PIH) scale (Battersby, Ask, Reece, Markwick, & Collins, 2003; 12 items) (see Appendix M)
2. Self-efficacy - Self-Efficacy for Managing Chronic Disease (SEMCD; Lorig et al., 2001; six items) (see Appendix N)
3. Health-related behaviours questionnaire (see Appendix O; including:

- Smoking behaviour: one question developed by the researcher
- Alcohol consumption - the Alcohol Use Disorders Test Consumption Questions Scale (AUDIT-C; Bush, Kiylahan, McDonell, Fihn, & Bradley, 1998; three items)
- Diet - the Self-Regulation of Eating Behaviour Questionnaire (SREBQ; Kliemann, Beeken, Wardle, & Johnson, 2016; five items)
- Physical activity - the International Physical Activity Questionnaire Short Form (IPAQ-SF; Craig et al., 2003; seven items)

4. Psychological distress - the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983; 14 items) (see Appendix P)
5. Health-Related Quality of Life (HRQoL) - the Short-Form Health Survey-12-Items (SF-12 Health Survey, version 1.0; Ware, Kosinski & Keller, 1996; 12 items) (see Appendix Q)

6. CKD knowledge - the CKD Self-Management Knowledge Tool (CKD-SMKT; Devraj & Wallace, 2013; 11 items) (see Appendix R)
7. Patient activation - the short version of the Patient Activation Measure (PAM; Hibbard et al., 2005; 13 items) (see Appendix S)

Additionally, a small amount of textual qualitative data was collected from the survey by asking the participants six questions related to the existence and use of person-centred care (PCC) plans and six questions concerning YAs' preferences for support delivery. The researcher analysed and reported this data by organising it into categories to determine the frequency of each category being mentioned by YA participants. Finally, the responses across all 10 areas of self-management support (SMS) previously identified by Havas et al. (2016) as needing additional support (from 0 "not at all" to 10 "very much") and one additional question asking for any further suggestions were analysed and the mean responses were reported.

8. CKD self-management and PCC plans (see Appendix T), including:
    - Questions related to PCC plans, developed by the researcher (six items)
    - 10 areas of SMS identified by Havas et al. (2016) that require additional support, and one additional question (11 items)
    - Six questions regarding the preferences for the delivery of the self-management intervention, taken from Havas et al.' (2017a) study (six items)

Psychometric properties of standardised instruments for YAs:

A description of the measures and their psychometric properties for each standardised instrument for YAs is provided below, taking into account whether the measurement has proven reliability and validity (Polit & Tatano-Beck, 2008) with a Cronbach Alpha coefficient α above 0.70 being desirable (Field, 2009).

PIH scale:

PIH is a 12-item self-administered measure developed by Battersby et al. (2003), which aims to assess self-management behaviour and knowledge in individuals with chronic conditions. Self-care habits are assessed with 12 questions (from four subscales: “knowledge”, “coping”, “symptoms management”, and treatment adherence”), scored on a zero to eight scale, with zero indicating “very little, never, or not very well”, and eight indicating “a lot, always, or very well”. The mean score was determined, with a higher score indicating better self-management behaviour and knowledge.

Petkov et al., (2010) measured the construct validity and internal reliability of the PIH scale. Psychometric analysis of the explanatory sample (N=176) showed high internal consistency with a Cronbach Alpha coefficient of 0.88. The authors confirmed that the PIH scale displays construct validity and internal reliability, and it is a comprehensive measure of health-related outcomes for individuals involved in a variety of chronic condition management and self-management programmes. It has been established that the PIH scale produces consistent reliable indications of the individual’s chronic condition self-management skills and knowledge.

SEMCD:

Self-efficacy, the confidence to perform certain behaviours to achieve a specific goal, was assessed using SEMCD developed by Lorig and colleagues in 2001. SEMCD is a self-reported instrument made up of a six-item scale (related to managing: 1-fatigue, 2-physical discomfort/pain, 3-emotional distress, 4-other symptoms/health problems, 5-tasks/activities required to manage health conditions, and 6-things other than just taking medication) ranging from one (not at all confident) to 10 (totally confident), with a total score ranging from zero to 60. The mean score of six items was determined, with a higher score indicating higher self-efficacy (Lorig et al., 2001).

Ritter and Lorig (2014) reviewed eight independent studies and conducted two new studies in order to test the psychometric properties of the SEMCD, and reported a Cronbach Alpha coefficient of a minimum of 0.88 across all studies, which indicates high internal consistency. SEMD appears to be a reliable and valid measure for assessing self-efficacy for managing chronic conditions, and it is applicable across a variety of programmes, different countries as well as for individuals with various diseases (Ritter & Lorig, 2014).

AUDIT-C:

Alcohol use was measured with AUDIT-C (AUDIT's questions one to three), which assessed the frequency of drinking, the number of drinks consumed on a typical drinking day, and the frequency of binge drinking (Bush et al., 1998). The original, full-scale version of AUDIT also includes questions related to alcohol dependence (questions four to six) and issues related to alcohol consumption (questions seven to 10) (Shevlin & Smith, 2007). Several studies have validated the AUDIT scale and reached improved specificity and sensitivity values with diverse cut-off points (Adewuya, 2005). It has also been established that males and females require different cut-off points (Dawson, Grant, & Stinson, 2005; Dybek et al., 2006; Reinert & Allen, 2007). AUDIT is applicable across a variety of settings, including primary care settings as well as health care and community settings (Lima et al., 2005).

Additionally, given the need for a faster way to apply screening instruments and the high internal consistency of the AUDIT full-version, the abbreviated versions of the full-scale were developed. The present study used the AUDIT-C reduced version, which included the first three questions of the full scale, measured on a scale of zero to 12, with zero indicating no alcohol use (Bischof et al., 2007). Consistent with AUDIT-C, the higher the score, the more likely it is that the individuals' drinking is affecting their health and safety. In men, a score of four or more indicates risky drinking, and in women, a score of three or more specifies the threshold for risky drinking (Bradley et al., 2003; 2007). This abbreviated version of AUDIT has been validated in several studies (e.g., Dawson, Grant, Stinson, & Zhou, 2005; Frank et al., 2008). For instance, one study by Osaki and colleagues (2014) examined the psychometric properties of the AUDIT-C among the general population in Japan, and reported high reliability and validity of the scale with a Cronbach Alpha coefficient α=0.98, indicating that AUDIT-C is a useful measure for identifying risky drinking or alcohol use disorders.

SREBQ:

SREBQ developed by Kliemann and colleagues (2016) was used to assess the individuals' capacity to self-regulate or control their eating behaviour. The questionnaire comprises two parts. The first part involves screening questions (questions one to three) applied to exclude those who do not have healthy eating intentions. The second part of SREBQ involves a measure of self-regulation skills on eating behaviour (question four) which includes five questions with the answer options represented on a five-point Likert scale (never, rarely, sometimes, often, and always). Items one, three, and five of the SREBQ question four were coded reversed as per recommendations, and then the mean score was calculated (Kliemann et al., 2016). To gain a greater overview of the self-regulation skills on eating behaviour, the responses were divided into the official categories (Kliemann et al., 2016): "low" (<2.8), "middle" (2.8-3.6), and "high" (>3.6), with a higher score indicating better self-regulative skills on eating behaviour.

Additionally, this novel measure of eating self-regulatory capacity has been confirmed to be consistent, valid, and reliable for use in the general adult population in the UK (Cronbach's α=0.75; Kliemann et al., 2016). According to the authors' validation study, the SREBQ measures individuals' ability to control and manage their eating behaviour to attain and/or sustain their eating intentions (Kliemann et al., 2016). Most recently, psychometric properties of the SREBQ (German version) were assessed by Schmalbach and colleagues (2021) who concluded from their study that SREBQ comprises good reliability and validity, and is applicable in psychological, nutritional, and medical research.

IPAQ-SF:

IPAQ is one of the most widely used physical activity measures (van Poppel, Chinapaw, Mokkink, van Mechelen, & Terwee, 2010), with two versions available, including the nine-item short-form (IPAQ-SF; which was used in the current study), and 31-item long-form (IPAQ-LF). IPAQ-SF collects information on the time (e.g., number of days and average time per day) spent being physically active. It includes seven questions to record the activity of three different intensity levels, including 1) vigorous-intensity activities, 2) moderate-intensity activities, and 3) walking. These activity levels can be calculated and reported as both, continuous and/or categorical variables. In the current study, a spreadsheet for automatic scoring of the IPAQ-SF developed by Cheng (2016) was used. This Microsoft Excel spreadsheet was generated based on the "*Guidelines for Data Processing and Analysis of the International Physical Activity Questionnaire (IPAQ) Short and Long forms*" (IPAQ Group, 2005). The responses were recorded as a categorical variable, which included three levels of physical activity: low, moderate and high. The "high" category is used to define a higher level of total physical activity, the "moderate" category is described as doing some activity, whereas the "low" category specifies not meeting any criteria for any of the previous categories, indicating a "low" physical activity level.

The reliability and validity of the IPAQ-SF were originally tested across 12 countries, among individuals aged between 16 and 69 years old. Given its acceptable reliability (Cronbach α between .63 and .85; IPAQ, 2016), the authors recommended the use of the short-form of the questionnaire that assesses physical activity by self-report over the previous seven days (Craig et al., 2003). Since then, more validation studies have been published, mainly for the short-form of IPAQ (van Poppel et al., 2010).

HADS:

HADS includes 14 items, seven of which assess levels of Anxiety (HADS-A), and the other seven assess levels of Depression (HADS-D), where each item is coded from zero to three. Thus, the total scores for anxiety and depression can vary from zero to 21, depending on the occurrence and severity of the symptoms. Zigmond and Snaith (1983) have suggested thresholds or cut-off points as follows: a score between zero and seven indicates that there is no presence of anxiety or depression symptoms; a score between eight and 10 suggests that there is a presence of the symptoms of anxiety and depression, however to a moderate degree; and a score equal or higher than 11 shows a significant number of the presence of the symptomology.

Bjelland, Dahl, Haug, and Neckelmann (2002) reviewed 747 studies concerning the accuracy of the above-mentioned thresholds, and all showed to be reliable. Bjelland et al. (2002) concluded from their study that the cut-off point of eight is conclusive to not exclude individuals who suffer from anxiety or depression, which would happen if the cut-off point of 10 alone was taken into account. The researchers have also reported Cronbach’s alpha for the HADS-A subscale which varied from 0.68 to 0.93, and for the HADS-D subscale which varied from 0.67 to 0.90. Since this review, further research has assessed the HADS’s specificity and sensitivity in England (Poole & Morgan, 2006), Germany (Hinz & Brahler, 2011), and Norway (Olsson, Mykletun, & Dahl, 2005), and all recommended the cut-off point of eight for both (anxiety and depression) subscales. The concurrent validity of each of the two scales has been established in individuals who suffer from several pathologies, in different countries, and with various methodologies (standardised tools and/or interviews) (e.g., Michopoulos et al., 2008; Muszbek et al., 2006; Mystakidou et al., 2004; Sultan, Luminet, & Hartemann, 2009).

SF-12 Health Survey:

SF-12 Health Survey is the abbreviated version of the 36-item Short-Form Health Survey (SF-36) that was developed as an applicable measurement for assessing HRQoL (Ware, et al., 1996). SF-12 Health Survey is a measure used to assess generic health outcomes from the individual’s perspective. Generic patient-reported outcome measures (PROMs) like the SF-12 Health Survey assess general health and well-being (or HRQoL), together with the impact of any and all diseases on a wide range of functional domains. SF-12 contains a subset of 12 items from SF-36, including the same eight domains of health outcomes: physical functioning (1), role-physical (2), bodily pain (3), general health (4), vitality (5), social functioning (6), role-emotional (7), and mental health (8). In order to score and report SF-12, an online tool (Ortho ToolKit, 2021) was employed. Two summary scores were reported from SF-

12, including a mental component score (MCS-12) and a physical component score (PCS-12), where higher scores represented better health.

The SF-12 Health Survey's psychometric properties have been widely examined in several studies worldwide, and all results have suggested the instrument is a valid and reliable measure, which can be used in various population groups (e.g., Brown, Lee, Joshi, & Pashos, 2009; Cheak-Zamora, Wyrwich, & McBride, 2009; Fong et al., 2009; Gandhi et al., 2001; Hoffman et al., 2005; Jayasinghe et al., 2009; Lam & Tse, 2005; Lee, Browell, & Jones, 2008; Linde et al., 2009; Sutton & Raines, 2008). Most recently, Shah and Brown (2020), examined the reliability and validity of the SF-12 Health Survey's PCS and MCS scores in an older US population and reported a high internal consistency for both, PCS (Cronbach's α=0.87) and MCS (Cronbach's α=0.86), and good and moderate validity (interclass correlation coefficient; ICC; PCS=0.79; MCS=0.59).

CKD-SMKT:

CKD-SMKT developed by Devraj and Wallace (2013) is a brief 11-item measure suitable for administration to all kidney disease individuals, including those patients with low health literacy skills. The responders are asked to answer the questions related to the knowledge aspect for each CKD-SMKT behaviour item (sections A and B), using the responses: "true", "false", or "don't know", and then to indicate whether they had performed the respective behaviours in the past three to six months using a dichotomous "yes or no" response. The last, 11th question (section C) relates to the overall knowledge of their kidney health with responses ranging from 1 ("I know everything I need to know") to 5 ("I know nothing"). The percentage of correct responses was recorded.

The authors of CKD-SMKT concluded from their validation study that the instrument is content valid, designed to measure the individual's kidney disease knowledge of several key self-management behaviours, and is suitable to use in the clinical setting (content validity ratio of 11 items >0.49, $p>.05$, and an overall Lexile score of the final CKD-SMKT of 470, correspondent to a ≈3rd-grade reading level; Devraj & Wallace, 2013). Thus, CKD-SMKT has been content validated and reported in the previous study (Devraj et al., 2015).

PAM-13:

The short version of the PAM developed by Hibbard and colleagues (2005) from the 22-item version (Hibbard et al., 2004), was applied to measure a participant's self-management ability. The PAM's short version includes 13 items measured on a five-point Likert scale (with responses ranging from one - strongly disagree, to four - strongly agree, and an additional response option - "not applicable"), where a higher score suggests a higher level of activation. The PAM's short version indicates how ready, willing, and able a person is to manage their health and healthcare. In other words, this instrument determines health engagement and thus self-reported behaviours, skills, confidence, and knowledge for chronic disease self-management. To calculate the total PAM score, the raw score was divided by the number of items answered (except non-applicable items) and multiplied by 13. On completion of the PAM-13, the participants fell into one of four levels of activation, including "low activation" (levels 1 and 2), "higher activation" (level 3), and "highest activation" (level 4). Level 1 represents patient activation as "disengaged and overwhelmed", level 2 as "becoming aware, but still struggling", level 3 as "taking action and gaining control", and level 4 of patient activation indicates "maintaining behaviours and pushing further". The researcher obtained the research licence for PAM-13 from Insignia Health (licence number: 1619433407-1650969407) and employed their Excel tool to collect and score PAM-13.

The instrument has been validated in the early stage with demonstrated reliability and validity (Hibbard et al., 2004). The validation of the short version of PAM has been assessed across different settings, population groups, and various illnesses (e.g., Ahn, Yi, Ham, & Kim, 2014; Brenk-Franz et al., 2013; Hung et al., 2013; Packer et al., 2015; Skolasky et al., 2011; Stepleman et al., 2010; Zill et al., 2013). For instance, Prey and colleagues (2016) examined the reliability and validity of PAM-13 in the inpatient setting and reported from their study that it confirmed satisfactory internal consistency overall (Cronbach's α=0.81).

A summary of survey questions for YAs can be seen in Appendix U, including the Figure presenting the self-efficacy model as a rationale for selecting specific outcomes and outcome measures in the current study.

Participant group 2 - professionals:

The second group of participants completed the survey which included two sections (see Appendix V). Section 1 asked eight questions related to PCC plans, including their presence, use, and personalisation, and the results from this section were also analysed and presented in the form of textual qualitative data. Section 2 of the survey also comprised questions related to previously identified 10 areas of CKD self-management (Havas et al., 2016) and an additional question for further suggestions. In this section, professionals rated the extent to which they believe that YAs require support with recognised areas of support and it was analysed using exploratory analysis.

2.4.6 Procedure and Data Collection

Participant's identification and recruitment:

This study involved two research sites, the Kidney Wales Foundation in Cardiff, and the NHS site (the Cardiff and Vale University Health Board; CVUHB). The researcher employed the assistance of one staff member from the Kidney Wales Foundation (Patient Information and Support Manager), and NHS staff members (Renal Youth Worker and Renal Social Worker) who were acting as the study gatekeepers. Their role was to screen both groups of participants for eligibility against the study inclusion and exclusion criteria to identify potential participants. They were also involved in advertising the study via social media (such as Facebook, Twitter, Instagram, Kidney Wales website, etc.) and by distributing and displaying advertising flyers and posters developed by the researcher and designed by the professional designer (see Appendix W) at the Cardiff office and NHS clinics. Due to difficulties in recruiting participants during the pandemic, several other organisations were involved in publicising the study on social media platforms and by displaying advertising materials in their organisations, including the National Kidney Federation, Welsh Kidney Research Unit, Kidney Care UK, Kidney Research UK, and some Renal Social Workers.

Once the study gatekeepers identified potential participants, they contacted them via email using a template generated by the researcher (see

Appendix X), to inform them about the study and seek expressions of interest to take part. The gatekeepers' role was also to briefly inform eligible participants about the study and ask for their permission to be contacted by the researcher using the "consent-to-contact" form (see Appendix Y). Once initial contact and expressions of interest had been made, the researcher contacted all potential participants. The researcher did not meet with the participants in person due to the COVID restrictions but instead corresponded via email to discuss the research in more detail and answer any questions they had while providing them with a detailed participant information sheet. The advertising emails, flyers, posters, and video (available upon request) included the researcher’s contact details so any potential participants, interested in taking part in the study, could contact the researcher directly. The participant identification and recruitment process began in December 2019, just before the Christmas period, therefore the study gatekeepers sent a “friendly reminder” a few weeks after the initial emails and re-posted the information about the study on social media regularly to remind the potential participants about the research that they may be interested in. The recruitment process ended in August 2022 as the researcher’s PhD candidature was coming to an end and no further progress in the recruitment process was made. The last interested participant enrolled in May 2022.

Participants’ consent:

Once participants agreed to take part in the study, the researcher obtained written consent. The participants were given a copy of the consent form at the same time as the participant's information sheet, before the commencement of the study, to ensure that all participants fully understood and considered what was being asked of them. They were able to take their time to read and understand the information on the participant's information sheet and discuss and sign the consent form before data collection began.

In this study, consent was an ongoing process, assuming participants’ capacity unless they proved otherwise. The consent form was designed to promote understanding, excluding those unable to give consent. Participation was voluntary, with no impact on their care, and their welfare was a top priority. Moreover, because the studies took part online, if participants wished to take part but were physically unable to fill in the questionnaires, had literacy or sensory impairments that affected their ability to complete the questionnaire, they were provided with the researcher’s contact details if they had any questions, required help, or wished to withdraw from the study. Participants were reminded that they could withdraw at any time, up until the data was anonymised.

Additionally, given that the future stages of work (phase 2 part 2, and initial intentions for phases 3 and 4) were going to be designed in line with the findings from phase 2 part 1, the consent form included a section informing the participants about the next phases of the research and seeking their consent to be contacted by the researcher in the future, without any obligation to participate in the future studies. Therefore, the consent for YAs was separated into 3 parts (refer to Appendices: D, E, and F), while health and social care professionals were given two-part consent forms (refer to Appendices: G and H). Note that, professionals were not asked to participate in future phases of the study, and due to the low recruitment rate, all participants were advised by email that the focus groups were no longer available.

Data collection - survey:

The data collection took place between December 2019 and August 2022. The participants who gave their consent to take part in the research were asked to complete a set of questionnaires, followed by semi-structured interviews, which were optional. It was estimated that completing the questionnaires would take YAs approximately 30-40 minutes and the questionnaires to be completed by professionals would take approximately 5-10 minutes. Following the survey, participants were thanked for their time and participation and they were provided with a detailed debrief information sheet (refer to

Appendix K) which was distributed via email to inform them of the nature and outcome of the research, the potential risks as well as the contact details of the researcher and the research supervisor should they have any further questions or concerns about the research.

Data collection - semi-structured interviews:

Shortly after completion of the questionnaire, participants were invited via email to take part in the semi-structured individual interviews (see Appendix Z for an invitation email sent and the example of available dates and time slots). Those participants who agreed to take part in the interviews were invited to participate in the interviews over the telephone or via video conference (Zoom), all choosing the latter. The duration of the semi-structured interviews depended on how engaged in the conversation the participants were, however, it was estimated to take between 30-60 minutes.

The researcher and all study gatekeepers completed a Good Clinical Practice course and registered for “be INFOrMED” at CVUHB (see Appendix AA for the researcher’s certificate and

Appendix BB for “be informed” registration). During the interviews, the researcher welcomed participants, introduced herself and thanked them for taking part in the study. Following this, the researcher provided a brief overview of the study topics, confirmed that participants signed the consent form and checked if they had any questions. The researcher confirmed that participants were comfortable and willing to continue and were happy for the interviews to be audio-recorded. Then, the researcher began the interviews by asking for some background information and then moved on to discuss the main topics. Throughout the interviews, the researcher encouraged participants to expand on their responses by using open-ended questions, using a formerly prepared topic guide to guide the interviews (see Appendix CC for a topic guide and schedule for both groups of participants).

Finally, at the end of each interview, participants were thanked for their time and participation, and they were once more provided with the debrief information sheet. The researcher also reminded YA participants that those who agreed to be contacted about the next phases of the research on the consent form may be invited to take part in the future, without any obligation to participate in future studies. The schedule of procedures for the overall study and phase 2 can be seen in the protocol for this phase in additional file 2 (available upon request).

2.5 Phase 2 - Data Analysis and Synthesis

Data analysis and synthesis for phase 2 are presented below, beginning with part 1 questionnaire-based study, and following with part 2, semi-structured interviews. Then the findings from these two studies are provided in Chapters 6 and 7 accordingly.

2.5.1 Quantitative Study - Research Aims, Objectives and Hypotheses

The evidence discussed throughout this thesis shows that there is an increasing focus towards supporting individuals with CKD to self-manage their condition, however, self-management practices and patient activation levels within this population remain low. Special attention from HCPs is required to support YAs to learn to take control of their CKD; thus, it is important to establish if they are ready to do so. In particular, it is important to examine whether they understand what to do and how (knowledge), if they can perform essential behaviours (skills), and whether they feel confident (self-efficacy) that they can do it.

The relationship between these three variables was previously examined (e.g., Wu et al., 2016) and the role of self-efficacy as a mediator in the relationship between CKD knowledge and self-management was reported. Although some further studies concluded that self-efficacy is also a predictor of self-management (e.g., Chuang et al., 2021) the predicting effect of self-efficacy was not explored extensively. Similarly, patient activation (which to some extent overlaps with self-efficacy) and its predicting effect on self-management is unclear. Given the common low baseline self-efficacy in younger individuals as identified in the present literature review (refer to Chapter 3), and the importance of patient activation, particularly the documented lower activation level in those who suffer from CKD compared to those with other long-term conditions (LTCs; e.g., Gair et al., 2019), it was decided to examine self-efficacy and patient activation as predictors of self-management behaviours in YAs with CKD, while controlling for time since diagnosis.

The time since diagnosis as a covariate for the above regression analysis was selected based on their potential association with the predictor variables (self-efficacy and patient activation), and their impact on changes in the association between the predictors and outcome variable (self-management). Previous studies that included the assessment of time since diagnosis variable reported that a longer disease duration (from initial diagnosis) relates to improved self-efficacy and self-management (Lai et al., 2021). A study by Tsai et al. (2021) found that the duration of CKD influences CKD knowledge and self-care behaviour. Similarly, Wu et al. (2022) observed that individuals with end-stage kidney disease (ESKD) have higher self-care knowledge compared to those with an early-stage CKD, likely due to longer disease duration and increased health education exposure. Additionally, Harwood et al. (2005) proposed that individuals with later-stage CKD are keen to learn and wish they valued the significance of self-management in the past. Havas et al.’s (2017a) study supports this by suggesting that those who live with CKD longer (over 10 years) show a stronger desire for support compared to those who live with CKD for a shorter period. Therefore, based on the previous findings suggesting the potential influence of time since diagnosis on self-efficacy and self-management, in order to exclude this impact from the current analysis, it was decided to include time since diagnosis as a covariate in multiple linear regression analysis.

Further, to support Havas et al.’s (2016) study, we also aim to examine the 10 areas of SMS pre-identified by authors and determine whether YAs’ time since diagnosis will predict their interest in receiving SMS across all 10 areas while controlling for their level of self-efficacy, as well as how these desires for support will differ across YAs with different CKD stages (early-CKD stages: 1-3a/b versus late-CKD stages: 4-5). Finally, we aim to assess the variances in responses across all 10 recognised areas of receiving SMS between YAs and their professionals. Accordingly, the following hypotheses are considered and presented in Table 2.2 below.

Table 2.2

Quantitative Study's Aims and Hypotheses

Analyses:	Aims:	Hypotheses:
1 (Multiple linear regression analysis)	Influence of self-efficacy and patient activation (predictors) on self-management behaviours (outcome) with time since diagnosis as a covariate	**H_1:** the YAs' levels of self-efficacy and patient activation will be significant predictors of their level of self-management behaviours while controlling for time since diagnosis
2 and 3 (Multiple linear regression analysis and the independent-sample t-test for group comparison)	Influence of time since diagnosis (predictor) on 10 SMS areas (outcome) with self-efficacy as a covariate, as well as, whether the level of interest in receiving SMS differs based on the stage of CKD	Those YAs who have been living with CKD for a long time and are in the later stages will desire the support more compared to those who had CKD for a shorter period and are at earlier stages of CKD while controlling for their level of self-efficacy. Thus: **H_2:** There will be a significant impact of time since diagnosis on 10 SMS areas while controlling for self-efficacy **H_3:** There will be a significant difference between the level of interest in receiving SMS based on the stage of CKD
4 (Independent-sample t-test)	The difference in responses regarding YAs' interest in receiving SMS across 10 areas between two groups of participants (YAs vs. health and social care professionals)	**H_4:** There will be significant differences in responses regarding YAs' interest in receiving SMS across 10 areas between YAs and their professionals

CKD Chronic Kidney Disease; *SMS* Self-Management Intervention; *YA* Young Adult.

2.5.2 Statistical Analysis and Synthesis - Survey

Statistical analyses were conducted using the IBM Statistical Package for the Social Sciences (SPSS), version 26 (IBM Corp., 2019) and later updated to version 28 (IBM Corp., 2021). In order to examine the independent association between self-efficacy, patient activation, and self-management behaviours, while controlling for time since diagnosis (*hypothesis 1*), a linear multiple regression analysis was applied using the enter method (including all relevant variables simultaneously). Similarly, *hypothesis 2* was also tested with regression analysis using the enter method to examine the independent association between time since diagnosis and the average across all 10 recognised SMS areas, while controlling for self-efficacy. Further, to establish whether the level of interest in receiving SMS differs based on YAs' CKD stage (early vs. late-CKD stage), the independent two-sample t-test was employed (*hypothesis 3*). The t-test was also used to examine the difference in mean responses about the interest across all 10 recognised areas of receiving SMS between YAs and their professionals (*hypothesis 4*). Finally, data concerning PCC plans, from both groups of participants, and YAs' preferences for support delivery was presented textually.

All recruited YAs (N=18) were included in the current statistical analysis and synthesis. Multiple regression was chosen for the main analyses in the current study as this method allows for the control of potential confounders, providing clearer insights into the unique contributions of each predictor. Despite the small sample size, all other assumptions of regression analyses were met (see below), suggesting the validity of the parametric tests. Additionally, even with a small sample, multiple regression can offer valuable preliminary insights into the relationships between variables, which are significant for guiding targeted interventions and informing future research. The specific focus on YAs with CKD means that the findings, even from a small sample, can provide important context-specific insights. The results can serve as pilot data, offering a foundation for more extensive studies and aiding to refine hypotheses for subsequent research efforts. Other types of analyses were considered, for instance, a correlation analysis, however, it is argued that this analysis requires also at least 30 participants (Fraenkel, Hyun, & Wallen, 2012), thus employing multiple linear regression analysis appeared more appropriate if sufficient data were available.

Firstly, data were checked for outliers (defined by investigation of residuals for regression analyses and by visual inspection of the boxplots for t-tests, refer to Appendices DD-GG), and then for any missing values. Consequently, no serious outliers were recognised, and a few missing values were identified (less than two percent) which were imputed using the mean responses. Then, the descriptive statistics were calculated and presented as ranges, mean (M) and standard deviation (SD) for continuous variables, as well as frequencies (n) and percentages (%) for categorical variables, in order to describe the participants' demographic characteristics. Then, the descriptive characteristics of the measured variables were calculated and reported as clinical characteristics, and the median scores with interquartile range (IQR) were used to summarise the continuous variables, and frequencies (n) and percentages (%) to present the categorical variables. However, note that, mostly, continuous variables were used for analyses to increase statistical power given the small sample size in the current study.

Determining the distribution of variables is important for choosing an appropriate statistical method (particularly when dealing with a small sample size), thus prior to analysing the quantitative data, the assumptions of regression analyses were examined, for example, the normality of variables, linearity, homoscedasticity, and multicollinearity (Field, 2009; see Appendix DD and Appendix EE for assumptions testing for both regression analyses 1 and 2). The assumptions of the independent-sample t-tests were also examined, for example, the independence of observations, normality, and homogeneity of variance (see Appendix FF and Appendix GG for assumptions testing for both analyses 3 and 4). Apart from the sample size, all assumptions were met for all four analyses, thus parametric tests were employed in the current research. Note that, a *p*-value less than or equal to .05 was set as a significance threshold in the below analyses.

2.5.3 Thematic Analysis and Synthesis - Interviews

Qualitative semi-structured interviews were conducted to complement the quantitative data and identify existing self-management behaviours among YAs (18-35 years old) living with CKD and to further answer research questions by gaining the participants' experiences and views. Specific for this part of the phase 2 question was: *How does CKD affect YAs and what do they require to effectively self-manage their condition?*

In the current study, a topic guide was employed to guide semi-structured interviews (refer to Appendix CC). However, it allowed other relevant themes to emerge throughout the interviews (Choak, 2012), thus the interviews resembled a "flowing conversation" (Rubin & Rubin, 2005) where participants were encouraged to elaborate on their responses or other related areas. In this qualitative study, the method of analysis was driven by research questions and broad epistemological assumptions. Thematic analysis (TA) is a flexible approach, which can be employed across various research questions and epistemologies (Braun & Clarke, 2006). TA is an appropriate method to use when the researcher seeks to understand views, thoughts, experiences, or behaviours across a data set (Braun & Clarke, 2012). TA was chosen for this study as it sought to understand the views and experiences of YAs living with CKD and those who look after them, particularly health and social care professionals.

Generally, qualitative researchers recognise TA as their method of analysing data, however, they often fail to provide a clear explanation of the strategies used to make sense of their data (Campbell et al., 2021). Reflexive TA proposed by Braun and Clarke (2006; 2019), is an analytical method decisively placed within a qualitative paradigm, and per se a feasible analytic option for qualitative health researchers (Campbell et al., 2021). As opposed to other approaches to analysing the qualitative data (some of which were considered for the current analysis), for instance, grounded theory (Glaser, 1992; Strauss & Corbin, 1998) or framework analysis (Smith & Firth, 2011), reflexive TA is defined as independent of epistemology and theory which allows comprehensive and flexible application of the analytic method across various epistemologies, including constructionist and essentialist paradigms (Braun & Clarke, 2006). This method has become the most widely adopted method of TA and was deemed the most appropriate method of analysis for the current qualitative study (Clarke & Braun, 2017; Howitt & Cramer, 2007). The current TA follows the guidelines for the application of TA by Braun and Clarke (2006) together with their contemporary approaches (e.g., Braun & Clarke, 2019; 2020). Their guideline developed in 2006 was considered because of its flexibility as one of the advantages of TA, and an attempt has been made to use both inductive and deductive coding, also known as the hybrid approach to coding (Fereday & Muir-Cochrane, 2006).

Semi-structured interviews in the current study covered two main topics: the challenges associated with CKD, specific to YAs (Topic 1) and CKD self-management (Topic 2). The interviews were audio-recorded and transcribed verbatim to extract and code data using thematic synthesis. According to Attride-Stirling (2001), qualitative researchers must be clear about what and why they are doing as well as the frequently omitted "how" they analysed their data. To promote the flexibility of reflexive TA but ensure its quality and the trustworthiness of findings, the analysis involved six reflexive steps as recommended by Braun and Clarke (2006), (1) familiarising oneself with the data; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) producing the report. Note that these steps are not necessarily unique to TA as some of them overlap with the phases of other qualitative analyses.

Reflexivity:

Before analysing the qualitative data, the researcher made critical decisions regarding, for example, themes, types, and levels of analysis, as well as considered reflexivity as a process of self-examination, which involved self-awareness (Lambert, Jomee, & McSherry, 2010), and reflecting on oneself as an individual and researcher while considering personal biases which may have influenced the research process (Berger, 2015; Patton, 2014). As per Thurairajah (2018), it was a continuous process, which placed the researcher within an analytic activity that involved reflection on, for example, ethnicity, race, age, gender, and so on. The researcher engaged in reflective exercise throughout all aspects of the research through individual self-examination of personal assumptions and biases, and the consideration of the analytic process. After careful reflection on the latter, the researcher decided on the analytic process described in detail below. The researcher continued reflective exercises and discussions with research supervisors throughout all steps, which was a recursive rather than linear process, where the researcher moved back and forth throughout the steps as required (Braun & Clarke, 2006).

In addition, the research question for this qualitative study was addressed within a paradigmatic framework of interpretivism and constructivism. A main principle adopted in this study was to reflect YAs' and their health and social care professionals' views, opinions, and experiences as authentically as possible, while also accounting for the reflexive influence of my own interpretations. Thus, the reflexive TA was considered to be an appropriate method for this study in the context of the underlying theoretical and paradigmatic assumptions addressed before implementing (and reviewed during) the current TA. These assumptions and why these conceptualisations are appropriate to answering the current research questions are briefly described below.

Methodological assumptions:

Constructionist epistemology was considered over essentialist epistemology as the current TA not only considered the recurrence of noticeably significant information when developing and interpreting codes and themes but also its meaningfulness. By adopting constructionist epistemology, we acknowledged and appreciated the meaning and meaningfulness as the essential criteria while coding. In order to further emphasise meaning and meaningfulness as attributed by participants, the experimental orientation to data interpretation was adopted over the critical orientation. Implementing this approach meant that data analysis did not aim to make claims about the social construction of the research topic (critical perspective), but rather recognise its socially constructed nature when investigating the subjective, personal states of participants (experimental perspective).

Additionally, it was decided to combine both inductive and deductive analyses (described in more detail in step 2 below). According to several publications by Braun and Clarke (2012; 2013; 2019; 2020), the analysis hardly ever falls into just one of these approaches and more frequently it involves a mixture of both. Although the current analysis involved a major element of inductive methodology, the hybrid method of coding was chosen as some of the interview questions were generated before the interviews, and designed to complement some of the quantitative questions and explore them in greater depth, however, it also allowed for "data-driven" analysis. The researcher also engaged in the relevant literature prior to the qualitative analysis (in phase 1 of this project) which enhanced the deductive approach. Similarly, the current analysis also combined a mixture of semantic (descriptive) coding, and when relevant the analysis is broadened, moving on from descriptive to a latent (interpretive) level of coding. This meant that semantic coding was utilised when interpreting meaningful semantic information communicated by participants, and latent coding was used following the latent meaning communicated by the researcher, which was reflective of the paradigmatic framework of interpretivism and constructivism adopted in this study.

The analytical process:

Step 1: Familiarising oneself with the data:

The researcher began the process of familiarising oneself with data (during and post-data collection) by transcribing the interview data. The Zoom Videoconferencing platform was used to record and transcribe the data, however, to safeguard that the interviews were transcribed word-by-word and to avoid missing any data, the researcher listened to each recording while reading the hard copy of transcriptions ensuring that they were transcribed precisely. Consequently, by transcribing the interviews, the researcher began familiarising with the data. Some argue that transcribing data should be perceived as the main step in data analysis (Bird, 2005). The process of familiarisation involved repeated listening and reading of the data, correcting orthography, noting down initial ideas, pauses and tones, and searching for possible patterns and meanings within the data, and it continued throughout the whole analysis.

Step 2: Generating initial codes:

Following active familiarisation with the data, the researcher began organising data by generating initial codes, that is organising it into meaningful groups (Tuckett, 2005). Data was organised in a meaningful and systematic way by writing notes using the "comments" function in Microsoft Word (2021) as well as highlighting all potential patterns with different colours (see Appendix HH for a worked example of the process). The hybrid approach was employed in this analysis by integrating the two key complementary philosophical methods of reasoning, including deductive, theoretical process, and indicative, data-driven process. Thus, using a top-down, deductive approach, a set of priori (or pre-empirical) codes/themes were largely drawn from the research aims and questions, and the individual questions asked in the semi-structured interviews, before initial familiarisation with the data. Whereas, following familiarisation, a bottom-up, inductive approach led to a set of emerging posteriori codes (or post-empirical), which derived from an examination of the generated data. The researcher coded (using both, semantic and latent codes) any item of data that could be useful in addressing the research question and tracked the evolution of codes to ensure transparency and to document the analytic process (see Appendix II and **Error! Reference source not found.**).

Additionally, a set of priori and posteriori codes was then combined in the codebook (Appendix II and **Error! Reference source not found.**). The visual representation of codes presented in the tables aided in later stages, particularly in organisation and making decisions related to main overarching themes, potential sub-themes, and those, perhaps temporarily, that do not fit - termed as miscellaneous. Throughout these steps, the researcher frequently revisited research questions and discussed the coding process with research supervisors, while respecting contrary codes. Any discrepancies were resolved by consensus. Following this, the list of priori and posteriori codes was then merged into themes.

Step 3: Searching for themes:

Searching for themes or generating initial themes, as recently renamed by Braun and Clarke (2019) to emphasise that themes are actively generated by the researcher as opposed to passively waiting to be found in data, involved organising codes that share a similar underlying concept into meaningful themes or sub-themes which help to answer the research question. Thus, in this step, the researcher’s focus shifted from the interpretation of single data items within the dataset to the interpretation of shared meanings and meaningfulness across the dataset to form themes or sub-themes. Both the inductive and deductive approaches to theme identification were employed (Braun and Clarke, 2012). The inductive approach derives themes from the data, while the deductive approach derives themes from the pre-existing theory or framework (Varpio, Paradis, Uijdehaage, & Young, 2020) or research aims and questions in this case. Some of the priori codes formed main themes, whereas some posteriori codes formed single codes, and vice-versa. The data linked with each theme was colour-coded and all the relevant coded data extracts within the recognised themes were later organised into a thematic map developed by the researcher (refer to Figure II1 in Appendix II for the initial thematic map). This visual representation also aided with exploring, organising, and making decisions concerning main themes, sub-themes, single codes, and miscellaneous data, as well as developing and presenting the final analysis.

Step 4: Reviewing themes:

Step 4 involved the modification of generated themes. Braun and Clarke (2006) recognised two levels of reviewing and modifying themes: (1) reviewing at the level of the coded data extracts (from individual transcripts); (2) reviewing the whole data set (making sense of the data as a whole). Thus, the researcher reviewed the candidate themes and initial thematic map, while ensuring that it was reflective of the data set, which allowed for the next step of the analysis to begin. This dual-level review meant that some themes or sub-themes were reorganised by removing or adding codes, or removing or adding themes or sub-themes. While reviewing themes, the researcher considered several questions to ensure that themes are coherent and distinct from each other, for instance: Is this a theme? or perhaps just a code? Does this theme make sense? Does it tell me something useful about the data and research question? Is there enough meaningful data to support this theme? does it overlap with other themes? Is there another theme within this theme (sub-theme)? and so on. The finalised thematic map that resulted from the review of the potential themes is presented in Chapter 7.

Step 5: Defining and naming themes:

According to Braun and Clarke (2013), themes should be named using “catchy”, thoughtful names that capture the essence of the analysis (Braun & Clarke, 2013, p.258). In order to organise the story into a “coherent and internally consistent account, with accompanying narrative” (Braun & Clarke, 2006, p. 22), the researcher revisited collated data extracts for each theme. Each identified theme was analysed in detail, including identification of the story (e.g., what each theme tells) and how this story fits into a wider overall story based on the research question. Descriptions and names for each theme were generated based on, for example, direct quotes or the focus of the data. Data extracts were presented both illustratively and analytically when appropriate. This was based on a straightforward test to decide on a particular reporting convention, which suggests that if the extract is removed and the write-up still makes sense, the reporting style is illustrative, whereas if the extract is removed and the write-up no longer makes sense, the reporting style is analytical (Terry, Hayfield, Braun, & Clarke, 2017).

Step 6: Producing the report:

The “final” (but also recursive) step in this TA process involved writing the findings from the analysis. It involved choosing extracts from coded and collated data to demonstrate the several characteristics of the theme and writing a narrative around those extracts. The writing-up process was initiated in step 1, through the process of note-taking, describing themes, and selecting relevant data extracted in prior stages. King (2004) defined the final step of analysis and interpretation as a continuum (that already has happened) as opposed to a separate step. In this final step, the researcher first decided the order in which themes were to be reported, and then narratively described and illustratively represented data extracts (e.g., participants’ direct quotations), while relating back to the research question as well as confirming and comparing examined evidence with pertinent literature to tell a compelling story about the data and what they mean (Braun & Clarke, 2013). While PhD theses typically report findings of the analysis in a “results” section and then synthesise and contextualise the findings in a “discussion” section, the current TA adopted Braun and Clarke’s recommendation of reporting findings together with synthesising and conceptualising data in the “results” section (Braun & Clarke, 2013), thus the findings of the analytical process are presented in Chapter 7.

Note that, although both groups of participants were asked similar questions around two main topics, the TA of interviews from health and social care professionals included one additional theme (“challenges faced by professionals”), and some single codes were specific to either participant’s group 1 or 2. Thus the findings for both groups are presented separately in Appendix II and **Error! Reference source not found.**, but later combined and presented narratively and visually in Chapter 7 section 7.1 qualitative findings. The rigour in both analyses was maintained by following the same process for both groups of participants and ensuring consistency through the use of codebooks.

2.6 Ethical Considerations

Before the research was conducted, all research procedures were carefully reviewed and approved by the NHS REC (refer to Appendix C). Swansea University was a sponsor of this research. Several non-substantial amendments that required review by NHS REC were not implemented until the review and other mechanisms were in place to implement at the sites (refer to additional file 2 for the amendment's history; available upon request). This study was protecting the participants’ privacy and personal information. The methods chosen (questionnaires and interviews) were unlikely to cause any risks to the participants. However, it was taken into consideration that some participants might find some questions sensitive, embarrassing or upsetting. Therefore, to minimise this possibility, it was important for the researcher to identify any potential risks before the study. Some of these potential risks considered by the researcher are recorded in

Appendix KK - the “summary of ethical considerations”. Fortunately, none of the potential risks were identified during the study.

2.7 Chapter Summary

This Chapter described the overall research methodology, including protocol deviations, revised study design, and detailed methodology and methods employed for phase 2 parts 1 and 2 of this project. The following Chapter 3 reviews the literature related to this study examining key elements of the existing CKD SMIs (Phase 1).

Chapter 3: Phase 1 - Systematic Literature Review

3.1 Introduction

This Chapter commences by briefly explaining the important concept of self-management in chronic conditions, particularly chronic kidney disease (CKD) and then it moves on to review the existing literature on CKD self-management interventions (SMIs) and further explores their key elements. First, the rationale and objectives of the current systematic literature review are described in the sections below (sections 3.1.1 and 3.1.2). Following this, the methods used for conducting this review are detailed in section 3.2, and its results are then narratively synthesised in section 3.3. All other relevant information for this review is provided in section 3.4. The Chapter ends with a discussion section (3.5) where the strengths and limitations of the current review are discussed and implications of the results for practice, policy, and future research are suggested. Finally, section 3.6 concludes the review and summarises the Chapter.

As recognised in the introduction Chapter, the management of CKD is complex and burdensome, requiring long-term lifestyle changes. This often results in decreased levels of quality of life (QoL) and increased levels of depression and anxiety (Kimmel & Peterson, 2006). According to Beattie and colleagues (2003), strategies that promote person-centred care (PCC), including self-management of chronic conditions, can lessen the burden of these conditions (Beattie, Whitelaw, Mettler, & Turner, 2003). Wilkinson and Whitehead (2009) have recognised the importance of PCC, a holistic view of self-management, and the important integration of the person who suffers from a chronic condition and those who look after them, as well as the impact of the disease. The authors described self-management as a person’s ability, alongside family, healthcare professionals (HCPs), and community, to manage treatments, symptoms, lifestyle modifications, as well as psychosocial, cultural and spiritual consequences of chronic conditions (Wilkinson & Whitehead, 2009).

It has been recognised that individuals with long-term conditions (LTCs) need to be actively involved and undertake responsibility for addressing their healthcare (Narasimhari, Allotey, & Hardon, 2019; Riegel et al., 2019; 2020). The importance of the initiatives of self-care and self-management to encourage health and well-being, prevent illness and decrease the demand on healthcare resources, has been increasingly recognised by policymakers and healthcare providers (El-Osta et al., 2019). Initially, the term self-management was used to define a patient as an active participant in their care who takes control over their chronic condition and its treatment on a day-to-day basis (Creer, Renne, & Christian, 1976). The notion of self-management is founded on Bandura's self-efficacy theory (Bandura, 1977; discussed in more detail in the next Chapters), according to which, the person is an active participant in their care through carrying out specific behaviours which lead to the anticipated outcomes (Lorig & Holman, 2003).

Several terms and definitions have been used to describe self-management and/or its key components, including for example, "self-efficacy", "self-monitoring", "self-care", and "self-management support" or self-management interventions" (Audulv, Asplund, & Norbergh, 2012; Richard & Shea, 2011). These and similar terms have been used to search the current literature on CKD self-management (Appendix LL). However, it is important to note that these concepts, particularly self-management, and self-care differ. For instance, Richard and Shea (2011) suggested that "self-care involves both the ability to care for oneself and the performance of activities necessary to achieve, maintain, or promote health" (Richard & Shea, 2011, p. 256). The authors proposed that the notions of self-management, symptom management, and self-monitoring fall within the wider domain of self-care. Matarese, Lommi, de Marinis, and Riegel (2018) further described self-care as a wide-ranging notion encompassing self-management, self-monitoring, and self-efficacy, which are described with reference to the roles and responsibilities of a patient, carer, and HCP. In their model, the authors described self-management as a subcategory of self-care occurring in the context of a recognised health condition with a level of input from HCP (Matarese et al., 2018). The term "self-management" (considered a subcategory of self-care; Matarese et al., 2018) has been chosen and applied throughout this document to define the way that individuals with chronic conditions, particularly CKD, actively engage in managing their illness and its consequences daily (LeBlanc & Jacelon, 2016).

One particular definition by the United States (US) Institute of Medicine (2004) has been selected and adopted in the current study, in which self-management is described as the tasks that people have to undertake to live with chronic conditions. Such tasks comprise confidently dealing with the medical management, role management, and emotional management of illness. What’s more, the terms “self-management support” (or “SMS”) or self-management interventions” (or SMIs) have been used throughout this thesis to describe the consistent delivery of care that improves an individual’s knowledge, skills, and confidence in dealing with and managing all aspects of their condition (Pearce et al., 2016). As per this concept, the current literature was reviewed to establish any strategies, activities, resources, and services designed in the form of supportive interventions for people with CKD. Further, to improve the understanding of chronic disease self-management, several self-management theories have been proposed (e.g., Lorig & Holman, 2003; Novak et al., 2008; Ryan & Sawin, 2009). Some of the relevant theories related to this thesis are discussed in more detail in the next Chapter.

In addition, SMS or SMI can vary from providing disease-specific information (e.g., through a leaflet or website) to wide-ranging general programmes, such as the one proposed by the Department of Health (2001), namely the Expert Patients Programme. This programme aims to promote behaviour change by developing the confidence in individuals with LTCs to use their knowledge and skills to effectively manage their illness and its biopsychosocial effects (Department of Health, 2001). Another example of a generic programme is the Personalised Care Planning programme proposed by Gheera (2012), which involves enhanced access to, and delivery of, information for individuals with LTCs. This programme focuses on individual contribution and choice in healthcare (Department of Health, 2010; Miles & Hall, 2010). Moreover, self-management is also one of the six crucial components recognised in the Chronic Care Model (CCM) proposed by Wagner (1998). This model seeks to enhance quality and outcomes by focusing on system-level variations that impact patient-and-provider-related factors (Wagner, Austin, & Davis, 2001). According to the Institute of Medicine (2012), the CCM is progressively being used as a framework for recognising elements of the system believed to influence chronic disease outcomes. However, the implementation of these or similar programmes remains sparse (Department of Health, 2005), thus the following sections review such self-management programmes or interventions specific to CKD and identify their key elements.

Note that: in this Chapter, the term "review author" refers to the PhD candidate and those who were involved in the literature review are identified by their role.

Further, it is also important to note that the initial intentions were to conduct a rapid evidence assessment (REA), thus rapid review guidelines were utilised to address time and resource constraints in the current review (see objectives and methods sections below). However, as the review progressed, it became clear that the complexity and scope of the evidence required a more detailed and careful approach. Despite the initial constraints, it was decided to adopt a more systematic and thorough methodology to ensure the accuracy and reliability of the findings. This shift was driven by the application of systematic and rigorous methods throughout the review process and involved expanding the search criteria, implementing rigorous data extraction procedures, and applying comprehensive quality assessment tools.

3.1.1 Rationale

The initial literature review identified CKD self-management as a top priority in preventing the progression of the disease. We have seen through the introductory Chapter that implementing strategies that promote PCC, and those that empower and support individuals with CKD to develop the necessary knowledge, self-confidence, and skills to manage their health can lessen the burden of the disease. Scholars have recognised many benefits of SMIs, and PCC in CKD, however, there is a gap in the SMIs literature concerning individuals with CKD. As per the English National Health Service (NHS) Five Year Forward View, there is a need for models of care to face the challenges of the current, progressively increasing CKD population in the United Kingdom (UK; NHS England, 2014). To face these challenges, healthcare systems promote self-care or self-management (World Health Organisation; WHO, 2002). In England and Wales, leading health organisations, including the Health

Foundation (2008), recommend and encourage self-care as an essential element of contemporary healthcare. The increasing interest in support for self-care and/or SMS motivated by the need to decrease the costs and unscheduled care, and enhance patient outcomes, resulted in the abundance of Department of Health policies and inventiveness, however, the implementation of these remains sparse (Department of Health, 2005), and more proactive methods, scope, and definitions of SMS are required (Hunt, 2013).

Furthermore, previous systematic reviews on CKD self-management (e.g., Kim, Park, & Song, 2021; Lin, Liu, Hsu, & Tsai, 2017; Lopez-Vargas, Tong, Howell, & Craig, 2016) established that SMIs are effective in managing and preventing the progression of the disease. Although these reviews added to knowledge about CKD SMIs, most of them have limited their eligibility criteria (e.g., excluding studies that involved patients on dialysis, end-stage kidney disease [ESKD], and/or transplant patients) and have not clearly reported intervention features (e.g., reporting complex SMIs, tailoring, and/or person-centeredness). Therefore, it is important to review the existing literature on CKD SMI to establish its key element with an attempt to recognise what currently works and what does not, by investigating the “who”, “what”, and “how”.

3.1.2 Objectives

The UK Government Civil Service listed six types of review methods that aim to maintain the rigour of systematic reviews but are less expensive and more rapid (Government Social Research; GSR 2013). REA is one of the review methods favoured by policy researchers (Khangura, Konnyu, Cushman, Grimshaw & Moher, 2012), which was found effective in social research like public health (Watt et al., 2008), and in the academic literature (Thomas, Newman & Oliver, 2013). It simplifies the systematic review process to generate information promptly. Taking into consideration the constraints of a given timetable for this PhD project and available resources (small team), initially, REA was determined to be an appropriate review methodology to use to establish the key elements of the existing CKD SMIs and to understand what academic research has discovered about the existing interventions. Consequently, phase 1 of this research addressed the following question: *What are the key elements of CKD SMIs identified in the existing literature?*

However, as acknowledged in the introduction section of this Chapter, this REA evolved into a full systematic literature review. Finally, the findings from this systematic review will be beneficial in informing future research in the CKD SMIs field, and aid in the development of a person-centred, theory-based SMI for young adults (YAs) living with CKD stages 1-5 (phase 3 of this project).

3.2 Methods

The above-mentioned guidance on how to carry out REA (GSR, 2013) and Interim Guidance (Garritty et al., 2020) for conducting rapid reviews, developed by the Cochrane Rapid Reviews Methods Group (RRMG; Garritty et al., 2021), were employed to review existing evidence as comprehensively as possible.

Systematic reviews are valued evidence synthesises that inform decisions, however, their methodological rigour and process which makes them trustworthy can take a long time to complete, and can be resource-intensive (Bero et al., 2012; Ganann, Ciliska, & Thomas, 2010; Tsafnat et al., 2014). REA allows for a rapid review of the available evidence on the research question, by a small team, and offers an approach to reviewing existing evidence-based literature, which pursues meeting the needs for speed and rigour (Thomas et al., 2013). While REA cannot ensure identifying and reviewing every relevant study, the aim is that the included literature is representative of the body of research evidence (Government Social Research Service, 2014). The current literature review employed a standardised, transparent, and systematic approach to identify, evaluate, and report published evidence relevant to the research question.

The design and methods for this systematic literature review are reported in line with the most recent Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement, the PRISMA 2020 checklist (see Appendix MM), PRISMA 2020 elaboration and explanation, and PRISMA 2020 flow diagram (Page et al., 2021). Preliminary searches aided in refining the eligibility criteria, specified using the PICOS approach (Higgins & Green, 2011), and search terms.

3.2.1 Eligibility Criteria

This systematic literature review included primary randomised-controlled trials (RCTs) of SMIs, compared with a control group (CG), for adults (over 18 years old) with CKD (stages 1-5). This review was limited to RCT studies since RCTs show the highest levels of validity and reliability in providing evidence for cause-and-effect relationships (Hariton & Locascio, 2018). CKD was classified by an estimated glomerular filtration rate (eGFR) that is less than 60mL/min/1.73m^3 for a period of longer than three months, with or without the occurrence of kidney impairment (Bonner, 2012). The study characteristics, specified by the PICOS approach (Higgins & Green, 2011), are presented below. Each letter characterises an element: the Participants (P), Interventions (I); Comparisons (C); Outcomes (O); and Study design (S) (O'Connor, Green, & Higgins, 2008).

<u>Study inclusion criteria:</u>

(P) Participants: adults over 18 years old with CKD at any stage (1-5). It is important to highlight that given the focus of this research project on developing SMI for YAs aged 18-35 years old with CKD, it would be ideal to include studies specifically targeting this age group. However, a preliminary search revealed that there is a significant gap in the literature concerning CKD SMIs for this specific age group and that most of the existing research tends to focus on broader age groups, often encompassing older adults who form the majority of the CKD patient population. Therefore, the review included studies across all age groups to identify universally applicable SMI components. This broader approach provides a foundation for adapting and tailoring these elements to YAs, addressing a critical research gap.

(I) Intervention**:** CKD self-management (including person-centred and theory-based self-management) described as per the adopted self-management definition outlined in the introduction section above, including strategies, activities, resources, or tools in any format of delivery (e.g., face-to-face, electronic, print) in a form of supportive interventions that aimed to lessen the burden of the disease. These included the ability to self-manage CKD, its symptoms, treatment, physical and psychological consequences of the disease, associated comorbidities, and/or making lifestyle changes.

(C) Comparator**:** care as usual/standard care.

(O) Outcomes: Must include at least one of the outcomes (assessed using standardised measures):

Note that, outcomes were chosen based on the initial literature review and the theoretical underpinnings of the current study (presented in Chapters 4 and 5). Similar outcomes have also been applied in phase 2 (part 1) of this project (refer to Chapter 2 section 2.4.5). Additionally, once all possible and relevant outcomes were identified, the review author and two research supervisors assessed the importance of outcomes to decide on the most important outcomes to be included in the Summary of Findings (SoF) table (Table 3.9 presented in section 3.3.4) for the main comparison and the assessment of the quality and certainty of the evidence. The team rated the relative importance of the outcomes (regardless of whether there were data available for the outcomes) using a 9-point scale, where 1-3 indicated: "not important", 4-6 indicated: "important but not critical for making a decision", and 7-9 indicated: "critical for making a decision". Consequently, the review author and supervisors reached a consensus on the decisions resulting in five outcomes being considered as critical or important for making a decision and they were considered as the review's primary outcomes, while the remaining outcomes were considered as secondary outcomes.

Primary/"critical" (for decision-making) outcomes:

- Self-efficacy
- CKD knowledge
- CKD self-management

Primary/"important" (but not critical for decision-making) outcomes:

- Adverse events (e.g., complaints, side effects, levels of dissatisfaction, increased inequalities, or death)
- Clinical indicator (particularly, alteration in eGFR)

Secondary outcome (not included in the SoF table for the main comparison):

- Other clinical indicators (including, blood pressure [BP] and weight)
- Behavioural and patient outcomes, including:
    - Health-related behaviours (smoking, alcohol consumption, diet, and physical activity)

- Psychological distress (particularly, anxiety and depression)
- Health-Related Quality of Life (HRQoL) or Quality of Life (QoL)
- Patient activation

(S) Study design: primary randomised studies.

<u>Limits:</u>

Publication date: between 2011 and Present (2021, at the time of the review). Preliminary searches indicated that the literature on self-management was too extensive to complete the review within the timescale without a date limit. Consequently, the date limit accommodated the most recent research on SMIs.

Language: English language. The decision to limit studies to the English language was pragmatic considering the lack of resources for the translation of non-English language studies.

Human studies

<u>Study exclusion criteria:</u>

(P) Participants: participants without the diagnosis of CKD; below 18 years of age.

(I) Intervention**:** no intervention or any intervention other than specified in the inclusion criteria.

(C) Comparator**:** no comparison.

(O) Outcomes**:** outcomes other than those specified in the inclusion criteria.

(S) Study design**:** any studies other than those specified in the inclusion criteria.

<u>Limits:</u>

Publication date: prior to 2011

Language: non-English language

Non-human studies

Table 3.1 below summarises the study characteristics according to the PICOS approach.

Table 3.1

Study Characteristics According to the PICOS Approach

P Participants	**I** Intervention	**C** Comparison	**O** Outcomes	**S** Study Design
Adults over 18 years old with CKD stages 1-5	CKD self-management, including theory-based and person-centred self-management	Care as usual/ standard care	Primary outcomes: -Self-efficacy -CKD self-management -CKD knowledge -eGFR -Adverse events Secondary outcomes: -BP -Weight -Health-related behaviours (smoking, alcohol consumption, diet, physical activity) -Psychological distress (anxiety, depression) -HRQoL/QoL -Patient activation	Primary RCTs

Adapted from Higgins & Green, (2011). *Note:* limits: 2011-2021; English language; Human studies. *BP* Blood Pressure; *CKD* Chronic Kidney Disease; *eGFR* estimated Glomerular Filtration Rate; *HRQoL* Health-Related Quality of Life; *RCT* Randomised-Controlled Trail.

In order to ensure sufficient appraisal and review, only studies accessible in the full text in English and with clear inclusion criteria were included. In the case of studies where the eligibility criteria were not sufficiently clear, or full text was not available, the review author would contact the corresponding authors to seek clarification. This was the case with four articles in which full text was not available in English. The review author contacted the authors (via ResearchGate, an academic profile and social networking site), however, no reply was received. Consequently, the review author contacted Swansea University's library to seek access to these articles, which resulted in one out of four articles being available in full text in English, and this article was included in the review, whereas the remaining three studies were excluded.

3.2.2 Information Sources

The databases were searched between 06/04/2020 and 01/05/2020 (initial search) and between 02/05/2021 and 01/12/2021, with a pre-determined strategy (see section 2.2.3). Interim Guidance recommends searching the Cochrane Central Register of Controlled Trials (known as CENTRAL or TRIALS), Embase (if available access), and/or MEDLINE (Garritty et al., 2020). Thus, the main search engine employed in this review was MEDLINE searched via PubMed, chosen due to its estimates of high yields of included studies (Halladay, Trikalinos, Schmid, Schmid, & Dahabreh, 2015). Additionally, although the guidance recommends limiting or omitting the specialised databases search if resources and time are limited, the supplementary search was conducted in this review using two specialised databases, including the Cumulative Index to Nursing & Allied Health Literature (CINAHL) via Cochrane CENTRAL and PsycINFO. This supplementary search resulted in 29 additional articles. All these databases are commonly used and were chosen due to their extensive coverage of many disciplines, the quality of the provided information, and their accessibility (Brophy & Bawden, 2005). Finally, an additional search also included screening the reference lists of included studies after the full-text screening (detailed below), however, a grey literature search, including theses, was not included, which was recorded as a limitation of this systematic review in section 3.5.

3.2.3 Search Strategy

Literature search strategies were developed using a combination of keywords and Medical Subject Headings (MeSH) terms related to CKD, self-management, and RCT, which were combined using Boolean phrases (e.g., “and”, “or”) (see example in Appendix LL). As per the eligibility criteria, the literature search required published studies, limited to the English language, publication date between 2011 and Present (2021, at the time of the review), and human studies, relevant to the review questions. As per recommendations from Cochrane’s interim rapid review guidance (Garrity et al., 2020), the quality of the search strategy was evaluated by two librarians at Swansea University with expertise in database searches for systematic reviews and by research supervisors.

Additionally, to ensure literature saturation, the review author also undertook an additional rigorous and comprehensive scoping exercise and searched the reference lists of main papers, using citation chaining. This search method begins with one paper, and then it produces a chain of relevant references linked backwards and forwards from the original paper (Nyakang'o & Booth, 2018). Thus, following the screening of the titles and abstracts as well as full-text articles, the reference lists of included studies and relevant reviews of the articles identified through the search were also searched electronically and manually and were also included for data collection based on their title. The research supervisors have also randomly reviewed the supplementary search and solved any discrepancies by consensus. This supplementary search was beneficial as it yielded four additional records.

3.2.4 Selection and Data Collection Process

The review author obtained full copies of all articles identified by the search, that met the eligibility criteria, based on their title and abstract, for data synthesis. Following this, the review author screened full-text articles against the eligibility criteria. Both searches involved review by two research supervisors. Any disagreements between reviewers regarding decisions to include or exclude studies were solved by consensus (see Appendix NN for an example of a full database search). Thus, the screening was a two-stage process, which involved title and abstract screening (stage 1) and full-text screening (stage 2). Prior to the start of title and abstract screening, as per recommendation from the Cochrane RRMG, a pilot exercise was conducted using a minimum of the same 30-50 abstracts screened by the whole team to calibrate and test the review form (title and abstract level 1, see Appendix OO). Title and abstract screening actively removes articles from the review, thus, it is important to not overlook the potential bias (Borah, Brown, Capers, & Kaiser, 2017). The Cochrane guideline as well as other guidelines, including guidelines from the Centre for Reviews and Dissemination (Tacconelli, 2010) or the Agency for Healthcare Research and Quality (McDonagh, Peterson, Raina, Chang, & Shekelle, 2013), provide similar guidance to two-stage process for avoiding bias in screening studies for inclusion. The title and abstract level 1 screening form for this review was developed (based on best practice guidelines for abstract screening; see Polanin, Pigott, Espelage, & Grotpeter, 2019) prior to the literature search and it includes clear and brief questions based on the inclusion criteria, organised hierarchically with the easiest questions at the start of the form. The included items in the form are objective and “single-barrelled” and include the same sentence structure, and yes, no, or unsure/unclear answers only.

Following minor changes to the screening form, to ensure the trustworthiness of the systematic review findings, dual, independent screening was employed as endorsed by the Cochrane RRMG. The review author and one research supervisor independently screened the titles and abstracts (approximately 20 percent of abstracts) identified by the search against the inclusion and exclusion criteria (stage 1). Subsequently, the review author screened the remaining abstracts, and the second supervisor screened all excluded abstracts.

Full articles that met eligibility criteria were obtained and duplicate publications were removed. Similarly, a pilot exercise was also undertaken before the start of the full-text screening, using approximately 10 full-text articles screened by the whole team to calibrate and test the review form (data extraction form, see Appendix PP) against the eligibility criteria and practical relevance. This was also followed by dual, independent screening, which involved the review author independently screening all included full-text articles, followed by a research supervisor screening the excluded full-text articles (stage 2).

The review author sought additional advice from the study supervisors to resolve any questions about eligibility. Disagreements were resolved through discussion and the reasons for excluding studies were recorded (see Tables QQ4 and QQ5 in Appendix QQ - the characteristics of included studies). The same process was followed for screening the reference lists of included studies.

Data management:

Records were managed using EndNote, which is a specific software for managing bibliographies. The obtained literature was referenced in accordance with the American Psychological Association (APA) sixth edition referencing style, the same as the references related to this thesis. However, it was later changed to Vancouver/National Library of Medicine (for included studies only), a numbered referencing style, by using bookmarks for a better presentation of the results and was recorded in the reference list for this systematic literature review at the end of this thesis. Furthermore, to ease the process of the title and abstract screening, the review author and research supervisors used the Rayyan software where they could access all relevant articles via the website or mobile phone app (Ouzzani, Hammady, Fedrowicz, & Elmagarmid, 2016) and collaboratively make decisions on studies inclusion. Other software used for data analysis and synthesis (including the quality and certainty assessments) is detailed in the next sections.

3.2.5 Data Extraction

Data extraction involved the collation of the results and other information on the included studies. Cochrane's guidance suggests that a single reviewer extracts data using a piloted form, and a second reviewer checks the extracted data for correctness and completeness (Garrity et al., 2020). In this review, the review author used a self-developed data extraction form designed specifically for this synthesis, based on the Cochrane Consumers and Communication Group Data extraction template for included studies, using minimum and some optional standards (Ryan, Synnot, Prictor, & Hill, 2016). The data extraction form comprised information relevant to the current systematic review question, including seven sections, particularly general review information, methods of the study, risk of bias (RoB) assessment, and study characteristics including participants, interventions and comparisons, and outcomes, as well as data and results.

It should be noted that data on interventions were extracted based on the Template for Intervention Description and Replication (TIDieR) checklist and guide developed by Hoffman and colleagues (2014). Any missing data were coded as "unclear" or "not described". The data extraction form also included a "cheat sheet" at the end of the document, containing instructions and decision rules to ensure consistency among the reviewers (refer to Appendix PP). Following minor revisions to the data extraction form, the review author extracted data and organised it by selecting the most relevant information and recording it in the characteristics of the included studies (refer to Appendix QQ) and the study supervisors reviewed independently the extracted data for accuracy and completeness. Once more, any discrepancies were resolved through discussion and the reasons for excluding studies were logged. Other relevant information was recorded in additional tables presented in the result section for this systematic literature review.

3.2.6 Study Risk of Bias Assessment

Cochrane's guidance recommends assessing the quality of included studies by one reviewer, and fully verifying all judgments by a second reviewer, as well as limiting the RoB ratings to the most important, primary outcomes (Garrity et al., 2020). However, the review author rated the RoB for all 23 included studies, without limiting the RoB ratings to the primary outcomes (the RoB was rated based on the secondary outcome only in three studies: 7; 20; 21). Following this, the research supervisors independently verified it of all judgments.

Further, to assess the methodological quality of the eligible studies and to simplify the assessment of the possible RoB for each study, the information was collected using the recommended tool specifically designed to assess the RoB in RCT studies, namely the revised version of the Cochrane RoB tool, known as RoB2 (Sterne et al., 2019). RoB2 tool includes several signalling questions for each of the five domains to guide reviewers. Five domains through which bias may be presented include bias arising from the randomisation process, bias due to deviations from intended interventions, bias due to missing outcome data, bias in the measurement of the outcome, and bias in the selection of the reported results. The final judgment on the RoB based on answers to the signalling questions was presented by an algorithm at the end of each section. Proposed judgments were "low" or "high" RoB, or could display "some concerns", and each item in the RoB assessment was considered independently without trying to collate and allocate an overall score. Finally, the review author followed the Methodological Expectations for Cochrane Intervention Reviews (available in Cochrane Interactive Learning, Module 5, C52-60; Page, Higgins, Sambunjak, Cumpston, & Watts, 2017) standards for assessing the RoB in included studies (refer to Tables QQ1-QQ5 in Appendix QQ). The review author also used the *Robvis* visualisation tool (McGuinness & Higgins, 2020) to create forest plots with traffic lights to visually represent RoB2 data (refer to section 3.3.3 and Appendix QQ).

3.2.7 Investigation of Heterogeneity and Effect Measures

In this systematic literature review, the investigation of heterogeneity was not pre-specified, and informal methods to investigate heterogeneity were used. This involved ordering tables by, for example, subpopulations (e.g., dialysis and non-dialysis population, and CKD stage) and intervention features. Consequently, obtaining the standardised effect sizes for all included studies was not possible. Thus, the effect direction was used as a standardised metric to enable the synthesis of diverse effect measures in order to provide evidence to indicate an improvement, deterioration, or no change in an outcome. To support the synthesis of effect direction and to provide a transparent reporting of the combination of visual data and narrative, the review author followed the revised effect direction plot approach, the Cochrane guidance on an alternative synthesis method developed by Boon and Thomson (2021).

To create the effect direction table, first, the author categorised the review's related primary and secondary outcomes into outcome domains, as suggested by the outcome categorisation from Grey and colleagues (2015). These compromised the following five outcome domains: 1) physiological outcomes (eGFR, BP, and weight), 2) cognitions (self-efficacy, patient activation, CKD knowledge and self-management), 3) health-related behaviours (smoking, alcohol consumption, diet, and physical activity), and 4) individual outcomes (HRQoL/QoL, and psychological distress, including anxiety and depression), as well as 5) health status (adverse events, such as complaints, side effects, levels of dissatisfaction, increased inequalities, or death). Following this, the positive and negative effect estimates within each domain were calculated and the overall effect direction for each domain, based on an appropriate algorithm, was determined. Finally, the review author undertook the sign test, a non-parametric test to calculate two-tailed *p*-values for each outcome domain. The *p*-value in the sign test indicated the possibility of detecting the number of positive and negative results in the intervention group (IG) if the null hypothesis was true. As per the guide (Boon & Thomson, 2021), GraphPad online software [see: *Sign and binomial test (graphpad.com)*] was employed for the calculation. Note that, the studies with conflicting or unclear effects were not included in the sign test analysis.

The effect direction for each outcome in each study was visually presented as an upward, downward, or bidirectional arrow in the effect direction plot. The size of the arrow indicated the sample size, whereas the shape of the arrow specified statistical significance (or not) for the majority of results for an outcome. Moreover, the study quality was represented by colour shading, the same as for the RoB assessment, where green indicated a low RoB, amber indicated some concerns, and red indicated a high RoB, while the studies were ordered from low to high RoB for the synthesis. The raw data for identifying the effect direction can be accessed in Appendix RR.

3.2.8 Synthesis Methods

Considering the body of literature, particularly the statistical heterogeneity as well as the wide variability of included studies (clinical and methodological diversity), a meta-analysis was not considered. The review author conducted a narrative synthesis, with consideration given to the PRISMA (2020) checklist (refer to Appendix MM), to conclude and explain the characteristics and findings of the included studies. The review author combined all separate findings into a coherent summary of the evidence that answers the review question, from which the conclusions have been drawn. The narrative synthesis was provided with the information presented in the text and tables.

The synthesis was organised around the PICOS approach (Higgins & Green, 2011) with findings clustered by the participants, interventions, comparisons, and outcomes. Additionally, given that self-management for individuals with CKD may differ for those on dialysis and those without, the findings were also divided into two groups, particularly those studies that included participants on dialysis (N=11) and those without dialysis (N=12). Interventions were further synthesised according to the TIDieR checklist, and thematically grouped by intervention features. Finally, data on outcomes were categorised and reported narratively, descriptively (e.g., counts and frequencies), as well as tabularly and graphically. The effect direction was also presented visually and narratively and was ordered by study ID, sample size, and four main outcome domains while prioritising studies with low RoB, then those with “some concerns”, and high RoB. Following this, the review’s primary outcomes for the main comparison were selected based on the studies at low RoB only and were further analysed and reported in the SoF table. Results were then synthesised by the outcome, where results for each outcome were described.

Given that the meta-analysis was not possible, alternative synthesis methods were employed. Namely, in addition to the PRISMA (2020) checklist, in order to ensure transparency in reporting methods the review author also employed the Synthesis Without Meta-analysis (SWiM) guideline, using nine reporting items checklist (Campbell et al., 2020; see

Appendix SS). This guideline has been developed as an extension to PRISMA to guide clear reporting of quantitative findings in reviews of interventions in which meta-analysis is not possible and alternative synthesis methods are used.

Together with the SWiM guide, the review author also considered the Cochrane data synthesis and analysis guide to narratively synthesise and analyse the data (Ryan, 2013) as well as Popay and colleagues' (2006) guidance on the conduct of narrative synthesis in systematic reviews. According to both guidance, the narrative synthesis involves four key elements, including 1) developing a theory of how the intervention works, why, and for whom; 2) developing a preliminary synthesis of findings of included studies; 3) exploring relationships in the data; and 4) assessing the robustness of the synthesis (Popay et al., 2006; Ryan, 2013). These steps have been employed in the current review to offer a systematic, rigorous, and transparent process of synthesising and presenting the findings of this systematic review. As per Popay and colleagues (2006), the narrative synthesis can be used to answer various questions and is important to decide whether the synthesis focuses on the effectiveness review or the implementation review as the above-listed four key elements to a narrative synthesis have a different purpose for each. Given the nature of the question addressed in this systematic literature review, this review focuses on the effects of interventions. Table 3.2 below presents the key elements of narrative synthesis applied in the current review, including a description of how these steps were applied, particularly the examples of tools and techniques used within the appropriate elements of current narrative synthesis.

Table 3.2

Key Elements of Narrative Synthesis

Key elements of synthesis	Elements of review's narrative synthesis	Examples of tools/techniques employed
1) Developing a theory of how the intervention works, why, and for whom	The theory of change, described in Chapter 4, namely self-efficacy theory was adopted as a theoretical underpinning to explain and predict behaviours in individuals with CKD and was considered as most likely to inform the pathways of behaviour change. Moreover, based on the adopted definition of SMIs (refer to section 3.1), the critical outcomes chosen for this review were self-efficacy, CKD knowledge and CKD self-management. As per Pearce et al. (2016), targeting a person's knowledge, skills, and confidence will lead to successful CKD SMI.	Initial literature review
2) Developing a preliminary synthesis of findings of included studies	The preliminary synthesis involved systematically assessing the results from included studies and reporting them in narrative, descriptive, tabular, and graphical forms. Each of the included studies was described in the characteristics of included studies by summarising the same features in the same order, as well as textually and in additional tables. Studies were summarised by the intervention according to the TIDieR checklist, and grouped by those that included dialysis and non-dialysis patients.	-Tabulation -Textual descriptions of included studies -Grouping and clusters -Translating data (thematically identifying common areas between studies) -Vote-counting as a descriptive tool
3) Exploring relationships in the data	To explore the relationship in the data, several visual and graphical tools were used (e.g., tables, graphs and plots). Refer to Appendix QQ for the example of textual descriptions/qualitative case descriptions of included studies.	-A visual representation of the relationship between study characteristics and results -Textual descriptions -Vote-counting based on effect direction
4) Assessing the robustness of the synthesis	The robustness of the synthesis was assessed by examining the methodological quality and certainty, and critically reflecting on the synthesis process (e.g., review's strengths and limitations in section 3.5)	-RoB2 -GRADE

Adapted from Popay et al. (2006). *CKD* Chronic Kidney Disease; *RoB* Risk of Bias; *SMI* Self-Management Intervention.

3.2.9 Certainty Assessment

The Grades of Recommendation, Assessment, Development and Evaluation Working Group (GRADE Working Group) has developed a system for grading the certainty of evidence (Atkins et al., 2004; Guyatt et al., 2008; Guyatt et al., 2011; Schunemann, Best, Visit, Oxman, & Group, 2003; Schunemann et al., 2006). As per their recommendations, GRADE was employed to judge the quality and certainty of the evidence for the overall body of evidence and the review's primary outcomes of the studies that were identified as at low RoB (Andrews et al., 2013a; Andrews et al., 2013b). The certainty of the evidence was rated across the following domains: RoB, imprecision, inconsistency, indirectness, and publication bias. Starting with a "high quality" evidence rating for RCTs, we downgraded by one level for serious concerns (or two levels for very serious concerns) about all five domains. If required, additional domains were considered. Quality was judged using the following four levels of evidence: very low, low, moderate, and high. The review author graded the certainty of the evidence and one of the research supervisors independently verified it of all judgments, and any disagreements were resolved by consensus. Grading certainty of the evidence for each outcome can be seen in Appendix TT and the SoF for the main comparison (Table 3.9 in section 3.3.4), which was developed based on the standard Cochrane methodology to present findings for each outcome (Schunemann et al., 2019) and the Cochrane guidance for preparing SoF table (Ryan, Santesso, & Hill, 2016) and for grading evidence (Ryan & Hill, 2016). Data is presented in the SoF table developed using the GRADEpro software (GRADEpro Guideline Development Tool, 2022). Additionally, due to the absence of the estimate of effect, in order to provide a narrative summary of the effect, the review author used suggestions from Murad and colleagues (2017) on rating the certainty in evidence when the meta-analysis was not conducted (Murad, Mustafa, Schunemann, Sultan, & Santesso, 2017). Reasons for upgrading or downgrading were plainly described together with evidence in tabular and narrative form.

3.3 Results

3.3.1 Study Selection

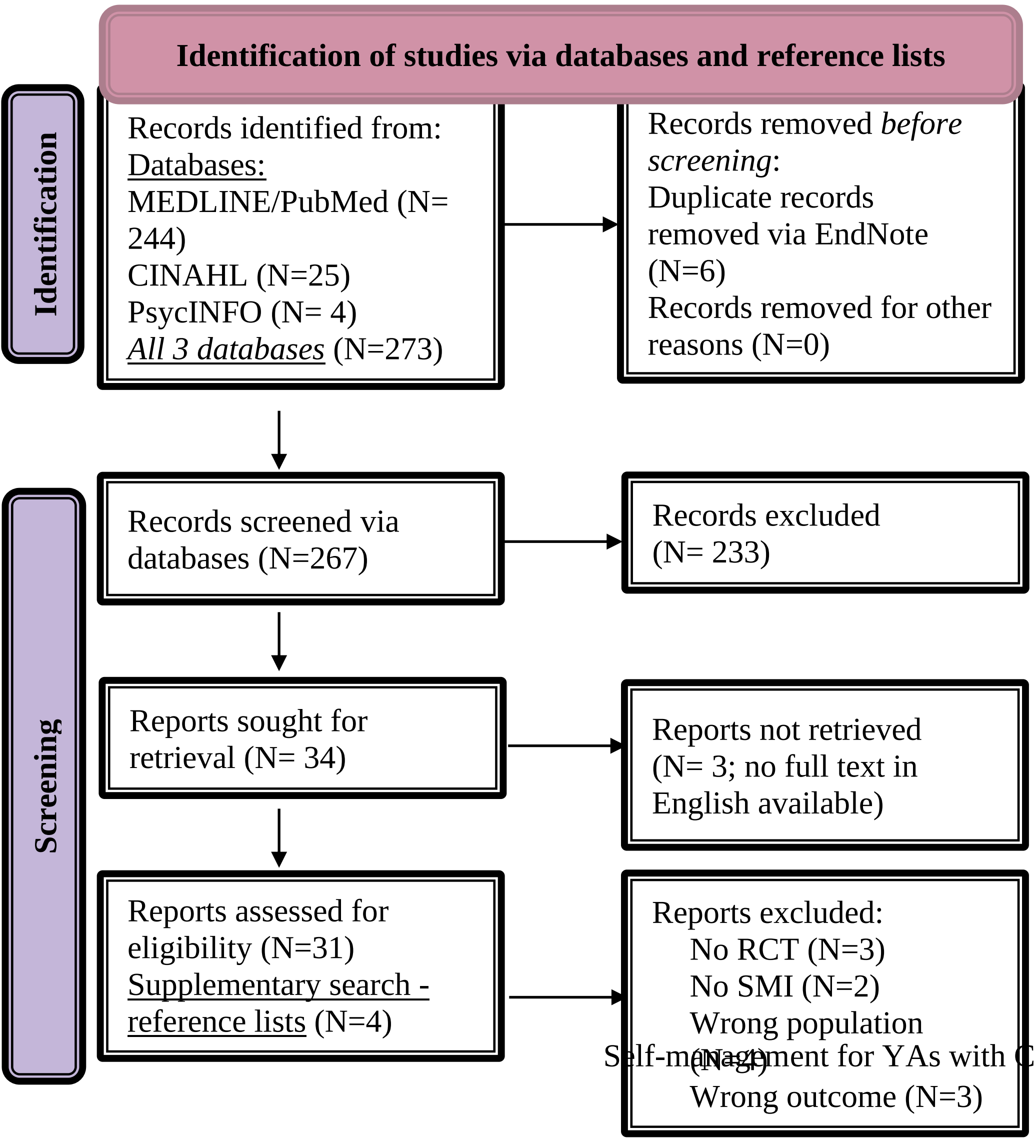
<u>*Search yield:*</u>

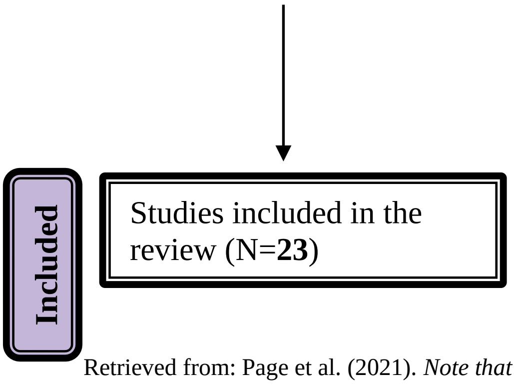
Both computerised and manual searches were performed. In total, 273 citations were identified through database searches. After the removal of duplicates (N=6), the title and abstract of 267 studies were screened for relevance, 233 of which were excluded. Altogether, 34 potentially eligible studies were retrieved for full-text screening, and three studies for which full-text in English was not available were excluded, leaving 31 studies for the eligibility assessment. The supplementary search of reference lists of included studies resulted in an additional four citations for retrieval. After the full-text screening of 35 articles, a further 12 were excluded and decisions for exclusion were recorded (refer to Tables QQ4 and QQ5 in Appendix QQ for authors' judgment). After the eligibility assessment, the review author and two research supervisors agreed to include 23 publications in the current review that met inclusion criteria, 11 of which included individuals with CKD on dialysis and 12 articles included individuals with CKD without dialysis.

Additionally, it is important to note that one study on the dialysis population (8) did not meet all eligibility criteria (particularly, the "comparator" element as the study involved post-hoc group-wise comparison) after the full-text screening. Thus, it was excluded from the main synthesis. However, because the findings of this study were considered relevant to the current review, it was decided to describe the study separately in section 3.4. Refer to below Figure 3.1 for details on the review process, particularly the screening and selection process for this systematic review.

Figure 3.1

PRISMA 2020 Flow Diagram - Selection Process





Retrieved from: Page et al. (2021). *Note that*: “registers only”, from the original PRISMA 2020 flow diagram, were replaced with “reference lists” for this review. *RCT* Randomised-Controlled Trail; *SMI* Self-Management Support.

3.3.2 Study Characteristics

Description of studies:

The clinical and methodological characteristics of the included studies are presented in tabular form in Tables QQ4-QQ5 in Appendix QQ, and these are also described narratively below and supported by additional tables.

Study and participant characteristics:

Overall, 23 studies, with a total of 3075 CKD patients, including 11 studies with CKD patients on dialysis (total of 1058 patients) and 12 studies with CKD non-dialysis patients (total of 2017 patients), were deemed eligible. Studies on non-dialysis patients (N=12) enrolled individuals with the following CKD stages: 1-3 (N=1); 1-4 (N=3); 3-5 (N=5), 3b-5 (N=1), and stage 3 (N=1), and one study did not specify the stage of CKD. Out of these 12 studies, two studies included concomitant hypertension and one study compromised individuals with CKD including one other risk factor or family history of kidney disease and diabetes. Whereas the included studies with patients on dialysis (N=11) enrolled individuals who were on haemodialysis (HD; N=7), dialysis (N=1), pre-dialysis (PD; N=2), and one study included patients with CKD stage 5 on maintenance HD (MHD; N=1). Of these 11 studies, two included end-stage kidney disease (ESKD) in addition to HD in their inclusion criteria.

All included studies were RCTs published between 2011 and 2021 in

English. However, some articles described their study design as a “controlled clinical trial” (1) or “clinical trial” (22), two studies identified their design as “open” RCT (3; 17), and one as a “longitudinal” RCT (13), and one study employed a randomised (two-group pre/post-tests) experimental design to test the effectiveness of the intervention (12). Studies took place in Europe (two in the UK, two in the Netherlands), North America (five in the US), and Asia (five in Taiwan, three in Iran, one in Vietnam, one in Korea, one in Singapore, and three in China). The studies were set in outpatient clinics and hospitals (including dialysis outpatients and centres for studies that involved dialysis patients; N=18), general practices and community-based clinics (N=4), and one study obtained clinical data from “a previously established cohort”. Participants were followed up for between four weeks/one month and 12 months. The included studies are summarised in the following tables below: Table 3.3 represents the summary of the characteristics of 12 studies with non-dialysis patients, whereas Table 3.4 demonstrates the summary of the characteristics of 11 studies with patients on dialysis, including the summary of the RoB assessment.

Table 3.3

Summary of Included Studies - Non-Dialysis Patients (N=12)

Study ID (author & year) **Bookmark** **Design** **Setting** **Country**	**Population (total N that completed the study); N(IG) and N(CG)**	**Intervention**	**Frame work**	**Control:**	**Outcomes of interest (and time point)**	**Duration/ Follow-up/ Dropouts**	**RoB2** **Low Risk** **Some Concerns** **High Risk**
Barahimi et al. (2017)1 Controlled Clinical Trial Noncommunicable centres Iran	131 participants (IG=39; CG=92) with CKD stages 3-5 (eGFR less than 60 mL/min/1.73m^2)	Self-care education through e-learning	ND	-Care-as-usual/“typical treatment”	eGFR (at baseline and 6 months)	6 months intervention and follow-up/ND on dropouts	**High risk**
Blakeman et al. (2014)2 RCT 24 general practices UK	436 participants (IG=215; CG=221) with CKD stages 3a and 3b	BRIGHT intervention	ND	-Usual care -Kidney information guidebook -PLANS booklet with links to the website (at the end of the trial)	BP, HRQoL, anxiety, self-care activities (at baseline and 6 months)	4 weeks/ 6 months/ Dropouts: 14.3%	**High Risk**

Study ID (author & year) **Bookmark** **Design** **Setting** **Country**	**Population (total N that completed the study); N(IG) and N(CG)**	**Intervention**	**Frame work**	**Control:**	**Outcomes of interest (and time point)**	**Duration/ Follow-up/ Dropouts**	**RoB2** **Low Risk** **Some Concerns** **High Risk**
Chen et al. (2011)3 Open-label RCT Outpatient clinic Taiwan	54 participants (IG=27; CG=27) with CKD stages 3-5 ("incidental CKD")	SMS interactive individualised education sessions	Standardised SMS	Usual care/"customary care from a nephrologist"	eGFR (at baseline, 6 months, and 12 months), CKD knowledge (at baseline and 12 months)	12 months/ 12 months/ Dropouts: 4 (lost to follow-up)	**Low Risk**
Flesher et al (2011)5 RCT Nephrologists and general practitioners US	40 participants (IG=23; CG=17) with CKD 3-5 (eGFR of 20-60 mL/minute for ≥3 months; hypertension)	Cooking and exercise programmes	ND	Standard care	eGFR, BP (at baseline, 6 months, and 12 months)	12-week/ 12 months/ Dropouts: IG(N=3); CG(N=2)	**High Risk**

Study ID (author & year) **Bookmark** **Design** **Setting** **Country**	**Population (total N that completed the study); N(IG) and N(CG)**	**Intervention**	**Framework**	**Control:**	**Outcomes of interest (and time point)**	**Duration/ Follow-up/ Dropouts**	**RoB2** **Low Risk** **Some Concerns** **High Risk**
Humalda et al. (2020)10 RCT Nephrology outpatient clinics Netherlands	94 participants (IG=50; CG=44) with CKD stages 1-4, or kidney transplants recipients ("if eGFR was ≥25 mL/min/1.73 m^2; no upper limit")	SUBLIME: self-management and e-health technology intervention	Self-regulation theory	Routine care	BP, HRQoL, self-management skills (at baseline, 3 months, and 9 months)	3 months intervention phase/ 6 months maintenance phase/ 3-and 9-months follow-up/ Dropouts: 5 (lost to follow-up)	**Low Risk**
Ishani et al. (2016)11 RCT Community-based clinics US	600 participants (IG=450; CG=150) with CKD stages 3-5 (eGFR less than 60 mL/min/1.73 m^2)	Telehealth and interprofessional case management	Components of the CCM	Usual care: -CKD education class -Follow-up with primary care providers regarding the CKD management	Adverse events (death, hospitalisation, emergency department visits, or admission to skilled nursing facilities) (at baseline and 12 months)	4.5 months/ 12-months/ Dropouts: IG(N=1) - withdrew consent	**Some concerns**

Study ID (author & year) **Bookmark** **Design** **Setting** **Country**	**Population (total N that completed the study); N(IG) and N(CG)**	**Intervention**	**Frame work**	**Control:**	**Outcomes of interest (and time point)**	**Duration/ Follow-up/ Dropouts**	**RoB2** **Low Risk** **Some Concerns** **High Risk**
Li et al. (2020)14 RCT Nephrology outpatient clinic Taiwan	49 participants (IG=25; CG=24) with CKD stages 1-4	Mobile health LINE app with social media to support CKD self-management	ND	Routine care: -Health education by a case manager -CKD diet manual at the end of the study (CG did not join IG or receive individualised dietary suggestions)	eGFR; self-efficacy, self-management, weight (BMI), QoL (at baseline and 90-day)	ND/ 90 days/ Dropouts: IG(N=5); CG(N=6)	**Some concerns**
Meuleman et al. (2017)17 Open RCT Nephrology departments Netherlands	138 participants (IG=67; CG=71) with CKD stages 1-4 (eGFR)≥ 20 mL/min/1.73 m^2)/ Hypertension	-Regular care -SMI	Self-regulation theory and CALORE taxonomy of BCTs	Regular care: -Consultations with the nephrologist every 3-6 months -If necessary, nutrition counselling by a dietician	Self-efficacy, HRQoL, weight (kg), BP (at baseline, after the 3-month intervention, and at the 6-month follow-up)	3 months/ 6 months/ Dropouts: IG (N=9 withdraw); CG (N=17 withdraw; N=3 lost in follow-up)	**Low Risk**

Study ID (author & year) **Bookmark** **Design** **Setting** **Country**	**Population (total N that completed the study); N(IG) and N(CG)**	**Intervention**	**Frame work**	**Control:**	**Outcomes of interest (and time point)**	**Duration/ Follow-up/ Dropouts**	**RoB2** **Low Risk** **Some Concerns** **High Risk**
Nelson et al. (2018)19 RCT Previously established cohort US	125 participants (IG=50; CG=48) with CKD (urine albumin-to-creatinine ratio≥30 mg/g and at least 1 other risk factor)	Home-Based Kidney Care	ND	-Standard clinical care -Lifestyle advice from Indian Health Service providers -Publicly available information about healthy lifestyle	Patient activation, HRQoL, eGFR, BP, weight (BMI) (at baseline, 6 months, and 12 months)	12 months intervention and follow-up/ Dropouts: IG (N=6 lost to follow-up; N=7 refused intervention); CG (N=7 lost to follow-up; N=7 refused)	**Low Risk**
Nguyen, Douglas, and Bonner (2019)20 RCT Renal outpatient clinics Vietnam	135 participants (IG=68; CG=67) with CKD stages 3-5 (not receiving dialysis)	SMI programme	SCT	Usual CKD care: -Brief verbal information (no structured programme or written material)	CKD self-management, CKD knowledge, self-efficacy, HRQoL, BP (at baseline, 8 weeks, and 16 weeks)	12 weeks /16 weeks/ Dropouts: at week 8, IG(N=2), CG(N=2). At week 16, IG(N=5), CG(N=6)	**High Risk**

Study ID (author & year) Bookmark Design Setting Country	**Population (total N that completed the study); N(IG) and N(CG)**	**Intervention**	**Frame work**	**Control:**	**Outcomes of interest (and time point)**	**Duration/ Follow-up/ Dropouts**	**RoB2** **Low Risk** **Some Concerns** **High Risk**
Teng et al. (2013)23 RCT Outpatient clinics Taiwan	103 participants (IG=52; CG=51) with CKD 1-3	Lifestyle modification programme-targeted intervention, matched to the TTM stage of change	TTM	-Face-to-face standard education on healthy eating and exercise -Educational booklet on kidney protection	Renal protection knowledge, weight (BMI) (at baseline and 3, 6, 9, and 12 months)	ND/12 months/ Dropouts: “64.4% retention rate. Follow-up rates: IG(59%) and CG(63%) at 12 months, respectively	**High Risk**
Wu et al. (2018)24 RCT Hospital Department of Nephrology Taiwan	112 participants (IG=45; CG=67) with CKD 3b-5 (patients with pre-ESKD)	Self-efficacy-based SMI	Self-efficacy theory	-Routine blood tests -Traditional health education provided by nurses or case managers	eGFR, BP, anxiety and depression, self-efficacy, self-management (at baseline and 3 months follow-up)	3 months intervention and follow-up/ Dropouts: IG(20%); CG(19.4%)	**High Risk**

BCTs Behaviour Change Techniques**;** *BMI* Body Mass Index; *BP* Blood Pressure; *BRIGHT* Bringing Information and Guided Help Together; *CG* Control Group; *CI* Confidence Interval; *CKD* Chronic Kidney Disease; *DBP* Diastolic Blood Pressure; *eGFR* estimated Glomerular Filtration Rate; *ESKD* End Stage Renal Disease; *HRQoL* Health-Related Quality of Life; *IG* intervention Group; *MHS* Mental Health Summary; *PHS* Physical Health Summary*;* *ND* No Data; *PLANS* Patient-Led Assessment for Network Support; *QoL* Quality of Life; *RCT* Randomised Control Trial; *SBP* Systolic Blood Pressure; *SCT* Social-Cognitive Theory; *SD* Standard Deviation; *SMI* Self-Management Intervention; *SMS* Self-Management Support; *TTM* Trans-Theoretical Model; *UK* United Kingdom; *US* United States.

Table 3.4

Summary of Included Studies - Dialysis Patients (N=11)

Study ID (author & year) Bookmark **Design** **Setting** **Country**	**Population (total N that completed the study);** **N(IG) and N(CG)**	**Intervention**	**Frame work**	**Control:**	**Outcomes of interest (and time point)**	**Duration/ Follow-up/ Dropouts**	**RoB2** **Low Risk** **Some Concerns** **High Risk**
Cho (2012)4 RCT Dialysis outpatients Korea	43 participants (IG=21; CG=22) Dialysis outpatients, receiving dialysis twice or 3 times a week for at least 3 months	HCI	Goal attainment theory	Routine care: -Checking the participants' self-care behaviours monthly and informing them of the results -Based on results, providing advice/guidance	Self-care behaviour, the mean weight gain (at baseline and 4 weeks)	4 weeks intervention and follow-up/ Drop-outs: IG(N=1) - participant underwent renal transplantation	**Some Concerns**
Griva et al. (2018)6 RCT 14 dialysis centres Singapore	235 participants (IG=101; CG=134) Patients on HD for a min of 6 months	-Usual care (educational booklet) -HED-SMART intervention	Principles of problem-solving and SCT	Standard renal care: -'Healthy Eating for People on Dialysis' educational booklet"	IDWG, self-efficacy, self-management skills (at baseline, 1-week post-intervention, 3 months, and 9 months post-intervention)	Total contact: 8h and 1 telephone follow-up/ 4-time points/ Total retention through study completion: 82.1%	**Low Risk**

Study ID (author & year) **Bookmark** **Design** **Setting** **Country**	**Population (total N that completed the study);** **N(IG) and N(CG)**	**Intervention**	**Frame work**	**Control:**	**Outcomes of interest (and time point)**	**Duration/ Follow-up/ Dropouts**	**RoB2** **Low Risk** **Some Concerns** **High Risk**
Hare, Clark-Carter, & Foreshaw (2014)7 RCT NHS Renal Service UK	15 participants (IG=8; CG=7) Patients receiving PD (CAPD and APD) for ≥3 months/ fluid non-adherent	LIP intervention: -Educational, cognitive and behavioural components, aimed to assist self-management of fluid	CBT techniques	"Deferred-entry CG": -Intervention in weeks 11-14	Weight, BP, psychological well-being, QoL [at baseline (T1), post-intervention (T2) and 3 follow-up points (T3, T4, T5)]	21 weeks/ 5 data collection points/ No drop-outs	**High Risk**
Huang et al. (2018)9 RCT Dialysis centre China	90 participants (IG=46; CG=44) Patients receiving regular HD 3 times per week for at least 3 months	SMS intervention: -Self-management education and motivational interviewing	ND	Common IG: -Standard care -Routine health education (verbal and educational flyers) -Access to the free automated electronic sphygmomanometer	BP (at baseline, at 1-, 3-, and 6-months post-intervention)	5-week intervention/ 1-, 3-, and 6-month follow-up/ Drop-outs: IG=4; CG=3	**Low Risk**

Study ID (author & year) Bookmark **Design** **Setting** **Country**	**Population (total N that completed the study);** **N(IG) and N(CG)**	**Intervention**	**Frame work**	**Control:**	**Outcomes of interest (and time point)**	**Duration/ Follow-up/ Dropouts**	**RoB2** **Low Risk** **Some Concerns** **High Risk**
Kauric-Klein, Peters, & Yarandi (2017)12 Randomised experimental design HD units US	118 participants (IG=59; CG=59) HD patients (a 4-week average pre-HD BP>150 mmHg or DBP>90 mmHg)	Educative self-regulation intervention	Self-regulation theory	Standard care: -BP monitoring based on BPs obtained in the HD unit -Medication adjustments by HCPs weekly as required	BP self-efficacy (at baseline and 12 weeks)	12-week intervention and follow-up/ Drop-outs: IG=7; CG=5	**Some Concerns**
Lee et al. (2020)13 Longitudinal RCT HD centre Taiwan	58 participants (IG=28; CG=30) ESKD patients receiving HD 3 times a week	SMP on renal function control in HD patients	Self-efficacy theory	Usual care/Conventional programmes: - 1 Individual health education (instruction either in writing or verbally)	eGFR, IDWG (at baseline, and at 3, 6, and 9 months)	4-week intervention/ follow-up at 3, 6, and 9 months/ Drop-outs: IG=3; CG=5	**High Risk**

Study ID (author & year) Bookmark **Design** **Setting** **Country**	**Population (total N that completed the study);** **N(IG) and N(CG)**	**Intervention**	**Frame work**	**Control:**	**Outcomes of interest (and time point)**	**Duration/ Follow-up/ Dropouts**	**RoB2** **Low Risk** **Some Concerns** **High Risk**
Liu et al. (2016)15 RCT Hospital of Harbin Medical University China	86 participants (IG=43; CG=43) CKD stage 5; patients on MHD >3 months)	A specialist knowledge-attitude-behaviour health education model	Change of attitude theory	-Usual care -Routine health education (patient follow-up by oral communication once every 2 weeks)	CKD knowledge, self-management behaviours (at baseline and 6 months)	6 months intervention and follow-up/ No drop-outs	**High Risk**
Luo et al. (2019)16 RCT Nephrology department China	128 participants (IG=64; CG=64) PD patients (regularly continuous ambulatory PD for at least 3 months)	MDT care based on 5E's renal rehabilitation on a self-management level	ND	Routine care: -Telephone follow-up -Outpatient follow-up -Routine health education by a specialised nurse	Self-management (at baseline and 12 months)	12 months intervention and follow-up/ Drop-outs: IG=9; CG=9	**High Risk**
Motarri et al. (2012)18 RCT Dialysis Centre Iran	48 participants (IG=25; CG=23) HD patients (diagnosed with ESKD and treated with HD for at least 3 months)	Empowerment programme	ND	Usual treatment	Self-care self-efficacy, QoL, BP, IDWG (at baseline and 6 weeks)	6 weeks intervention and follow-up/ Drop-outs: IG=0; CG=2	**Low Risk**

Study ID (author & year) Bookmark **Design** **Setting** **Country**	**Population (total N that completed the study);** **N(IG) and N(CG)**	**Intervention**	**Frame work**	**Control:**	**Outcomes of interest (and time point)**	**Duration/ Follow-up/ Dropouts**	**RoB2** **Low Risk** **Some Concerns** **High Risk**
Sevick et al. (2016)21 RCT Outpatient HD centres US	178 participants (IG=93; CG=85) HD patients (HD for at least 3 months)	BalanceWise Study intervention	SCT	6 educational modules on the HD diet	IDWGa (at baseline, 8 weeks, and 16 weeks)	16 weeks/ 8 and 16 weeks/ Drop-outs: IG=12; CG=7	**Some concerns**
Shad et al. (2018)22 Clinical trial Zabol Special Diseases Center Iran	59 participants (IG=29; CG=30) HD patients (a min 6 months of dialysis, 3 times a week)	Self-care programme	Dorothea Orem's SCDT	Routine training	Self-care behaviours in HD patients (at baseline and 2 months)	1-month intervention and follow-up: 1-month post-intervention/ Drop-outs: IG=1; CG=0	**High Risk**

APD Automated Peritoneal Dialysis; *BMI* Body Mass Index; *BP* Blood Pressure; *CAPD* Continuous Ambulatory Peritoneal Dialysis; *CBT* Cognitive Behavioural Therapy; *CG* Control Group; *CKD* Chronic Kidney Disease; *DBP* Diastolic Blood Pressure; *eGFR* Estimated Glomerular Flirtation Rate; *ESKD* End Stage Renal Disease; *HCI* Health Contract Intervention; *HD* Haemodialysis; *HED-SMART* Haemodialysis Self-Management Intervention Randomised Trial; HCP Healthcare Professional; *HRQoL* Health-Related Quality of Life; *IDWG* Interdialytic Weight Gain; *IDWGa* Average Daily Interdialytic Weight Gain; *IG* intervention Group; *LIP* Liquid Intake Programme; *MDT* Multidisciplinary Team; *MHD* Maintenance Haemodialysis; *ND* No Data; *NHS* National Health Service; *PD* Peritoneal Dialysis; *QoL* Quality of Life; *RCT* Randomised Control Trial; *SBP* Systolic Blood Pressure; *SCDT* Dorothea Orem's Self-care Deficit Theory; *SCT* Social-Cognitive Theory; *SMP* Self-Management Programme; *UK* United Kingdom; *US* United States.

Intervention and control group:

The methods of implementing SMIs in the included studies are presented in Appendix UU (non-dialysis population) and Appendix VV (dialysis population), reported in accordance with the TIDieR checklist and described below. Overall, 1628 participants (Mean=70.78) were randomised to the experimental group in all included studies (N=23).

Intervention features:

Trials included in this review involved several types of self-management. In the current review, SMIs differed in their topics, format, mode of delivery, and providers. Studies were grouped by their intervention features and presented in Table 3.5 below. The most common intervention topic in all included studies (N=23) was general CKD knowledge (91.3%) and the least common intervention topics were comorbidities (13.04%) and „other“ (8.7%). Out of all studies, 21 (91.3%) involved multiple intervention topics. Interventions were mostly delivered in an individual format (73.91%), however, the group format was only slightly less common (65.22%), while 10 studies (43.48%) combined both formats. The most frequent modes of delivering the interventions were face-to-face (86.96%) and print (78.26%), while virtual, social media, email, and homework (each 4.35%) were the least frequent delivery modes. Again, 21 studies (91.3%) incorporated multiple delivery modes. Finally, the interventions were mostly delivered by nurses (56.52%), „other“ (47.83%), and dietitians (30.43%), while 14 (60.87%) studies employed multiple providers.

Table 3.5

Intervention Features

Variable	Intervention count (non-dialysis population; N=12)	Intervention count (dialysis population; N=11)	Overall intervention count (N=23)
Intervention topics			
General CKD knowledge (educational content)	10	11	21
Diet/ nutrition	9	7	16
Alcohol and smoking cessation	4		4
Physical activity	7	3	10
Medication	4	2	6
Symptom management	8	5	13
Comorbidities	2	1	3
Lifestyle/ modalities	5	1	6
Other (e.g., community resources and activities)	2		2
Multiple	11	10	21
Intervention format			
Group	7	8	15
Individual	10	7	17
Multiple	6	4	10
Mode of delivery			
Face-to-face	9	11	20
Electronic (e.g., website; wearable devices; smartphone; electronic monitors; laptop/ computer)	5	3	8
Virtual (e.g., video conference)	1		1
Social media	1		1
Digital (e.g., video; DVD; CD)	2	2	4
Print	10	8	18
Telephone	6	4	10
Email	1		1
Homework		1	1
Multiple	11	10	21
Intervention providers			
Dietitian	5	2	7
Nurse	6	7	13
Physicians		2	2
Nephrologist	2		2
Psychologist	2	1	3
Case managers	2	1	3
Multiple	9	5	14
Other*	8	3	11

*Other providers: online e-learning (1); lay health workers (telephone support workers, staff members, undergraduate and postgraduate students) (2); peers and volunteers (3); certified exercise physiologist, cook educator and exercise physiologist (5); lifestyle coach (10); clinical pharmacy specialist, social worker, telehealth care technician (11); community health representatives (19); first author - nurse teacher (20); study researcher (4); medical social worker (6); nursing-led MDT (including 2 kidney attending physicians, 2 PD specialised nurses, a clinical dietitian, a clinical psychotherapist, a physical therapist, some social workers, and a postgraduate volunteer) (16). *CKD* Chronic Kidney Disease; *MDT* Multi-Disciplinary Team; *PD* Peritoneal Dialysis.

The theoretical basis of interventions:

In this review, 15 out of 23 studies (65.22%) included theoretical underpinning in their interventions. Overall, 12 different SMI theoretical frameworks were included. These comprised Social-Cognitive Theory (SCT) (20; 21), and one study combined SCT with the principles of problem-solving (6), Cognitive Behavioural Therapy (CBT) techniques (7), self-efficacy theory (13; 24), self-regulation theory (10, 12); and one study combined self-regulation theory with CALORE taxonomy of Behaviour Change Techniques (BCTs; 17), the goal attainment theory (4), the Trans-Theoretical Model (TTM; 23), Kelman’s change of attitude theory (15), standardised SMS (3), one study employed the Dorothea Orem’s self-care deficit theory (SCDT; 22), and other study utilised components of the previously mentioned CCM (11; refer to section 3.1)

Personalisation of interventions:

In most of the included studies, the personalisation of interventions was unclear/not specified. Four studies clearly reported, „tailoring“, particularly the intervention tailored to education and motivating patients (9), intervention tailored based on readiness to change from TTM (23), one study included tailored information (2), and another study stated in the strengths of their study, the inclusion of “a tailored intervention according to the needs of patients and HCPs as assessed in a preparatory qualitative study” (17). Eight studies were unclear regarding the inclusion of personalisation in intervention but mentioned some personalisation. For instance, they stated the inclusion of individualised dietary prescriptions (16) and suggestions (14), individualised counselling (12), individualised education sessions (3), individualised information and support if necessary (15), problem-centred approaches (24), a customised education programme and a patient-specific treatment plan (11), and one study claimed that “the study centred on the patient's problems to encourage the patients to develop personal objectives” (13).

Control group (CG):

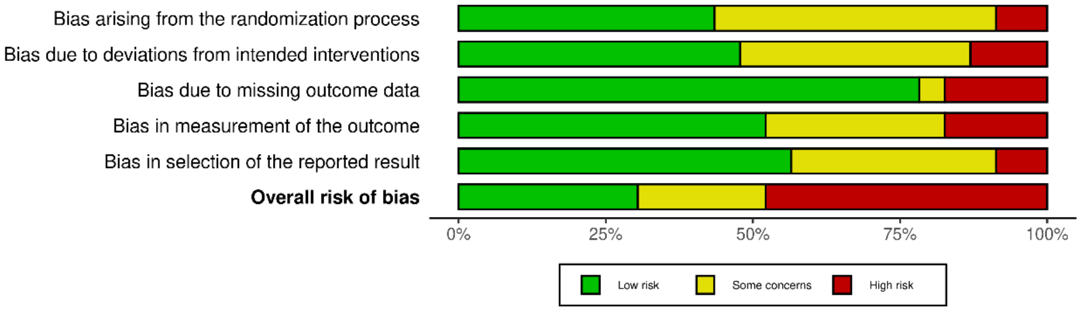
Overall, 1420 participants (Mean=61.74) were randomised to the CG in all included studies (N=23). In most of the included studies, the comparator was care-as-usual (alone), also described by studies as standard care, usual care, routine care, regular care, traditional care, and typical or usual treatment. In some studies, care-as-usual was supplemented by written information, including manuals, guidebooks, booklets, leaflets or flyers, and/or verbal information, such as advice, instructions, educational classes, and/or website resources, and/or telephone follow-up. One study also compromised six educational modules on HD (21) and another study included consultations and counselling in addition to care-as-usual (23). Finally, one study involved individuals in CGs in the intervention (in weeks 11 and 14 only; 15). We considered these small additions to care-as-usual as being within the variation of standard care provided in diverse settings.

3.3.3 Risk of Bias in Studies

The summary of RoB is presented in Figure 3.2 (summary plot) and RoB in each included study is shown in Figure 3.3 (traffic-light plot).

Figure 3.2

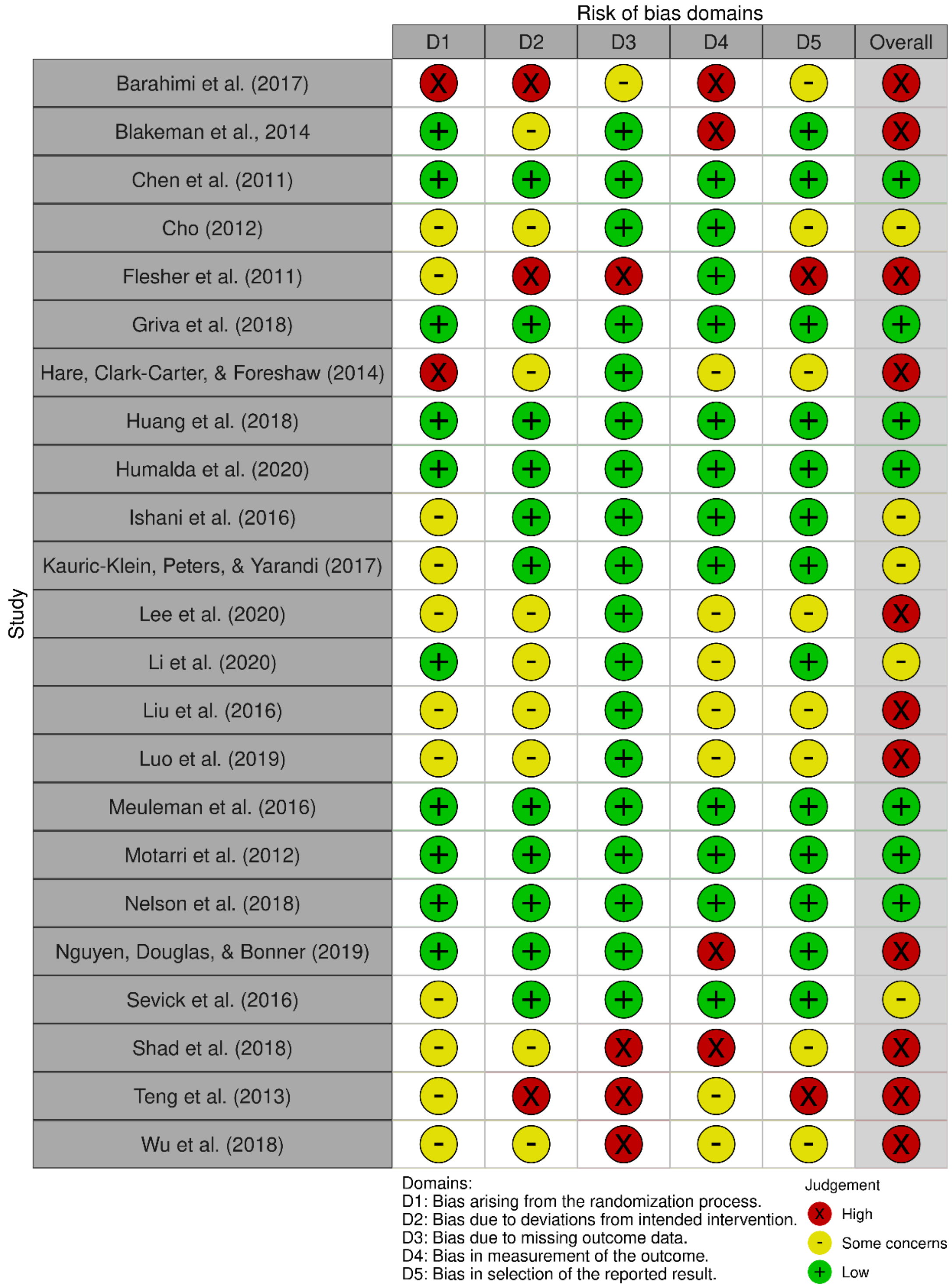
The Summary of RoB in All Included Studies (N=23)



RoB graph: the review author’s judgments about each RoB domain, presented as percentages across all included studies.

Figure 3.3

The RoB in Each Included Study (N=23)



Risk of bias domains

Study	D1	D2	D3	D4	D5	Overall
Barahimi et al. (2017)	X	X	-	X	-	X
Blakeman et al., 2014	+	-	+	X	+	X
Chen et al. (2011)	+	+	+	+	+	+
Cho (2012)	-	-	+	+	-	-
Flesher et al. (2011)	-	X	X	+	X	X
Griva et al. (2018)	+	+	+	+	+	+
Hare, Clark-Carter, & Foreshaw (2014)	X	-	+	-	-	X
Huang et al. (2018)	+	+	+	+	+	+
Humalda et al. (2020)	+	+	+	+	+	+
Ishani et al. (2016)	-	+	+	+	+	-
Kauric-Klein, Peters, & Yarandi (2017)	-	+	+	+	+	-
Lee et al. (2020)	-	-	+	-	-	X
Li et al. (2020)	+	-	+	-	+	-
Liu et al. (2016)	-	-	+	-	-	X
Luo et al. (2019)	-	-	+	-	-	X
Meuleman et al. (2016)	+	+	+	+	+	+
Motarri et al. (2012)	+	+	+	+	+	+
Nelson et al. (2018)	+	+	+	+	+	+
Nguyen, Douglas, & Bonner (2019)	+	+	+	X	+	X
Sevick et al. (2016)	-	+	+	+	+	-
Shad et al. (2018)	-	-	X	X	-	X
Teng et al. (2013)	-	X	X	-	X	X
Wu et al. (2018)	-	-	X	-	-	X

Domains:
D1: Bias arising from the randomization process.
D2: Bias due to deviations from intended intervention.
D3: Bias due to missing outcome data.
D4: Bias in measurement of the outcome.
D5: Bias in selection of the reported result.

Judgement
X High
- Some concerns
+ Low

RoB graph: the review author's judgments about each RoB domain for each included study.

As presented in Figures 3.2 and 3.3 above, out of 23 included studies, seven studies (30.43%) were judged to be at low RoB for all domains, five studies (21.74%) were judged to raise some concerns in at least one domain (but not to be at high RoB for any domain), and 11 studies (47.83%) were judged to be at high RoB in at least one domain or were judged to have some concerns for multiple domains so that considerably lowered confidence in findings (refer to Appendix QQ for author's judgment). The above figures indicate that two main domains through which bias was presented most frequently include bias due to missing outcome data (domain 3) and bias in the measurement of the outcome (domain 4). Moreover, in some of the included studies, the judgment could not be made due to insufficient information, particularly lack of sufficient information regarding allocation concealment (part of domain 1) and selection of the reported results (domain 5).

3.3.4 Results of Individual Studies and Synthesis and Certainty of Evidence

Description of outcomes and results:

The characteristics of the study outcomes (review's primary and secondary outcomes) and results for these outcomes are visually presented in the additional Tables WW1-WW4 in Appendix WW. These include the outcome of interest in the included studies, as well as results for included outcomes organised to studies involving non-dialysis patients and patients on dialysis. These findings were summarised in the summary of the study outcomes (Table 3.6) for all included studies (N=23) and further described narratively below.

Table 3.6

Summary of the Study Outcomes

Outcomes	Studies			Results (post-intervention) (N=23)			
	Non-dialysis (N=12)	Dialysis (N=11)	All (N=23)	Outcome improved 🟢	Outcome worsened 🔴	Outcome unchanged 🟡	Mixed results 🟣
Primary outcomes							
Self-efficacy	4	3	**7**	5			2
CKD self-management	6	6	**12**	10		1	1
CKD knowledge	3	1	**4**	4			
eGFR	6	1	**7**	3		3	1
Adverse events	1	NA	**1**			1	
Secondary outcomes							
BP	7	4	**11**	5	1	3	2
Weight (or IDWG)	4	7	**11**	5		5	1
Health-related behaviours	NA	NA	**NA**	NA	NA	NA	NA
Psychological distress	2	1	**3**			1	2
HRQoL/ QoL	6	2	**8**	5		1	2
Patient Activation	1	NA	**1**	1			

CKD Chronic Kidney Condition; *eGFR* Estimated Glomerular Flirtation Rate; *HRQoL* Health-Related Quality of Life; *IDWG* Interdialytic Weight Gain; *NA* Not Assessed; *QoL* Quality of Life.

The majority of articles (78.26%) included more than one outcome in their study that met the current review's eligibility criteria. The most common outcomes reported across all 23 studies were CKD self-management (52.17%), BP (47.83%), and weight or interdialytic weight gain (IDWG) (47.83%). The least common outcomes reported across all studies were adverse events (one study, 4.35%) and patient activation (one study, 4.35%), and no studies assessed health-related behaviours. As categorised in Table 3.6, out of all 65 reported results for all outcomes in all included studies, 38 outcomes improved (58.46%), 15 did not change (23.08%), 11 (16.92%) had mixed results (e.g., improvement in some parts of measure but not all), and only one outcome (BP) worsened post-intervention (1.54%). Out of 38 (58.46%) outcomes that improved, 12 were CKD self-management, 11 were BP, 11 were weight/IDWG, eight were HRQoL/QoL, seven were self-efficacy, seven were eGFR, four were CKD knowledge, three were psychological distress, one was adverse events, and one was patient activation.

Results of the effect direction:

Table 3.7 below summarises the results of the effect direction in the IG to the following outcome domains: physiological outcomes, cognitions, individual outcomes, and health status, while the health-related behaviours domain was excluded from the synthesis as no included studies assessed this domain (refer to Appendix RR).

Table 3.7

Summary of Effect Direction

Author (year)Bookmark	Final sample in the IG	Physiological outcomes	Cognitions	Individual outcomes	Health status
Chen et al. (2011)3	27	▲	▲		
Griva et al. (2018)6	101	▲	◀▶^{2}		
Huang et al. (2018)9	46	◀▶	▲		
Humalda et al. (2020)10	50	▲	◀▶	▲	
Meuleman et al (2016)17	67	◀▶^{2}	▲	◀▶	
Motarri et al. (2012)18	25	▲^{2}	▲	▲	
Nelson et al. (2018)19	50	◀▶^{3}	▲	◀▶	
Cho (2012)4	21	▲	▲		
Ishani et al. (2016)11	450				◀▶
Kauric-Klein, Peters, & Yarandi (2017)12	59	◀▶^{2}	◀▶		
Li et al. (2020)14	25	◀▶^{2}	◀▶^{2}	▲	
Sevick et al. (2018)21	93	◀▶			
Barahimi et al. (2017)1	39	▲			
Blakeman et al. (2014)2	215	▲	▲	◀▶^{2}	
Flesher et al. (2011)5	23	◀▶^{2}			
Hare, Clark-Carter, & Foreshaw (2014)7	8	◀▶^{2}		◀▶^{2}	
Lee et al. (2020)13	28	◀▶^{2}			
Liu et al. (2016)15	43		▲		
Luo et al. (2019)16	64		▲		
Nguyen, Douglas, & Bonner (2019)20	68	◀▶	▲^{3}	▲	
Shad et al. (2018)22	29		▲		
Teng et al. (2013)23	52	◀▶	▲		
Wu et al. (2018)24	45	◀▶^{2}	▲^{2}	◀▶	

Key:

Effect direction: upward arrow ▲ =positive health impact, downward arrow ▼ =negative health impact, sideways arrow ◀▶ =no change/mixed effects/conflicting findings. Sample size: final sample size in the IG: large arrow ▲ >300; medium arrow ▲ 50-300; small arrow ▲<50. Study quality: specified by row colour: green=low RoB; amber=some concerns; red=high RoB. Subscript numbers: If the number of outcomes within each domain was >1, the number of outcomes from the study was placed next to the effect direction arrow. *IG* Intervention Group.

As presented in Table 3.7 above, for the physiological outcomes domain, seven studies reported a positive effect direction and 12 studies reported conflicting or unclear effects. The results from the sign test identified the *p*-value for this outcome domain as 0.016, which indicates the probability of observing either seven or more successes, or zero or fewer successes, in seven trials. For the cognitions domain, 13 studies reported a positive effect direction and four reported conflicting or unclear effects (*p*-value for sign test 0.001). For the individual outcomes domain, a positive effect direction was noted in four studies and conflicting or unclear effects were reported in five studies (*p*-value for sign test 0.125). Finally, only one study assessed an outcome in the health status domain (particularly, adverse events) reporting conflicting or unclear effects, thus it was not possible to conduct the sign test for only one trial. Finally, Table 3.7 shows that out of all 23 included studies, only one study included a large sample size (>300) in the IG, 10 studies included a medium sample size (50-300), and 12 reported a small sample (<50) size in the IG.

Results of the certainty of evidence assessment:

In the current review, seven out of 23 studies were rated as low RoB (3; 6; 9; 10; 17; 18; 19), three of which involved patients on dialysis (6; 9; 18), while the remaining four included the non-dialysis population (see table 3.8 below for outcome measures). These studies were included in the certainty of evidence assessment. The detailed GRADE assessment for each outcome is presented in Appendix TT, which includes authors' judgments and reasons for down-or-upgrading, and narrative (and some quantitative) data from the GRADE assessment for each outcome is reported in the SoF Table 3.9 below.

The outcomes included for the certainty assessment were the review's primary outcomes, including "critical" outcomes (namely, self-efficacy, CKD knowledge, and CKD self-management) as well as "important" outcomes (including adverse events and eGFR), however, as illustrated in Table 3.8, the adverse events were not looked at by these studies and it was noted accordingly in the SoF table. Note that, one study assessed CKD knowledge outcome and reported its results but did not include it in their primary or secondary endpoints (3). Similarly, another study (19) assessed and reported results for eGFR outcome, however, they included it as a laboratory testing rather than the primary or secondary outcome. Nevertheless, it was decided to include both studies and their outcome assessment in the main comparison.

Table 3.8

Outcome Measures

Studies at low RoB		Outcomes included for GRADE assessment (assessed time-point/last follow-up)	Outcome assessed by	Scale and range
Dialysis population	Non-dialysis population			
	Chen et al. (2011)**3**	**-eGFR** **-CKD knowledge** (12 months)	-“Simplified Modification of Diet in Renal Disease Equation” -Standardised CKD knowledge checklist (Cronbach alpha=0.80)	-Higher absolute eGFR indicates a slowdown in the CKD progression -15 items with dichotomous responses (e.g., true or false) evaluated using a 5-point Likert scale
Griva et al. (2018)**6**		**-Self-efficacy** **-CKD self-management** (9 months)	-Validated scale (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001) and 8 additional items (with high internal reliability coefficient, 0.92) measuring confidence related to fluid intake, diet, and medication	-6 item scale, a higher score indicating better self-efficacy; the aggregate score for 8 additional items -ND

Studies at low RoB		Outcomes included for GRADE assessment (assessed time-point/last follow-up)	Outcome assessed by	Scale and range
Dialysis population	Non-dialysis population			
			-Validated tool for evaluating SMIs – HeiQ version 2 (Osborne, Elsworth, & Whitfield, 2007)	
Huang et al. (2018) **9**		**-CKD self-management** (consistency of HBPM; 6 months)	-2 self-administered questions assessing frequency and time of HBPM	-5 different response options for the first question and 2 responses for the second question
	Humalda et al. (2020)**10**	**-CKD self-management** (9 months)	-Standardised measure (PIH scale; Petkov, Harvey, & Battersby, 2010)	-4 items questionnaires
	Meuleman et al (2016)**17**	**-Self-efficacy** (6 months)	-Standardised, reliable measure (Cronbach alpha=0.73)	-Score ranged from 1 to 10, a higher score indicating a stronger belief in the ability to manage CKD
Motarri et al. (2012)**18**		**-Self-efficacy (**self-care self-efficacy**;** 6 weeks)	-29 items self-reported questionnaire (Cronbach alpha=0.91)	-Possible scores for the overall questionnaire were 29-145
	Nelson et al. (2018)**19**	**-eGFR** (12 months)	-Calculated using the Chronic Kidney Disease Epidemiology Collaboration equation (Levey et al., 2009).	-ND

CKD Chronic Kidney Disease; *eGFR* estimated Glomerular Filtration Rate; *HBPM* Home Blood Pressure Monitoring*; HeiQ* Health Education Impact Questionnaire; *ND* No Data; *PIH* Partners in Health; *RoB* Risk of Bias.

Based on the assessment of the importance of outcomes (refer to section 3.2.1 and Appendix XX for the "GRADE evidence profile" that includes explanations of the SoF table) and the quality of evidence, the results of the intervention ("benefits" and "harms") were reported. As illustrated in the SoF Table 3.9 below, SMIs improve self-efficacy, may improve CKD knowledge and self-management outcomes, and may improve slightly eGFR. No studies looked at the outcome of the adverse events. Results for each outcome are described narratively below. In the certainty of the evidence assessment, two reasons for downgrading were inconsistency and imprecision, and all other domains in the GRADE assessment showed no serious (or very serious) concerns. This indicates that three outcomes that were downgraded by one or two levels showed some inconsistency and imprecision in the reported results.

Table 3.9

Summary of Findings

SMI compared to care as usual/standard care for individuals with CKD

Patient/population: adults with CKD
Intervention: SMI
Comparison: care as usual

Outcomes	Effect	№ of participants (studies)	Certainty of the evidence (GRADE)
Self-efficacy assessed with: different, but valid and reliable measures used by the studies follow-up: range 6 weeks to 9 months	SMI improves self-efficacy outcome	421 (3 RCTs; **6; 17; 18)**	⊕⊕⊕⊕ High
CKD self-management assessed with: different measures used by the studies: 2 standardised measures and 1 self-administered questions follow-up: range 6 months to 9 months	SMI may improve CKD self-management outcome	419 (3 RCTs; **6; 9; 10**)	⊕⊕◯◯ Low[a,b]
CKD knowledge assessed with: a standardised CKD knowledge checklist follow-up: median 12 months	SMI may improve CKD knowledge outcome	108 (1 RCT; **3**)	⊕⊕◯◯ Low[c]
eGFR assessed with: ND on the assessment measure follow-up: median 12 months	SMI may improve slightly eGFR outcome	152 (2 RCTs; **3; 19**)	⊕⊕◯◯ Low[d,e]
Adverse events	No studies were found that looked at the outcome of the adverse events	(0 studies)	-

Retrieved from: GRADEpro software (2022). *CKD* Chronic Kidney Disease; *eGFR* estimated Glomerular Filtration Rate; *ND* No Data; *SMI* Self-Management Intervention.

Self-efficacy:

The effect of SMI on self-efficacy was evaluated in three trials (6; 17; 18) using different, but valid and reliable measures. The participants were followed up between six weeks to nine months, in medium samples (6; 17) and one small sample size (18) of patients on dialysis (two studies) and without. The result for self-efficacy outcome was based on high-quality evidence and indicated that SMIs improve self-efficacy. The common strategies to enhance self-efficacy employed in these three successful trials were goal setting, barrier identification, and problem-solving, with an element of social and peer support (6; 17; 18) and family involvement (18). One study employed self-regulation theory with the CALORE taxonomy of BCTs (17), while another study involved individual and group empowerment counselling (18), and another used SCT to improve confidence and ability to self-manage disease (6).

CKD self-management:

The effect of SMI on CKD self-management was also examined in three studies (6; 9; 10), using different measures (two standardised, and one self-administered measure), however, the range of follow-up for this outcomes was slightly longer compared to the self-efficacy outcome, ranging between six to nine months. The studies also employed medium samples (6; 10) and one small sample (9). The result for CKD self-management outcome was based on low-quality evidence and specified that SMI may improve CKD self-management in both, dialysis, and non-dialysis populations.

CKD knowledge:

The results for CKD knowledge outcome (assessed using a standardised checklist) come from one study at low RoB (3) and were based on low-quality evidence, which indicated that SMIs may improve CKD knowledge. In this study, the authors employed a small sample of 27 non-dialysis patients in the IG and followed them up for 12 months. Note that, the certainty of the evidence for this outcome may be “biased” given that only one study assessed and reported results for CKD knowledge, and consequently comparison across studies for this outcome was not possible. We downgraded the imprecision domain for this outcome by two levels (very serious) for the certainty of evidence assessment. We made this judgment based on insufficient information required (e.g., only one study with a small sample size).

eGFR:

The effect of SMI on eGFR was evaluated in two trials (3; 19) rated as low RoB, in small and medium samples of the non-dialysis population, which were followed up for 12 months. The results for eGFR outcome were based on low-quality evidence and indicated that SMIs may improve slightly eGFR.

Adverse events:

No trial at low RoB looked at the adverse events. However, one study (11), judged to have some concerns in RoB, assessed adverse events in a large sample of the non-dialysis population, and after 12 months of follow-up, the authors reported no change/mixed results for this outcome.

3.4 Other Information

Protocol:

Methods of the analysis, review questions, as well as inclusion and exclusion criteria were specified in advance and reviewed by the research supervisors and two librarians at Swansea University and were documented in a protocol for this phase (Additional File 1- protocol for this review; available upon request). It should be noted that this initial protocol has been revised throughout the review process and some minor amendments were applied accordingly. These protocol deviations are noted in Table 3.10 below.

Table 3.10

Protocol Deviations in Literature Review

Section of the protocol deviation	Deviations and rationale for changes
Review question	The review question was to some extent rephrased to ensure that it is relevant and answerable.
Eligibility criteria (prioritisation of outcomes)	The inclusion of the relevant outcomes remained the same, however, the review team assessed the importance of outcomes (during the review process) to decide on the most important outcomes for the main comparison, and thus categorisation of primary and secondary outcomes was amended.
Data synthesis	The primary aim was to include a meta-analysis, but after the informal heterogeneity assessment, it was no longer possible.
Contacting the corresponding authors for RoB assessment	The protocol indicated that the review author would contact the corresponding authors when necessary to gain access to missing information and clarify the reported data. However, due to time constraints, the studies' authors were not contacted and this was noted as one of the limitations of the review.
Methods (shift from REA to systematic literature review)	As outlined in the introduction section of this Chapter, although the review followed mostly guidelines for rapid reviews, the detailed and systematic approach ultimately transitioned to the systematic review methodology.

REA Rapid Evidence Assessment; *RoB* Risk of Bias.

It is believed that apart from the lack of contact with the corresponding authors when required for RoB assessment, these minor changes did not affect the review process.

The study excluded from the synthesis:

As mentioned earlier, one study (8) was excluded from the synthesis after the full-text screening, however, the review author collaboratively with the study supervisors decided to include it based on its relevance for the current review and describe its findings separately in this section. In this secondary data, post-hoc analysis of a 16-week, technology-supported SCT-based intervention to reduce dietary sodium intake, the impact of baseline self-efficacy on the efficacy of dietary interventions as well as its relationship with sociodemographic and clinical characteristics in HD patients were examined. The authors established that the benefits of interventions designed to improve self-efficacy may differ by baseline self-efficacy level, with those with low self-efficacy benefitting the most (8). Moreover, the results from sociodemographic variables were particularly interesting for the current study as the authors also reported that younger age and low income are associated with a low level of dietary self-efficacy. These findings were supported by another study which also reported that younger HD individuals show significantly lower confidence in regard to following dietary recommendations (Park, Choi-Kwon, Sim, & Kim, 2008).

3.5 Discussion

The general interpretation of the results

The REA methodology enabled summarising wide-ranging SMIs systematically and comprehensively for adults with CKD-all-stages and identifying their key features while evolving to a full systematic literature review. We recognised 23 studies that met the review's eligibility criteria and investigated CKD SMIs with considerable variation in the population, interventions, and outcomes assessed, as well as obtained results (particularly, some improved, some worsened, some did not change, and some had mixed results). Most articles (56.52%) were published within the past 5 years (from the review's end date - 2021), five out of which were published in the last 3 years. This indicates the growing interest in self-management and the urgent need for the appropriate SMI for individuals with CKD, as indicated in the introduction section of this Chapter. The introduction section has also recognised an emerging need for models of care to face the challenges of the progressively increasing CKD population in the UK. In this review, only 2 studies were conducted in the UK, while most studies took place in Asia (60.87%).

Our findings are similar to the previous reviews reporting a lack of theoretically driven and personalised interventions (e.g., Bonner, Haves, & Douglas, 2014). Although 65.22% of studies reported the inclusion of theoretical underpinnings in their intervention design, the SMIs were mainly designed by HCPs without patients' input, and personalisation of interventions was "clearly" reported by only four studies, while the remaining studies did not tailor the intervention to patients' needs and desires or just included some elements of personalisation. A previous scoping review by Donald and colleagues (2018) also revealed the lack of patient involvement in intervention design with less than one percent of programmes being co-developed with CKD patients, as well as failure to apply behaviour change theory with only 20 percent of programmes being designed based on a theory. The authors also reported the lack of person-centeredness, inclusion of physiological and non-physiological outcomes, and applicability to CKD-related comorbidities in the CKD SMIs (Donald et al., 2018).

Out of all 23 included articles, the majority of studies (91.3%) employed multiple intervention topics, while the most common intervention topic was general CKD knowledge (91.3%). Despite of common incidence of comorbidities in the CKD population, the least common intervention topics were comorbidities (13.04%) and „other "(8.7%, such as community resources and activities). As identified in the introduction Chapter of this thesis, those individuals who suffer from CKD and associated comorbidities must be provided with ongoing care and support, thus studies should consider the inclusion of strategies to help them manage comorbidities. Intervention topics were presented in multiple, various formats, modes of delivery, and providers, while the individual format, face-to-face and print, delivered by nurses were most common.

Most included articles (78.26%) reported more than one outcome. We found that the most common outcomes reported across all 23 studies were CKD self-management, BP, and weight or IDWG (for dialysis patients), while the least common outcomes were adverse events (one study) and patient activation (one study), and no studies assessed health-related behaviours. We have seen that an effective SMI requires the consistent delivery of care that improves an individual's knowledge, skills, and confidence in dealing with and managing all aspects of CKD (Pearce et al., 2016). The findings from this review indicate a lack of focus on patient activation (knowledge, skills, and confidence) and significant health-related behaviours (such as smoking, alcohol consumption, diet, and physical activity). Out of all 65 reported results for all outcomes in all included studies, 38 outcomes improved. Consequently, the SMI has been supported as an effective intervention to improve: CKD self-management (behaviours/skills), BP, weight/IDWG, HRQoL/QoL, self-efficacy, eGFR, CKD knowledge, psychological distress, adverse events, and patient activation. However, in one study BP outcome worsened, and 11 had mixed results, while the remaining 15 did not change post-intervention.

Furthermore, the results of the effect direction to the four outcome domains exposed whether there is any evidence of an effect on physiological outcomes, cognitions, individual outcomes, and health status, showing improvement in seven out of 19 studies, 13/17 studies, four out of nine studies, and one study respectively. No deterioration in any of the outcome domains was indicated. Additionally, the certainty assessment revealed from studies at low RoB that the SMIs improve self-efficacy, may improve CKD knowledge and self-management outcomes, and may slightly improve eGFR. No studies examined adverse event outcomes. Self-efficacy evidence was high-quality, whereas, the evidence on CKD knowledge, self-management, and eGFR outcomes was low-quality with some inconsistent and imprecise results.

In two (6, 17) out of three trials that assessed self-efficacy, the use of theory in intervention development and implementation was reported. This suggests that theory-based interventions to improve self-efficacy may be successful. Studies did not tailor interventions, however, one study stated that the intervention was tailored according to the patients' and HCPs’ needs which was examined in their preliminary qualitative study (17) but did not specify details. Moreover, these successful interventions to improve self-efficacy employed multiple intervention topics, with CKD knowledge, diet, medication and symptom management being the most common topics. Intervention topics were presented in various diverse formats, particularly one study involved a group format (6), another chose an individual format (17), and the third study combined both formats (18). All three interventions were delivered face-to-face and in print, while two studies also involved telephone contact in their mode of delivery (17; 6). In one study it was accommodated by the nurse (18), while the other two studies involved multiple providers. To improve self-efficacy in all three trials, the shared strategies involved goal setting, barrier identification, and problem-solving, while offering social and peer support (6, 17, 18). This suggests that including these strategies while employing self-regulation theory (17), empowerment counselling (18), and/or SCT to enhance patients' confidence (6) may lead to successful CKD SMIs.

In addition, the supplementary study (8) described in the previous section, which established that individuals with a low level of self-efficacy seem to benefit most from theory-based (particularly, SCT) interventions to reduce dietary sodium, further supported the importance of evaluating patients' self-efficacy level. Currently, the majority of clinical trials place little emphasis on the underlying behavioural constructs targeted by interventions (such as self-efficacy or patient activation), while identifying individuals that are likely to respond to treatment is significantly important and one way of addressing this is by examining baseline self-efficacy. The findings from this study also revealed important information for the current study looking at YA with CKD as the authors concluded that younger age and low income in the HD population are associated with lower confidence to follow dietary suggestions (8). Given that this project aims to develop SMI for YAs with CKD, based on these findings, it is important to assess the level of self-efficacy in YAs to design an appropriate intervention for this population.

The theory of change for the intervention that was considered as most likely to inform the pathways of behaviour change was the self-efficacy theory (described in more detail in the next Chapter) and the results of the current synthesis supported this theoretical underpinning (of how the intervention works, why, and for whom) to explain and predict behaviour in individuals with CKD. Scholars proposed that self-efficacy is the most significant variable in explaining and predicting self-care behaviours (Wang, Chao, & Hsu, 2016). Moreover, the relationship between the "critical" outcomes selected for this review, namely self-efficacy, CKD knowledge and self-management of individuals with chronic conditions was previously investigated in several cross-sectional studies. For instance, the study by Wu and colleagues (2016) examined 247 individuals with CKD (stages 1-5) and established that self-efficacy is a significant mediator between CKD knowledge and self-management. The authors concluded that HCPs should not only provide relevant knowledge to CKD patients but also offer them theory-based strategies that can improve self-efficacy to increase self-management behaviours (Wu, Hsieh, Lin, & Tsai, 2016). Similarly, a recent cross-sectional study by Chuang and associates (2021) confirmed these findings when examining 130 individuals with early-stage

CKD and concluded that self-efficacy is a mediator and predictor for self-management. They suggested that to effectively manage the disease and significantly enhance individuals' self-management, after improving disease-related knowledge, the most significant factor to improve is self-efficacy (Chuang et al., 2021). The findings from these studies (and similar studies with patients on dialysis supporting self-efficacy as a mediator and predictor, for example, Li, Jiang & Lin, 2014) only further highlight the importance of these three outcomes in CKD SMIs, particularly self-efficacy, and its associations.

Finally, in terms of the two groups comparison, dialysis (N=11) and non-dialysis population (N=12), the studies that included patients on dialysis on average employed significantly smaller sample sizes in their trials (average sample size for 11 trials= 96.18; average sample size in the IG= 47) compared to studies that employed patients without dialysis (12 trials= 168.08; IG= 92.58). Out of 11 studies that included dialysis participants, three scored low on RoB assessment, three showed some concerns, and five were judged as high RoB, whereas in 12 studies that included a non-dialysis sample, four studies were judged to be at low RoB, two included some concerns, and six were at high RoB.

The most common outcomes assessed and reported in 11 trials involving the dialysis population were weight (29.92%), CKD self-management (23.08%), BP (15.38%), and self-efficacy (11.54%). Out of all 26 reported results for all included outcomes in these 11 studies, 14 (53.85%) showed a positive health impact (improved), 11 (42.31%) did not change, and one outcome (BP) had a negative health impact (worsened) post-intervention (3.85%). Patient activation and adverse events were not assessed in these trials. Out of 14 (53.85%) outcomes that improved, five were CKD self-management, three were weight, two were BP, two were self-efficacy, one was CKD knowledge and one was HRQoL/QoL. Whereas, the most common outcomes assessed and reported in 12 trials involving the non-dialysis population were BP (17.95%), eGFR and HRQoL/QoL (16.38% each), and CKD self-management (12.82%). Out of all 39 reported results for all included outcomes in these 12 trials, 23 improved (58.97%) and the remaining 16 (41.03%) did not change post-intervention. No negative health impact was reported for any of these 39 outcomes assessed in the non-dialysis population. Out of 23 (58.97%) outcomes that improved, four were CKD self-management, four were HRQoL/Qol, three were eGFR, BP, CKD knowledge, and self-efficacy respectively, two were weight, and one was patient activation.

Further examination of the certainty of evidence assessment for studies that were judged to be at low RoB, revealed that based on high-quality evidence two trials with dialysis patients (6, 18) improved self-efficacy post-SMI and two studies (6, 9) based on low-quality of evidence reported improvement in CKD self-management. The strategies used to improve self-efficacy in these two successful trials were goal setting, barrier identification, principles of problem-solving and SCT, with a component of social and peer support (6, 18) and family involvement in the empowerment programme (18). To improve CKD self-management, the studies involved principles of problem-solving and SCT (6) as well as self-management education and motivational interviewing techniques (9). Whereas, in trials with non-dialysis patients at low RoB, one study improved self-efficacy while combining self-regulation theory with the CALORE taxonomy of BCTs in their SMI (17). This was also based on high-quality evidence. Whereas low-quality evidence revealed that SMI may improve CKD self-management in the non-dialysis population while incorporating self-regulation theory in the intervention (10), as well as may improve CKD knowledge and may improve slightly eGFR when employing standardised SMS involving interactive individualised sessions (3) and/or home-based kidney care (19).

Little is known about the specific requirements for SMIs for these two different groups. According to Almutary and Tayyib (2022), globally, data on specific populations is limited. A few studies that looked at both groups examined individuals with ESKD and reported some variances between HD and non-HD self-management groups. For instance, in a systematic review comparing the scores of HRQoL between the two groups in four studies by Tsai and colleagues (2017), the authors established that the non-HD population reported higher mental composite scores and a maintained higher overall HRQoL compared to the HD population which showed higher physical composite scores, but which declined over time (Tsai, Chao, Chang, Hung, & Group, 2017). They concluded that the coping strategies (e.g., acceptance of the illness) used by the non-HD patients led to better HRQoL

(Tsai et al., 2017). This example suggests variances between these two groups and the current literature did not allow us to examine what works for whom and how in more depth, thus future studies should consider SMIs on the basis of population and examine the difference between SMIs specific for those CKD individuals on dialysis therapy and without.

Strengths and limitations of the current systematic literature review

This systematic literature review was conducted and reported in response to the need for the appropriate person-centred, theory-based SMI specific for YAs with CKD 1-5. The REA format was initially chosen due to time constraints and a small team, and although it later progressed into a full systematic review, it is recognised that there are limitations to these methods.

Firstly, considering the transferability of findings from the current systematic literature review to YAs with CKD, it is important to acknowledge the limitations of the broader age demographic of the reviewed studies. While the identified key elements of CKD SMIs provide insight into effective strategies, their direct applicability to YAs may be limited. The reviewed literature predominantly focuses on older adults, whose lifestyle, psychosocial factors, and health priorities may significantly differ from those of YAs. As such, there may be variations in engagement, adherence, and specific needs. To address this issue to some extent, YA participants in phase 2 (in both quantitative and qualitative studies) were asked questions about, for example, their preferences concerning support delivery and intervention content. Despite these challenges, core principles of effective SMIs, such as personalised interventions, self-monitoring, or behavioural support, are likely to be relevant across all age groups. However, for these findings to optimally benefit YAs, they must be adapted to address age-specific preferences, technological proficiency, and developmental considerations. This underscores the necessity for future research explicitly targeting the YA population to develop more tailored and effective interventions.

Additionally, the primary strength of this review is that it included a rigorous and systematic search of the available literature. This systematic review employed a standardised, transparent, and systematic approach and valid tools to identify, evaluate, and report published evidence relevant to the research question while following several guidelines for conducting rapid and systematic reviews. It also involved thorough quality assessment using the RoB2 tool for RCT studies, and certainty assessment using the GRADE approach. The review author rated the RoB, conducted data extraction, and rated the certainty of the evidence, whereas research supervisors checked the credibility of decisions and the correctness of data. These steps were undertaken independently and dually; therefore, the risk of error was reduced.

Another strength of this review is the inclusion of all CKD populations. The majority of literature on CKD self-management excluded articles that studied individuals with CKD on dialysis, typically without providing a reason for doing so. This review included all CKD individuals both on dialysis and without, and all CKD stages. To our knowledge, this is the first systematic rapid review that included both dialysis and non-dialysis patients with all stages of CKD, and which systematically summarised a wide range of SMIs and identified their features (including identification of theoretical frameworks and person-centeredness) by investigation of "who", "what", and "how".

Nevertheless, due to the rapid nature of this assessment, the search was limited to only three databases, including MEDLINE/PubMed, CINAHL and PsycINFO. Although Nussbaumer-Streit's (2018) study (based on 60 Cochrane reviews) indicated that for the methods for rapid reviews to be reliable, the reviews should be undertaken using at least two databases, or one database with an additional reference search, this may still have restricted the breadth of the potential studies available for inclusion. In light of this, an additional scoping exercise and search of the reference lists of main papers, using citation chaining, was undertaken. This supplementary search yielded four additional records for screening, which contributed to four studies that were deemed eligible for inclusion.

Similarly, no grey literature was searched. While this review was conducted as comprehensively as possible, relevant studies may have still been missed. However, searching the reference lists of main papers mitigated some of the risks of missing relevant publications. Furthermore, studies published after the end of the search (December 1st, 2021) will have been missed by this systematic review.

Therefore, given the methodology of the REA and the rapid flow of publications in the area of SMIs, it may not have been possible to find and assess all the relevant studies.

Additionally, for pragmatic reasons, articles published in the past 10 years (from 2011 to 2021) in English were included. No assumptions can be made as to how non-English studies and relevant studies published before 2011 would have contributed to the findings. There is a possibility that limiting the search to a set number of years and restricting language may have led to a loss of relevant studies and a change in the results. In other words, there is an increased risk that the literature reviewed may have not provided an exact representation of the complete body of research evidence relevant to the research question (GSRS, 2014). Thus, this may have increased the risk of publication and language bias at the review level. However, evidence suggests that limiting inclusion criteria to English language publications from systematic reviews on clinical interventions had a minimal effect on overall conclusions and it may be a feasible methodological shortcut for rapid reviews (Nussbaumer-Streit et al., 2020).

In addition, out of all 23 included studies, seven studies in this review scored highly on the RoB 2 tool presenting low RoB and five showed some concerns, whereas the remaining 11 studies were judged to be at high RoB which could have decreased the validity of the review findings. One of the reasons for downgrading RoB in the included studies was a lack of information, particularly the lack of protocol or registry. Due to time constraints, the review author did not contact the authors to retrieve this information when unavailable. Omitting difficult-to-obtain materials may have introduced potential bias in the review process, however, we are confident that these methodological limitations would not change the overall conclusion of this review.

Furthermore, one of the challenges in the current review was synthesising the heterogeneous data. To address this challenge, the review author employed a standardised tool, namely the TIDieR checklist (Hoffman et al., 2014) to extract data on interventions. However, due to the heterogeneous nature of the data (e.g., characteristics of included studies being too diverse to provide a meaningful summary estimate of effect), the meta-analysis was not possible, and consequently, we were unable to report the intervention effect (estimate of effect) but rather whether there is any evidence of an effect. The wide differences in the content, delivery, and components of SMIs, together with outcomes assessed and obtained results, make it challenging to compare findings across studies that evaluated these programmes. Accordingly, there is a major knowledge gap about which components of SMIs are the most effective (Zimbudzi et al., 2018). Moreover, the power of the sign test could also be limited given that several studies reported unclear effect direction, which consequently reduced the number of trials in the test. To address this issue to some extent, the effect direction was visually presented in Tables, enabling the representation of all included studies, which the sign test does not do.

Additionally, we were unable to assess and report data on health-related behaviour outcomes and adverse events as no articles at low RoB included it in their study. Another challenge in the current review was the difficulty in assessing the certainty of the evidence given the synthesis method applied. For instance, it was particularly difficult to assess and judge the consistency of effects while undertaking vote counting for direction effect and not conducting meta-analysis. Moreover, the RoB, effect direction and GRADE assessments required some subjective judgments, thus to address this and to reduce the risk of error, the review author and research supervisor assessed the quality and certainty of evidence independently and dually and resolved any disagreements by consensus. The final limitation was the short-term follow-up and small sample size of included studies.

Implications for practice, policy, and future research

Given that the current review identified that since 2011, only two RCTs investigated CKD SMIs in the UK, future studies should consider the UK population. Moreover, the lack of tailored and theory-driven SMIs is still present. Although it is not clear whether theoretically driven interventions are more successful than atheoretical interventions (refer to Chapter 4 for further discussion on this topic), future research should consider the principles of PCC and the importance of theory in designing and evaluating CKD SMIs. Further, as we advance, future research should focus on developing and rigorous testing of SMIs tailored specifically for YAs aged 18-35 with CKD to foster proactive management strategies specific to this demographic and ensure that YAs receive optimal support throughout their CKD journey.

Additionally, considering the common prevalence of comorbidities in the CKD population and the lack of support for managing comorbid conditions, future studies should include the assessment of comorbidities and tailor the intervention to the individual condition and needs by including the management of comorbidities in the intervention topics. The studies should also consider tailoring the intervention to the patient activation level to improve a person's knowledge, skills, and confidence to effectively manage CKD. The assessment of the health-related behaviours and adverse events, which were not assessed by any of the included studies at low RoB in this review, should also be considered in the future. Involving CKD patients in co-designing the intervention will ensure that their values, preferences, needs, personal circumstances, and culture are addressed in SMIs (Welch et al., 2015). However, it is important to note that tailoring healthcare interventions may be challenging (for instance, there is a risk of the intervention becoming too specific and individually based, and it may be difficult to implement) and intervention developers need to consider how to compromise this individual approach with pragmatic needs of healthcare service.

Forthcoming studies, like the current study, which include younger age individuals, should consider the common low baseline self-efficacy in this population. The intervention for YAs with CKD should evaluate baseline self-efficacy and include theory-based self-efficacy strategies (like those employed in three successful trials 6, 17, 18) designed to enhance self-efficacy in this population. Self-efficacy as a mediator and predictor, as well as its important association with CKD knowledge and self-management, should also be considered in CKD SMIs.

Future RCTs of SMIs should measure the relevant outcomes after an appropriate length of follow-up, while employing a large sample size, and should provide full and detailed descriptions of the intervention assessed and each of its components. Whereas, in future systematic reviews, the efficacy of SMIs for adults with CKD should be studied in more depth and with a more rigorous quality assessment, including the assessment of reporting biases, as well as, different (non-RCTs) study designs. The certainty of evidence assessment in the current review was restricted to studies at low RoB and the review's primary outcomes only. In the future, grading the quality of evidence should be undertaken for all outcomes in a review as recommended by Ryan and Hill (2016), including studies at high RoB and those judged to have some concerns. Future reviews should expand on the set of databases, including unpublished resources, such as grey literature search (e.g., theses, reports, books, government documents), and when assessing the RoB, in the situation of missing information, the review authors should contact the study authors for clarification to reduce the potential bias in the review process.

Finally, further research is very unlikely to change our confidence in the effect of SMI on self-efficacy showing "benefits" based on high-quality evidence. However, our confidence in the effect of SMI on CKD self-management, knowledge, and eGFR outcomes is limited, thus future studies should examine these outcomes, including the adverse events, in more trials, a larger study design, and longer follow-up. Unfortunately, the current review did not allow us to consider what works and what does not work in depth. Future research should also explore different requirements for SMIs specific to dialysis and non-dialysis patients in more detail to identify and statistically determine effective strategies for these two diverse populations.

3.6 Chapter Summary

This Chapter critically reviewed the existing literature related to CKD SMIs among 1058 dialysis patients and 2017 non-dialysis patients compared to usual care in the form of narrative synthesis. The findings from this systematic literature review revealed important information for future studies and for the current study that aims to develop an appropriate SMI for YAs with CKD. Overall, it appears that SMI may be an effective intervention in improving outcomes, particularly self-efficacy, and those with low self-efficacy, typically YAs, benefit from SMIs the most. However, more evidence from high-quality studies is needed to support future CKD SMIs. The following two Chapters take a reader through the theoretical underpinning of the present research.

Chapter 4: Explaining Health Behaviour Change

4.1 Introduction

To effectively self-manage their chronic kidney disease (CKD), individuals may need to make cognitive and behavioural changes. For this reason, in order to address the overall research question on the most optimal intervention for young adults (YAs) with CKD, this chapter and the following chapter examine the relevant cognitive and behavioural change theories, models, frameworks, and approaches. Particularly this Chapter aims to explore the relevant concepts that explain and predict health behaviour change, whereas the following Chapter 5 aims to explore the relevant concepts used to elicit health behaviour change.

4.2 Use of Theory in Intervention Development

Theoretical frameworks allow researchers to form coherent connections between observations and evidence that may make research more valuable, testable, and replicable as well as stimulate new research and the extension of knowledge (Polit & Beck, 2012). In behavioural research, the use of theory can offer a foundation to explain behaviour, examine relationships, and predict the intervention effects (Davis, Campbell, Hildon, Hobbs, & Michie, 2015). Applying theory can be beneficial in providing a framework for intervention design and evaluation, as well as a shared language for communication, fostering the gathering of evidence that could be used to predict and explain an outcome in a new context (Dalgetty, Miller, & Dombrowski, 2019; Jaarsma et al., 2020a; Michie & Prestwich, 2010).

According to Glanz and Bishop (2010), interventions that are driven and guided by an appropriate theoretical framework are more likely to be effective than interventions with less empirical and theoretical frameworks. Several studies reported that the use of theory to inform the development of behaviour change interventions is linked to greater intervention effects (Taylor, Conner, & Lawton, 2012; Webb, Joseph, Yardley, & Michie, 2010). The United Kingdom Medical Research Council (UK MRC, 2000; and recently updated version of the guidance by Skivington et al., 2021) recommends using theory, particularly early in the design of interventions, to guide the development and implementation of health interventions (Coryn, Noakes, Westine, & Schroter, 2011; Craig, et al., 2008; Siemonsma, Schroder, Roorda, & Lettinga, 2010). However, is this always the case? Does this mean that atheoretical interventions are less or not effective?

Theory can be especially beneficial for interventions that involve a number of interacting management strategies, and which are usually hard to assess and replicate, for instance, those interventions focused on chronic illnesses (Craig et al., 2013). Evidence suggests that approximately 22-36 percent of interventions report the use of any theoretical framework or some elements of theory to guide the development of their interventions (Davies, Walker & Grimshaw, 2010). Nonetheless, Prestwich and colleagues (2014) conducted a meta-analysis to establish whether theory influences the effectiveness of health behaviour interventions. The authors reviewed 140 studies including comparisons of 190 interventions to examine the extent to which studies have reported the use of theory in developing interventions to increase healthy eating and physical activity and to assess whether the use of different theories was linked to the intervention effectiveness. They reported that 56 percent of interventions were theory-based and 90 percent of these did not report the relationship between all the Behaviour Change Techniques (BCTs; discussed further in the next Chapter) with explicit theoretical constructs. Further, 91 percent of theory-based interventions did not report the relationship between all specific constructs with BCTs. The reviewers concluded from their findings that in the reviewed studies, the theory was not frequently used in intervention development. They also reported that the links between the type of theory applied and the extent of the theory's use with effectiveness were mostly weak. The authors suggested that attempts to use those theories commonly applied in their review are unlikely to increase the effectiveness of interventions, and interventions based on these theories were not more effective than atheoretical interventions (Prestwich et al., 2014).

In a more recent scoping review by Jaarsma and colleagues (2020b), the rate of reporting the use of theory to guide self-care research was even lower than reported in Prestwich et al.' (2014) review. The authors established that only one of every three studies on self-care employed theory to support their rationale, intervention, outcomes, and/or to discuss the results (Jaarsma et al., 2020b). Consequently, the relationships between the use of theory as a basis for designing an intervention and intervention effectiveness are not always fully understood. While some reviewers have suggested that using theory to guide the development of health behaviour change interventions is related to greater intervention effects (e.g., Avery, Donovan, Horwood, & Lane, 2013; Protogerou & Johnson, 2014), other evidence has distinguished small or no association between the use of theory in designing intervention and intervention effectiveness (e.g., Angus, Cairns, Purves, & Bryce, 2013; Bhattarai et al., 2013; Hill, Skouteris, & Fuller-Tyszkiewicz, 2013; Lara et al., 2014).

There are several possible reasons for these inconsistencies in the literature between theory-based interventions and intervention effects. For instance, some reviews (e.g., Ammerman, Lindquist, Lohr, & Hersey, 2002) have reported the use of theory in categorical terms (e.g., simple yes or no). More in-depth methods of reporting theory use (e.g., the 19-item Theory Coding Scheme; see Michie, Prestwich, & de Bruijn, 2010) would give more insight into how theory has been used and whether using theory another way would result in greater behaviour intervention effects. Poor reporting of theory has been identified in theory-based interventions, which did not apply theory extensively (Booth, Prevost, Wright, & Gulliford, 2014; Mama et al., 2015; West et al., 2013). Other reasons for these inconsistencies include the risk of confounds (Diep, Chen, Davies, Baranowski, & Baranowski, 2014), and theories not being integrated effectively (Hagger & Chatzisarantis, 2014; Pound & Campbell, 2015; Rhodes, 2014).

Further, researchers reported that there is little guidance on how to select an appropriate theory for a specific context, which may potentially be the reason for under-using theory in designing interventions (Eccles et al., 2012; Michie, van Stralen, & West, 2011). Lastly, there are a large number of theories available, and their concepts often overlap while reflecting diverse contexts, disciplines, or philosophical viewpoints. Thus, choosing a suitable theory may be challenging. Researchers may struggle to determine which theory to select, why, and how to use this theory for a specific purpose (Jaarsma et al., 2020a). This could be due to theories being frequently poorly or inconsistently used in the research, with many terms (e.g., terms: “self-management” and “self-care”, as seen in the previous Chapter) operationalised synonymously (Jaarsma et al., 2020b), or related to a particular diagnosis or setting (Jones, MacGillivray, Kroll, Zohoor, & Connaghan, 2011). Therefore, it is not surprising that some have completely given up and claimed that using theories is unneeded (Dalgetty et al., 2019). In order to truly establish whether the theory is of value in the intervention development, simply determining whether authors used a theory in the intervention development is not enough. A more thorough examination of, for example, the variables addressed in the intervention and their relation to theoretical perspectives is needed.

Overall, it is evident that there is a need for broadly accepted guidelines for reporting the use and non-use of theory in the development of interventions, and well-designed experimental tests of the theory. Therefore, given the discrepancies in the evidence of the effectiveness of theory-based interventions, more research into behaviour change and intervention effects is required. Although some studies have reported a small or no association between the use of theory in designing the intervention and intervention effectiveness, these could be due to the abovementioned issues. In relation to this thesis, as per the UK MRC (2000; 2021) recommendations and other advocates of theory-based interventions, as well as per the findings from the current literature review exposing that employing appropriate theories may lead to successful CKD self-management interventions (SMIs), the novel SMI for YAs with CKD will be theory-based, and the theoretical frameworks that were used to guide this intervention are presented below.

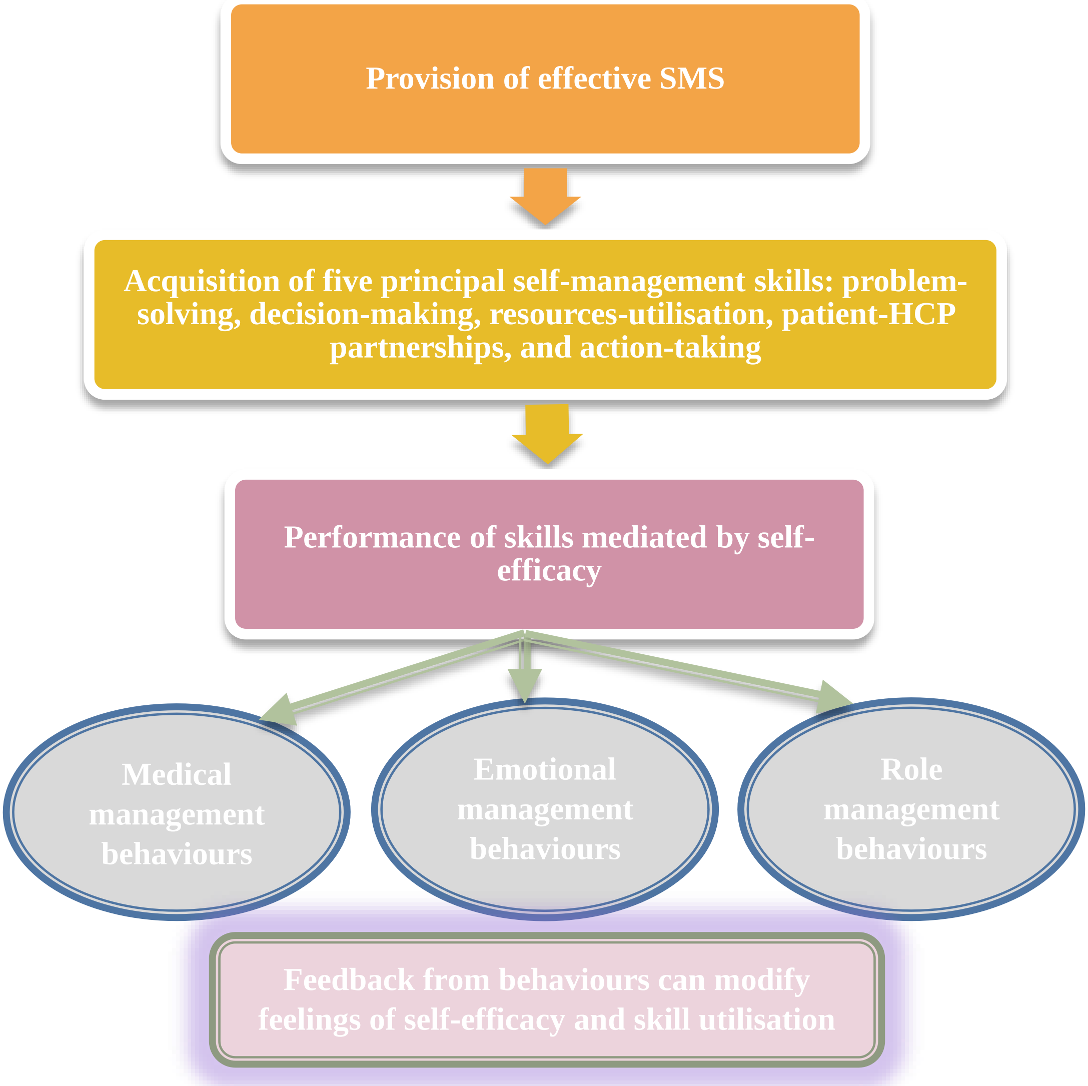
4.3 Self-Management Theories and Models

As acknowledged in the literature review, the self-management definition adopted in this thesis is described as the tasks that individuals have to undertake to live with chronic conditions, and SMIs as the consistent delivery of care that improves a person’s knowledge, skills, and confidence in dealing with and managing all aspects of their illness. Formerly, Corbin and Strauss (1988) in their qualitative study, based on issues perceived as significant by people with chronic illnesses, recognised three essential tasks for effective self-management. These include medical management (e.g., taking medication or modifying diet), role management (e.g., modifying lifestyle), and emotional management (e.g., coping with feelings, such as anger, frustrations, sadness, fear, and depression). Over a decade later, Lorig and Holman (2003) expanded their framework and added to the three proposed core tasks, the five principal processes (self-management skills). These include problem-solving, decision-making, resource-utilisation, patient-healthcare professional (HCP) partnerships, and action-taking. According to the authors, through these five self-management skills, individuals achieve self-management tasks (Lorig & Holman, 2003). However, it is important to note that the self-management processes do not necessarily happen linearly, instead, self-management skills and tasks overlap, influencing each other (Schulman-Green et al., 2012).

Additionally, self-efficacy (discussed in more detail in the next sections) focuses on improving a person’s confidence in their ability to perform a specific task or behaviour, thus empowering them to self-manage (Bandura, 1978). According to Marks and Allegrante (2005), self-efficacy is frequently viewed as the mediator between the attainment or possession of self-management skills and the performance of self-management behaviours. This process of self-management behaviours implementation is graphically illustrated in Figure 4.1 below.

Figure 4.1

Process of Implementation of Self-Management Behaviours



Adapted from Corbin and Strauss (1988) and Lorig and Holman (2003). *HCP* Health-Care Professional; *SMS* Self-Management Support.

The self-management model proposed by Lorig and Holman (2003) has been evaluated in a number of chronic conditions, including diabetes, heart and lung disease, and arthritis (Lorig et al., 1999; 2001), translated into several languages and adopted in various countries (Grady & Gough, 2014). Self-management skills and tasks form the main components of the Chronic Disease Self-Management Programme (CDSMP; Stanford Medical School, 2017) developed by Lorig and colleagues (1999; 2001) and applied widely since. According to the authors, SMIs depend on the presumptions that 1) people with diverse chronic conditions have alike disease-related worries and issues; 2) they will develop the required skills and confidence (self-efficacy) to manage their illness daily, and 3) improved confidence and knowledge in self-management will result in enhanced health outcomes and reduced use of healthcare resources (Lorig et al., 1999; 2001). Self-management skills and domains of self-management behaviour are explored further in the next Chapter where both, self-management skills and behaviours are incorporated.

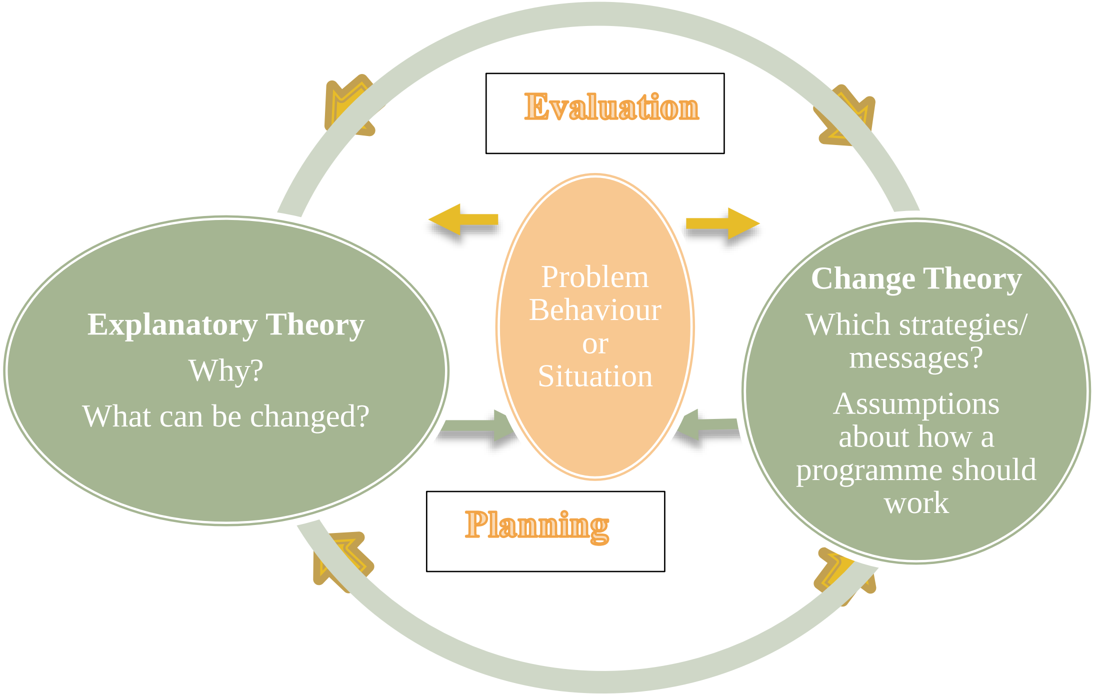
4.4 Social Cognitive Theory (SCT)

When addressing the research question, "What will be the most optimal intervention for YAs (18-35 years old) with CKD?" it's essential to consider the vast array of theories available for designing health behaviour change interventions. Selecting an appropriate theoretical framework for this study is crucial, as it will guide the development of an intervention tailored specifically to the needs and behaviours of YAs with CKD. In deciding upon a theoretical framework for the current study, a number of alternative theories of behaviour change were carefully considered (e.g., the theory of planned behaviour; Ajzen, 1985; 1991; and the theory of reasoned action; Fishbein & Ajzen, 1975; 2010). There is no existing theory without some shortcomings. Thus, the intervention developers need to make compromises between diverse criteria for theory choice. For instance, one of the limitations of the theory of planned behaviour is the gap between behaviour and intentions, which is difficult to identify (Rich, Brandes, Mullan & Hagger, 2015). One of the shortcomings of the theory of reasoned action is that it assumes that all behaviour has a purely rational basis and does not account for emotions (e.g., depression and anxiety) and their role in explaining behaviour (Reyna & Farley, 2006).

Consequently, SCT (Bandura, 1989), particularly its main element self-efficacy, was selected as a theoretical underpinning of the current research for several reasons. Amongst many theories of behaviour change, SCT delivers a clear understanding of why and how health behaviour changes, and it explains the aspects that impact this change (McAlister, Perry, & Parcel, 2008). Health behaviour theories may be used to explain a problem (e.g., an explanatory theory) or to inform how a problem can be addressed (e.g., a change theory) (Rimer & Glanz, 2005). See Figure 4.2 below for explanatory and change theory for planning and evaluating the programme.

Figure 4.2

Explanatory and Change Theory



Adapted from Rimer & Glanz (2005).

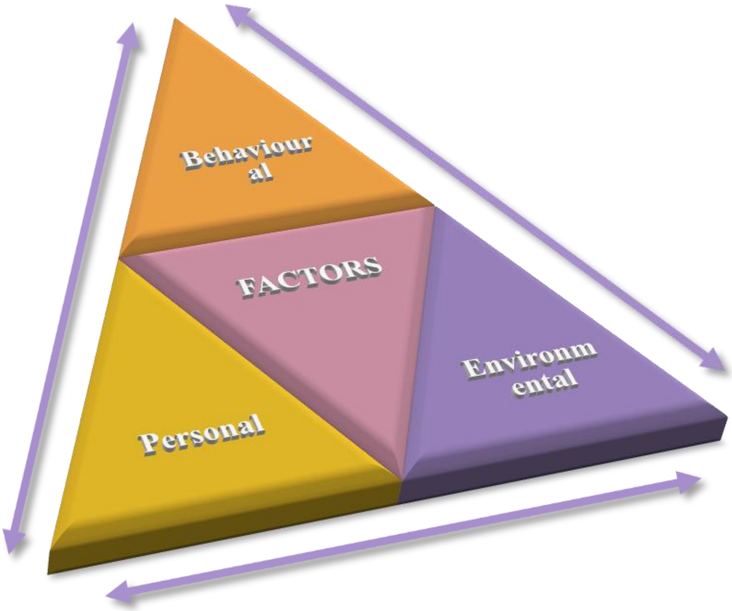
SCT involves both explanatory and change theory, which not only gives means to understand the issue of CKD self-management (e.g., lack of self-efficacy), but also proposes strategies to address the issue (e.g., social support) (Bandura, 1997; 2002; 2004; Glanz, Rimer, & Viswanath, 2015). The above discussions, as well as the current literature review in Chapter 3, revealed that self-efficacy is crucial in SMIs. Indeed, self-efficacy has been considered an essential component in health behaviour change models for decades (Strecher, McEvoy, deVellis, Becker, & Rosenstock, 1986). A person's self-efficacy has a key role in how goals, tasks, and challenges are approached (Bandura, 1986). SCT provides clear recommendations for improving important self-efficacy (Bandura, 1997), making it an optimal choice for designing an intervention aimed at explaining and changing behaviour.

Additionally, SCT is one of the most common theories used in the management of chronic health disorders (Painter, Borba, Hynes, Mays & Glanz, 2008) including CKD (Su et al., 2009). The majority of the self-management literature has been built upon SCT, and self-efficacy particularly. According to Armitage and Conner (2000), one of the reasons for this focus is that empirical work that looked at the descriptive and predictive power of SCT as a model of behaviour change has reported that it does not improve beyond what can be explained by self-efficacy. The researchers have concluded that due to the central role of self-efficacy in many theories and models, and the lack of empirical support for other components of SCT, the element of self-efficacy is then perhaps more important than SCT as such (Armitage & Conner, 2000). Finally, unlike other theories of behaviour change considered for the current study, SCT accounts for the role of emotions and their impact on behaviour and behaviour change (Bandura & Adams, 1977).

SCT, founded on the principles of social learning theory, proposes that learning happens dynamically in social settings and is a product of the interaction between personal, behavioural, and environmental factors. This interaction is known as triadic reciprocal causation (Bandura, 1986) (see Figure 4.3).

Figure 4.3

SCT - Triadic Reciprocal Causation



Adapted from Bandura (1986).

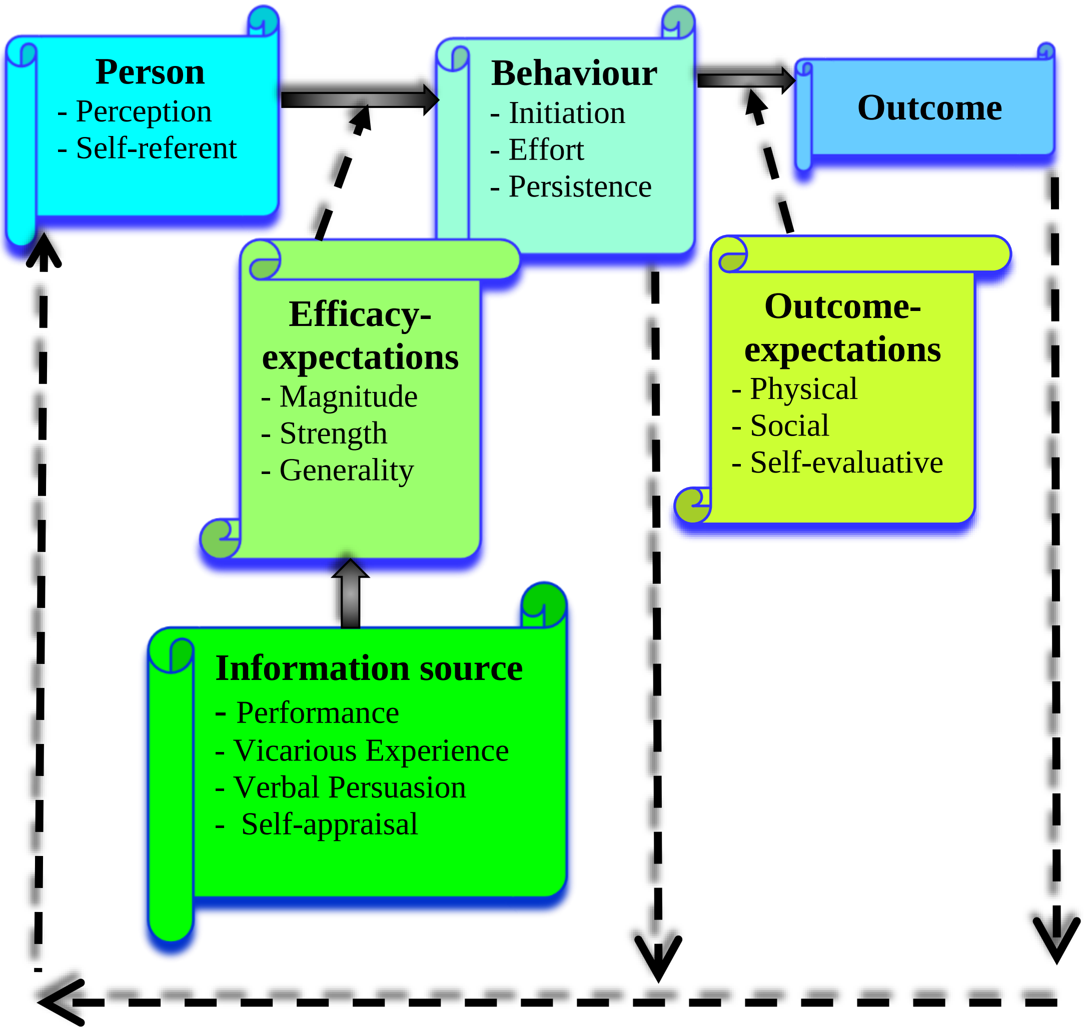
Personal, behavioural and environmental factors influence and interact with each other in order to determine motivation and behaviour (Crothers, Hughes & Morine, 2008). Personal factors (such as self-efficacy and knowledge) are a person's skills to control his/her actions based on self-regulation and self-determination. Behavioural factors, such as abilities, knowledge, and practice directly influence health, either through promoting or compromising it. Finally, environmental factors (such as observational learning and social support) may either support or depress a person's health behaviour and can be real or perceived. SCT explains a person's behaviour and how the environment and personal circumstances affect it. As presented in above Figure 4.3, alteration in one component will impact other components.

In addition, the notion of self-efficacy is at the centre of Bandura's (1977; 1986) SCT. It is important to distinguish between two types of self-efficacy (belief in own ability; Bandura, 1989), such as (1) perceived general self-efficacy, and (2) task-specific self-efficacy. General self-efficacy is a person's perception of their own ability to perform across a variety of situations (e.g., I am generally capable of dealing with what life throws at me). In contrast, task-specific self-efficacy assesses a person's perception of their ability to perform the actions specific to a situation (e.g., I am capable of dealing with my condition). This thesis focuses mainly on task-specific self-efficacy.

The basic principle of self-efficacy is that the expectation of individual ability (efficacy expectation or self-efficacy) and achievement (outcome expectation) determine whether a person will participate in certain behaviours. The visual representation of the self-efficacy model can be seen in Figure 4.4 below.

Figure 4.4

SCT - Self-Efficacy Model



Adapted from Lenz and Shortridge-Baggett (2002).

These expectations can be physical, social, or self-evaluative (Bandura, 1986; 2004). Self-efficacy is crucial because it more effectively predicts behaviour than outcome expectations alone (Bandura, 1986). For YAs with CKD, enhancing self-efficacy could motivate adherence to SMIs. Self-efficacy can be strengthened through four main sources: past performance, vicarious experience, verbal persuasion, and self-appraisal (Lenz & Shortridge-Baggett, 2002). Successful past experiences increase self-efficacy, while failures reduce it (Bandura, 2012; Hayden, 2009). Observing others' successes can also boost self-efficacy (Luszczynska & Schwarzer, 2005). Verbal encouragement and self-assessment of emotional and physical states further influence self-efficacy (Bandura, 1977; Lenz & Shortridge-Baggett, 2002). These mechanisms can be leveraged in designing SMIs to enhance self-management behaviours in YAs with CKD.

Other related concepts, such as self-confidence, locus of control, self-esteem, and social support, also impact self-efficacy (Schneewind, 1995). The SCT thus provides a robust framework for addressing the overall research question - “what will be the most optimal SMIs for YAs with CKD stages 1-5” by aiming to identify the most effective intervention strategies (Sue, Lu, Chen & Wang, 2009) and clinical evidence supports its benefits (Griffiths, Mortilib & Azad, 2005; Lorig et al., 2001; Steed et al., 2005; Walker, Weeks, McAvoy & Demetriou, 2005).

4.4.1 Self-Efficacy and Self-Management

Self-efficacy, a key component of Bandura’s SCT, is critical for effective self-management of CKD. Confidence in one’s ability to manage CKD increases engagement in self-management behaviours, leading to better health outcomes (Bandura, 2018). Studies have reported that one way of improving CKD self-management is by improving self-efficacy (Aliasgharpour, Shomali, Moghaddam & Faghihzadeh, 2012). Individuals with a high level of self-efficacy and beliefs that they can manage their disease will perform better in self-management behaviours (Cutler, Crawford & Engleking, 2018; van Berkel, Lambooij & Hegger, 2015).

Self-efficacy has been shown to improve health behaviours and outcomes generally (Du & Yuan, 2010; Marks & Allegrante, 2005), and specifically in CKD

(Curtin et al., 2008; Eknoyan et al., 2013). Several studies have reported that self-efficacy in individuals with various stages of CKD is positively related to health-related quality of life (HRQoL), medication and treatment adherence, improved CKD-related knowledge and problem-solving skills, self-care behaviours, and increased communication and partnership with HCPs (Calia et al., 2015; Elliot, Ortman, Almaani & Jordan, 2015; Kim et al., 2013; Weng, Dai, Wang, Huang & Chiang, 2008; Wu et al., 2016).

Support for SCT, especially in enhancing self-efficacy, is demonstrated in several studies. Jang and Yoo (2012) found that behavioural interventions using informational sources can boost self-efficacy in chronic illness management. Welch et al. (2014) concurred but highlighted gaps like the need for family involvement and addressing emotional aspects. Sorait (2018) emphasised understanding self-efficacy's role in CKD self-management and recommended incorporating it as a mediator in self-care strategies. Additionally, Curtin et al. (2008) linked higher self-efficacy in CKD patients with better self-management behaviours including medication adherence and communication with caregivers. Discussing self-efficacy alone can enhance these scores (Wierdsma et al., 2011). High self-efficacy in CKD patients is also associated with maintaining health and preventing disease progression (Li et al., 2014; Patterson, Umstattd Meyer, Beaujean, & Bowden, 2014; Washington et al., 2016). Several studies supported the role of self-efficacy as a mediator in self-management behaviours (Lii et al., 2007; Sritarapipat, Pothiban, Panuthai, Lumlertgul & Nanasilp, 2012).

Moreover, Kazawa and Moriyama (2013) and Byrne and colleagues (2011) designed CKD self-management programs using SCT but failed to detail how SCT elements were applied. Joboshi and Oka (2016) focused on self-efficacy in their CKD program but also lacked specifics on SCT application. Clarke et al. (2015) identified goal-setting and HCP guidance as crucial for overcoming exercise barriers in CKD patients, aligning with SCT's triadic reciprocal causation. Other studies, such as those by Tsay and Healstead (2002) and Wells and Anderson (2011), explored self-efficacy in end-stage kidney disease (ESKD) but not earlier CKD stages. Self-efficacy has also been related to increased communication with HCPs, self-care, and medication obedience in CKD individuals (Curtin et al., 2008).

Previous research has suggested that if a person reports a low level of confidence, HCP should work together with this individual to conquer barriers until his/her confidence increases (Coleman & Newton, 2005; Thomas-Hawkins & Zazworsky, 2005).

Finally, self-efficacy has been integrated into numerous approaches for CKD management, particularly for those on dialysis (Moattari et al., 2012; Slesnick, Pienkos, Sun & Schiller, 2015). Studies have examined self-efficacy's impact on behaviour in CKD patients (Drenzyk, Gardener & Welch, 2014; Echouffo-Tcheugui & Kengne, 2012; Tangri et al., 2013) and its application in ESKD (Montoya, Sole & Norris, 2016). However, few studies explored the link between self-efficacy and self-management in early CKD stages, and their implications remain unclear. Research often fails to detail how SCT factors enhance self-efficacy or self-management (Byrne et al., 2011; Joboshi & Oka, 2016). Studies on SCT in CKD often lack clarity on applying SCT elements to enhance self-efficacy (Byrne et al., 2011; Joboshi & Oka, 2016). Despite evidence supporting theory-driven SMIs (Glanz & Bishop, 2010), many studies do not use theory-based approaches (Bonner et al., 2014). More studies are needed to examine the association between self-efficacy and self-management behaviours, especially in early CKD stages. This research could inform the development of effective, theory-based SMIs tailored to individuals with CKD.

4.4.2 Limitations of SCT

Although evidence suggests that SCT provides a useful basis upon which to build SMIs, and enhance health-related behaviours in individuals with chronic conditions, including CKD, there are some limitations to the theory. For instance, Biglan (1987) claimed that with regards to explaining behaviour, SCT is no more beneficial than other behavioural theories and that strategies used to assess self-efficacy (verbal or written) fit into these models as behaviours rather than a cognitive construct. Biglan (1987) also criticised SCT for not placing enough emphasis on the environment and the impact it has on behaviour.

Another criticism of SCT is that due to its widespread focus, it is difficult to operationalise and it is often implemented only partially, therefore questioning its applicability to the development of interventions (Chironda, Bhengu, & Manwere, 2019). At present, only some elements of SCT are applied in the interventions, therefore this questions the applicability of the theory in predicting and improving adherence behaviours in individuals with CKD. Webb and colleagues (2010) reported from their review that effect sizes in interventions were lowest for interventions based on SCT with an effect size of 0.15 across 15 studies, compared to 0.2 for the Transtheoretical Model (TTM) and 0.36 for the Theory of Planned Behaviour. This smaller effect size may be due to the wide-ranging nature of the SCT, which makes its principles much more difficult to operationalise as there is a lack of an official or unofficial fully systematised model and standard procedure for intervention design. However, one can say that the strengths of SCT in CKD self-management outweigh its limitations and it remains a valuable theory that aids in improving self-management behaviours in individuals with chronic conditions.

4.5 Health Action Process Approach (HAPA)

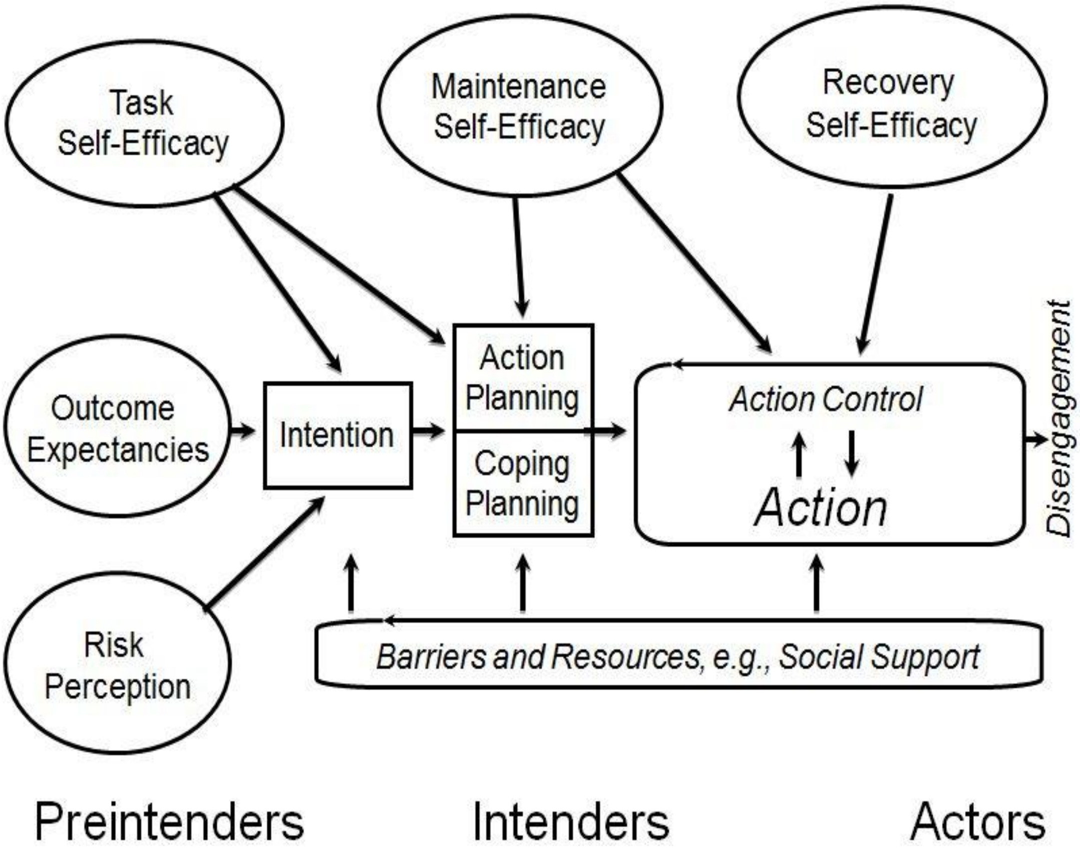
Scholars have proposed that the development of successful health behaviour change interventions requires the identification of potentially modifiable behavioural determinants that can be targeted by intervention content (Johnson & Acabchuk, 2018). Researchers have employed theories of motivation and behaviours to recognise these determinants to inform the content of health behaviour change interventions (Rothman et al., 2015). Thus, approaches that aim to improve the management of chronic diseases have drawn on the psychological theories of behaviour change as they provide an understanding of the determinants of behaviour, and thus can guide the interventions to alter them (Leventhal, Weinman, Leventhal & Phillips, 2008). However, the majority of these psychological theories mainly focus on motivational factors that are significant in forming the intention to change behaviour (e.g., goal setting) and do not include “volitional” or “action” elements that enable the translation of an intention into actual behaviour (e.g., goal pursuit).

According to Sheeran (2002), forming the intention to change behaviour is often not enough to warrant an actual change of behaviour and other factors moderate between intention and behaviour change outcome (known as the “intention-behaviour gap”; Sniehotta, Scholz & Schwarzer, 2006). Research has shown that decreasing the “intention-behaviour gap” and improving behaviour change (e.g., planning and self-monitoring, which are significant in ensuring that intended change of behaviour is acted upon and maintained), in addition to motivational factors, has the potential to make health-related behaviour change interventions more effective (Greaves et al., 2011). Additionally, current SMIs for chronic conditions often rely on theoretical frameworks, which are categorised into continuum and stage models. According to Schwarzer, Lippke, and Luszczynska (2011), continuum models (like SCT) are useful for predicting and explaining behaviour, while stage models (e.g., the TTM; briefly discussed in the next chapter) are better for guiding interventions. The researchers criticised continuum models for being too general, as they do not consider the specific needs of individuals, but they suggested integrating both models by using the continuum model as a theoretical template, and tailoring interventions by grouping participants into stages for more personalised treatment (Schwarzer et al., 2011).

Prominent among theories of motivation and behaviours is the HAPA developed by Schwarzer (1992), a social-cognitive model, which recognises the motivational and volitional determinants of health behaviour and related processes. The HAPA is one of the most comprehensive health behaviour change models that covers a wide range of psychological determinants. Built on SCT (and concepts of the earlier-mentioned theories, such as the Theory of Planned Behaviour, Theory of Reasoned Action, and the stages of change theory), this hybrid approach is a dual-phase model that includes two layers, the continuum and staging layers. The model comprises post-intentional factors that address the “intention-behaviour gap” and it identifies the significance of both, motivational and volitional determinants of health behaviour, and related processes. In the HAPA, behavioural intention is considered the most proximal predictor of future behaviour. The HAPA proposes a distinction between two different phases, 1) pre-intentional motivation processes, which lead to a behavioural intention (motivational phase), and 2) post-intentional volition processes, which lead to the actual health behaviour (volitional phase) (see Figure 4.5).

Figure 4.5

Health Action Process Approach



Retrieved from Schwarzer (2016).

In other words, according to the HAPA model, engaging in health-related behaviours is a process that is composed of motivational (1) and volitional phases (2) (Chiu, Lynch, Chan & Berven, 2011). The pre-intention aspect of the HAPA (1) compromises three concepts: risk perception, outcome expectancies, and task self-efficacy. Whereas, the post-intention aspect of the HAPA (2) includes four constructs: action planning, coping planning, maintenance self-efficacy and recovery self-efficacy (Lin, Scheerman, Yaseri, Pakpour, & Webb, 2017; Schwarzer & Luszczynska, 2008). In the HAPA, a person passes through three different stages, namely pre-intention (motivational phase) as well as intention and action (volitional phase), when adopting new behaviours (Lippke, Ziegelmann, & Schwarzer, 2005). This dual-phase model suggests that within two phases, diverse patterns of social-cognitive predictors may occur. In the motivational phase (1), an individual develops an intention to act, and then, in preparation for performing the behaviour, they enter the volitional phase (2) which focuses on translating motivation into action (Armitage & Arden, 2010).

In the motivational phase (1), as a person develops an intention to act, the influencing factors are recognised as task self-efficacy (beliefs in the ability to perform the behaviour), outcome expectancies (positive and negative expectations about whether engaging in behaviour will result in anticipated outcomes), and risk perceptions (beliefs concerning personal risk to particular outcomes). Several studies have established a positive relationship between these factors and intentions, mainly outcome expectancies and task self-efficacy (Bierbauer et al., 2017; Maher & Conroy, 2016). Other studies established that beliefs concerning the engagement in the behaviour itself, for instance, attitudes, self-efficacy, and outcome expectancies, are more prevalent health behaviour determinants than risk perceptions (Hagger et al., 2016; Hattar, Pal, & Hagger, 2016). Thus, evidence suggested that risk perception alone is a weak predictor of behaviour, however, it does enable the individual to start the process of considering and weighing the pros and cons of behaviour change (Schwarzer, 2008).

Unlike most other social cognition theories and models, the HAPA addresses the post-intentional factors and the processes necessary for translating intentions into sustained behaviour change. This involves self-regulatory skills and strategies (see Bandura, 1991 for more information on the self-regulatory theory), such as planning, action control, social support, and recovery self-efficacy (Schwarzer et al., 2011). Social support acts as a resource that facilitates maintaining behaviour change, as evidenced in chronic disease management research, like diabetes (Plotnikoff, Lippke, Courneya, Birkett & Sigal, 2008). Maintenance (or coping) self-efficacy involves confidence in coping with barriers, while recovery self-efficacy relates to overcoming setbacks, both directly impacting behaviour and both are likely to be correlated with one another and with task self-efficacy. The HAPA distinguishes between task self-efficacy (forming intentions) and maintenance/recovery self-efficacy (behaviour enactment and maintenance). Finally, planning in the HAPA is divided into action planning (identifying cues for action) and coping planning (anticipating and overcoming barriers), enhancing the intention-behavior link. Applying self-efficacy and planning as volitional mediators reduces the HAPA into an implicit stage model as it indicates the presence of both motivational and volitional phases, thus it allows a better prediction of behaviour as well as reflects the presumed causal mechanism of behaviour change. This dual-phase model, incorporating motivational and volitional phases, can be particularly useful in developing targeted SMIs for YAs with CKD, ensuring interventions are both theory-based and tailored to individual needs. Researchers that based their study on this continuum layer of the model used path-analytic methods to examine casual associations between different variables (e.g., Chiu, Lynch, Chan, & Berven, 2011; Chiu, Lynch, Chan, & Rose, 2012; Renner et al., 2008; Ziegelmann, Luszczynska, Lippke & Schwarzer, 2007).

Several studies have established that self-efficacy is needed throughout the whole process of behaviour adaptation and maintenance (Lippke et al., 2005; Luszczynska, Gregajtys & Abraham, 2007), and studies from rehabilitation samples reported that self-efficacy changes as individuals pass through different stages of change (Ziegelman & Lippke, 2007). Moreover, there is evidence from studies employing individuals with different chronic conditions and disabilities, that established that, in particular, planning (specifically coping planning; Pakpour et al., 2011) intervention and action control programmes are successful (Lippke, Ziegelmann & Schwarzer, 2004; Luszczynska, 2006; Sniehotta et al., 2006; Ziegelmann, Lippke & Schwarzer, 2006).

Other studies have used the HAPA and a combination of its main components in various populations in order to assess and predict health-related behaviours, and they supported the significance of HAPA’s motivational and volitional factors as predictors of behaviour change. These encompass, for instance, healthy eating (Chiu, Lynch, Chan & Rose, 2012; Schwarzer et al., 2007), alcohol consumption (Murgraff, McDermott & Walsh, 2003), smoking (Radtke, Scholz, Keller & Hornung, 2011; Williams, Herzog & Simmons, 2011), and physical activity (Barg et al., 2012; Caudroit, Stephan & Le Scanff, 2011; Perrier, Sweet, Strachan & Latimer-Cheung, 2012). Additional findings from research outside the HAPA context have reported that planning (particularly coping planning) independently predicts behaviour change (Pakpour et al., 2011; Luszczynska, Sobczyk & Abraham, 2007). Other research has established that interventions that implement both motivational and volitional factors are more effective in changing health-related behaviours, including physical activity (Milne, Orbell & Sheeran, 2002), than those that adopt motivational or volitional factors alone (Hagger et al., 2012).

The HAPA has been applied to evaluate treatment adherence and other health behaviours, including oral hygiene behaviour (Scheerman et al., 2017), hygienic food handling (Mullan, Wong, & O'Moore, 2010), condom use (Teng & Mak, 2011), diet adherence in adolescents (Lin et al., 2017), physical activity participation in individuals with schizophrenia (Arbour-Nicitopoulos, Duncan, Remington, Cairney, & Faulkner, 2014), and cardiac rehabilitation programmes (Greer, Milner, Marcello, & Mazin, 2015), and these studies recommended the use of the HAPA as an effective framework to predict health behaviours.

Further, a recent meta-analysis of the HAPA by Zhang, Zhang, Schwarzer, and Hagger (2019) highlighted the significance of stage-specific self-efficacy in predicting health behaviour in both motivational and volitional phases. Their meta-analysis revealed two forms of self-efficacy that have prevalent effects on behaviour, particularly task and maintenance self-efficacy, and it recognised that the effects of task self-efficacy are indirect via intentions and planning. The researchers recommended the use of strategies that target change in these two forms of self-efficacy (Zhang et al., 2019). Such self-efficacy-enhancing strategies may include developing skills to successfully set appropriate goals and monitor their progress, providing relevant feedback on progress, improving skills to cope with difficulties, and providing opportunities to reflect on past success with the behaviour. However, it is important to note that these researchers only focused on behavioural prediction and did not examine behavioural change. Thus, future studies are needed to assess behaviour change when implementing the HAPA. Finally, Zhang and colleagues' (2019) study brings added knowledge by providing information on the main processes to target when applying the HAPA to predict health behaviour and suggesting concepts that may be targeted in health behaviour change interventions.

4.5.1 Limitations of HAPA

Leventhal and Mora (2008) criticised the HAPA's theoretical structure. They voiced their concerns with the HAPA model "straddling two approaches to the analysis of health and illness behaviour" encompassing 1) "the assessment of indicators to predict behavioural outcomes" as well as 2) "the assessment and manipulation of variables to understand the processes underlying the performance of health behaviour" (Leventhal & Mora, 2008, p.52). However, we know that behaviour change is complex and often influenced by multifaceted interactions between individual, social, and environmental factors, which are important to consider when refining and developing effective interventions that go beyond the confines of any specific theoretical framework. The researchers also stated that the HAPA model is incomplete because of its incapability to completely explain the underlying process of health action (Leventhal & Mora, 2008). However, previous sections noted that there is no existing theory without some limitations and no single theory can fully explain health action. Some aspects of the intervention cannot be informed by behaviour change theories alone (briefly discussed further at the beginning of the next Chapter).

Another limitation of the HAPA, often discussed in the research, is its linearity, which can pose challenges in fully capturing the complexity of the behaviour change process. While the HAPA's structured approach offers a useful framework, it may oversimplify the dynamic and iterative nature of behaviour change. For instance, as per Schwarzer (2008), behaviour change is not always a straightforward progression through different stages. Rather, it may involve non-linear paths, relapses, and fluctuations in motivation and volition that are not entirely accounted for in the HAPA's sequential framework. The structured nature of the approach may not adequately represent the complexities of behaviour change, potentially limiting its applicability to real-world settings (Lippke & Schwarzer, 2015). Some researchers (e.g., Sniechotta, Schwarzer, & Scholz, 2005) suggested that a more flexible model may be required to accommodate the non-linear, iterative nature of the behaviour change process.

Finally, one of the most recognised shortcomings of the HAPA, and most other health behaviour models, is the lack of clear consideration of non-conscious processes. Various processes that determine people's behaviour are non-conscious

(Bargh, Szwader, Hailey, Dyer, & Boothby, 2012). Individuals are usually not aware of the emotional barriers and impulses that guide their actions, and those social-cognitive strategies to modify their behaviour are often ineffective.

4.6 Chapter Summary

Overall, we have seen that the effectiveness of theory-based interventions is unclear due to inconsistency in the literature, possibly caused by poor reporting, confounding factors, and ineffective integration of theories. Some researchers criticised SCT for being, for example, difficult to operationalise due to its widespread focus, and the HAPA model for being incomplete. However, both SCT and HAPA are encompassing, and it is believed that focusing on self-efficacy, which is considered a significant determinant of behaviour in both models, to develop the SMI may result in positive health behaviour outcomes.

This Chapter aimed to explore the theoretical underpinnings of the intervention design in the current research by reviewing concepts that explain and predict health behaviour change. The following Chapter 5, on the other hand, adds to this by exploring concepts used to elicit behaviour change and discusses relevant approaches to developing behaviour change interventions.

Chapter 5: Eliciting Health Behaviour Change

5.1 Introduction

The former Chapter presented the theoretical foundation of the current study and explained the reasons for including self-efficacy as an appropriate theory to guide the intervention design of the present research. Previous Chapters revealed that the use of theories in the intervention design and development to change behaviours is beneficial as they identify factors that need to be changed to produce the desired change in behaviour. According to Hardeman and colleagues (2005), a behaviour change theory may be embedded in a wider casual model that identifies the hypothesised causal relationships between the elements of the proposed intervention (including the anticipated behaviour change techniques; BCTs), the determinants of the target behaviour, behaviour itself, as well as the resulting clinical and health outcomes. However, some aspects of the intervention cannot be informed by behaviour change theories alone (Hardeman et al., 2005). For instance, these do not offer guidance on the ideal intervention sessions, such as schedule or the number of sessions, whether these should be groups or one-to-one sessions, whether to employ roleplays or visual-audio aids, and so on. For this reason, this Chapter aims to explore the relevant concepts used to elicit health behaviour change and review the relevant approaches for developing behaviour change interventions in order to address the research question: "What will be the most optimal intervention for young adults (YAs; 18-35 years old) with chronic kidney disease (CKD)?"

5.2 Self-Management Skills

Below, the self-management skills and domains of self-management behaviour are explored further in the context of CKD.

Problem-solving, decision-making, resource utilisation, patient and healthcare professional (HCP) partnership formation, action-taking, and self-tailoring have all been identified as crucial components in self-management (Lorig & Holman, 2003). Problem-solving skills enable patients to address the complex challenges of managing CKD by identifying problems, generating solutions, and incorporating disease management into daily life (Novak et al., 2013). Support for problem-solving interventions has been documented in the diabetes self-management literature (e.g., Philips & Knuchel, 2011). The current systematic literature review in Chapter 3 also revealed that trials that successfully improved self-efficacy included problem-solving strategies in their interventions (6, 17, 18). Additionally, decision-making, based on sufficient knowledge, is essential for responding to changes in health status, such as adjusting diet or medication in response to blood pressure (BP) levels (Kafkia et al., 2011). Effective resource utilisation, as emphasised by Gucciardi, Smith, and DeMelo (2006), involves not only accessing relevant resources but also knowing how to use them, a skill often overlooked in traditional self-management programs (Lorig & Holman, 2003). The formation of patient-HCP partnerships is important for shared decision-making, where both parties collaboratively decide on the best treatment options (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Poulos & Antonsen, 2005). Action-taking, grounded in Bandura’s self-efficacy theory, involves setting and achieving short-term goals to manage CKD effectively (Ong et al., 2013; Bodenheimer et al., 2002). Finally, self-tailoring (an additional skill not included in Figure 4.1 in Chapter 4), as defined by Lorig and Holman (2003), allows patients to apply self-management principles to their unique circumstances, differentiating it from traditional health promotion. These skills relate to the research question by demonstrating how a holistic and individualised approach to self-management could lead to more effective interventions for YAs with CKD, optimising their ability to manage the condition and improving outcomes.

5.2.1 Limitations of Self-Management Skills-Based Programme

The earlier-mentioned Chronic Disease Self-Management Programme (CDSMP; Stanford Medical School, 2017), a programme based on Lorig and Holman’s (2003) self-management skills, is a highly structured, group-based (typically 10-15 participants) programme delivered weekly for two and half hours over six weeks (Department of Health Victoria, 2008). In spite of its popularity, there are some limitations to the programme (LeBlanc & Jacelon, 2016). For instance, although group settings decrease isolation, thus enabling self-efficacy, these settings do not suit everyone and it is difficult to address individual requirements in such settings. According to Drury and Aoun (2014), to enable self-management support, the individual’s readiness for change needs to be determined, thus individual detailed assessment is required. The highly structured programme makes it hard to address individuals’ specific learning styles and needs. As established in the introductory Chapter, personal factors including age, gender, education, self-efficacy, as well as psychosocial and socioeconomic status (SES), all affect a person’s ability to self-manage their chronic conditions.

5.2.2 Domains of Self-Management Behaviour

Philips and Knuchel (2011) suggested that possessing relevant self-management skills is essential for performing self-management behaviours, which are critical for managing chronic conditions like CKD. Given CKD's complexity and associated comorbidities, patients often require extensive healthcare support (Sevick et al., 2007), including managing an average of 15 medications daily (Ong, Fernandes, Cesta, & Bajcar, 2006). Ong and colleagues (2013) proposed four primary domains of CKD self-management behaviour: food management, BP management, blood result management, and medication management, all of which are interrelated with self-management skills (Lorig & Holman, 2003; Ong et al., 2013).

Effective food management is crucial in CKD and involves adhering to dietary restrictions, such as controlling sodium, protein, phosphate, and fluid intake (Kidney Health Australia, 2015b). This requires planning and making informed choices during grocery shopping, cooking, and eating out (Ong et al., 2013; Palmer et al., 2015). Consultation with a dietitian can help patients understand the impact of dietary modifications on their health (Philips & Knuchel, 2011). Maintaining BP below specific thresholds is foundational in CKD management. BP management includes self-monitoring BP, adhering to prescribed medications, and making necessary lifestyle changes, such as diet modifications and increasing physical activity (Ong et al., 2013; Kidney Health Australia, 2015a; Chang & Winkelmayer, 2010). Self-monitoring at home provides more accurate readings than clinic-based monitoring, improving hypertension management (Cohen, Huan, & Townsend, 2014). Regular monitoring and responding to changes in blood biochemistry is important for CKD management. This behaviour involves organising and understanding blood test results, which vary depending on the stage of CKD (Ong et al., 2013; Kidney Health Australia, 2015a). Blood result management helps inform treatment adjustments and the need for urgent clinical reviews if kidney function rapidly deteriorates (Poulos & Antonsen, 2005). CKD patients must manage multiple medications to control symptoms and comorbidities. Medication management includes taking prescribed drugs, avoiding harmful ones, and understanding the purpose and side effects of each medication (Ong et al., 2013; Rifkin & Winkelmayer, 2010). Strategies such as using pill organisers and establishing routines can help manage this complexity (Devraj & Wallace, 2013; Raymond, Wazny, & Sood, 2011). Patients must avoid medications harmful to kidney function, including non-steroidal anti-inflammatory drugs, diuretics, or anti-retroviral drugs, and should receive comprehensive information from HCPs to improve adherence (Evans & Taal, 2015; Brown & Bussell, 2011). Finally, these self-management behaviours and skills are interdependent and important to consider when developing effective interventions for YAs with CKD, as they address the multifaceted nature of the disease and promote better health outcomes through informed and proactive self-care.

5.2.3 Self-Management Skills and Behaviours

Previous sections noted that CKD individuals must continuously maintain their care regimes, including diet management, BP control, blood result monitoring, and medication adherence. Supporting self-management is crucial as it empowers individuals to recognise problems, make informed decisions, and modify behaviours effectively (US Department of Defense, 2012). As proposed by Philips and Knuchel (2011), self-management skills are integral to performing self-management behaviours. For example, problem-solving skills, identified by Lorig and Holman (2003), play a critical role in how a person engages in self-management. Costantini et al. (2008) reported in a qualitative study that effective problem-solving allowed a CKD patient to self-monitor and adjust their treatment by recognising that their medication dose was causing dehydration, leading to a dose reduction after consulting with their prescriber (Costantini et al., 2008). This highlights the necessity of supporting CKD patients with problem-solving skills, especially in high-risk situations that could compromise adherence to medication, diet, BP, and blood result management (Eskridge, 2010; Ong et al., 2013).

In addition, daily decision-making is another essential aspect of CKD self-management, where patients must make choices about their diet, physical activity, and other aspects of their care (Costantini et al., 2008). According to Lorig and Holman (2003), problem-solving involves creating strategies to address issues and deciding on the appropriate course of action. For example, CKD patients may need to avoid or modify their intake of certain foods and fluids or choose suitable physical activities. Shared decision-making between patients and HCPs fosters a partnership that improves adherence to self-management behaviours (Ong et al., 2013). Understanding patient adherence requires discussing their challenges, such as side effects that might prevent them from taking their medications. Collaborative efforts between patients and HCPs can lead to individualised care plans that are more effective (Raymond et al., 2011).

Furthermore, Lorig and Holman (2003) also emphasised that identifying and utilising resources is both a skill and behaviour. Novak et al. (2013) identified resource activation as a self-management behaviour that involves recognising and accessing various resources, including community, healthcare, and social support. Ong et al. (2013) recommend using the Internet for tracking and recording clinical data to help CKD patients monitor their progress. Action-taking, which involves learning the necessary skills to change behaviour and address problems, is crucial for

CKD self-management, particularly in managing food, BP, blood results, and medication. These considerations are important for developing effective SMIs for YAs with CKD.

5.3 Importance of Person-Centred Care (PCC)

As previously recognised, managing CKD requires individuals to make significant lifestyle and dietary changes, which can be challenging and necessitate tailored support. However, not all patients receive the same level of personalised care (Ormandy, 2008). Many CKD patients report that they are rarely asked about the type of support they need to manage their condition effectively (Havas, Bonner, & Douglas, 2016). The systematic literature review in Chapter 3 also highlighted a lack of personalisation in current self-management interventions (SMIs), which are often disease-specific and designed primarily to meet the needs of healthcare providers (O'Hare, 2018; Morgan & Yoder, 2012). This approach contrasts with the principles of PCC, which emphasise treating patients with dignity, respect, and compassion (the Health Foundation, 2016), involving them in their care decisions, and tailoring treatment to their individual needs and preferences (Dixon, 2017; Richards, Coulter, & Wicks, 2015).

In PCC, patients and healthcare providers work as partners, engaging in shared decision-making to coordinate care that is meaningful to a person as a whole (Boulet, 2016; Kogan, Wilber, & Mosqueda, 2016; Morton & Sellars, 2019). This partnership model contrasts with the traditional paternalistic approach, where healthcare providers make decisions for patients and provide instructions to follow (Groll, 2014). PCC focuses on the person, including their family and social context, rather than just the disease, fostering an equal partnership between patients and providers.

Previous studies on CKD patients have revealed a widespread lack of personalised support for self-management from HCPs (Costantini, 2006; Youssouf, Harris, & O'Donoghue, 2015). Patients often struggle to understand the importance of lifestyle changes and treatments, leading to poor adherence (Clarkson & Robinson, 2010). The integration of PCC in CKD management has been recognised as overdue (Bear & Stockie, 2014), but recent years have seen a growing focus on its potential to enhance evidence-based care (Lockwood et al., 2020; O'Hare, Rodriguez, & Bowling, 2016). Research has documented numerous benefits of PCC, including improved patient and family satisfaction, increased patient engagement, better quality of life (QoL), enhanced health outcomes, reduced demands on healthcare services, and stronger relationships between patients and providers (Carlstrom & Ekman, 2012; Epstein & Street, 2011; Kim & Park, 2017; Martin & Felix-Bortolotti, 2014; Olsson, Jakobsson Ung, Swedberg, & Ekman, 2013; Rossom et al., 2016; Valentijn et al., 2018; van den Pol-Grevelink, Jukema, & Smits, 2012).

Furthermore, involving experienced CKD patients as experts in self-management training for HCPs has proven beneficial for both patients and providers (Towle et al., 2014). Peer mentoring, where trained patients support and empower their peers, has been shown to improve communication and decision-making among YAs with CKD (Heisler & Piette, 2005). These programs have successfully reduced fear about CKD and increased patients' confidence in discussing their needs with HCPs (Perry et al., 2005). Additionally, studies have demonstrated that peer support positively influences self-management in YAs with CKD (Sattoe, Jedeloo & van Staa, 2013). For example, a CKD YA clinic in Denmark (similar to the clinic in the United Kingdom; UK) reported that peer support enhanced patients' confidence in managing their condition (Finderup, Kristensesn, Christensen, & Jespersen, 2018). While these findings underscore the importance of peer support, implementing such programs can be challenging due to the small number of YAs with CKD and limited access to suitable peer mentors.

Lastly, it is important to note that the term "person-centred", rather than "patient-centred" has been chosen and applied throughout this thesis to capture the importance of the concept of patients as partners (Li & Porock, 2014). Although some argue that these terms are synonymous (Birmingham, 2015), the person-centred approach highlights the significance of addressing the individual's overall well-being, rather than focusing solely on the disease (Brummel-Smith et al., 2016; Lines, Lepore, & Wiener, 2015; Natan & Hochman, 2017). Despite the promising evidence of PCC in the CKD population, its practical implementation remains limited, indicating the need for further research to fully integrate PCC into routine nephrological care (Anderson, Calverti, Cockwell, Dutton, & Kyte, 2019; Breckenridge et al., 2015; Kuluski, Peckham, Williams, & Upshur, 2016; van de Veer, Aresi, & Gair, 2017).

5.4 Health Behaviour Change Interventions

As outlined earlier, chronic conditions, such as CKD, share behavioural risk factors, including poor diet, physical inactivity, and tobacco smoking (Lim et al., 2012), and individuals with chronic conditions are at an increased risk of developing mental health problems (Moussavi et al., 2007). Multimorbidity is also predominant in this population, thus health behaviours may benefit those individuals by positively impacting more than one condition (Barnett et al., 2012). Interventions that address risk factors and support behaviour change for effective self-management of chronic conditions can make a substantial difference to health and well-being, as well as lessen the costs of delivering healthcare to this population (OECD/EU, 2016). However, consistent with Craig and colleagues (2008), health behaviour change interventions are often complex. Addressing health behaviour change can be challenging, therefore should draw on theories and approaches to behaviour change (Michie, West, Sheals, & Godinho, 2018).

Several different frameworks can be used to inform the development of health behaviour change interventions. For instance, the Intervention Mapping (Bartholomew Eldredge et al., 2016), Person-Based Approach (Yardley, Morrison, Bradbury, & Muller, 2015), UK Medical Research Council (MRC) framework (Craig et al., 2008; Skivington et al., 2021), or Behaviour Change Wheel (BCW; Michie et al., 2011). Although each of these frameworks has a different focus and approach, they share an important set of main steps, including analysing the problem and developing an objective for the intervention, fundamental modelling, defining treatment features, developing materials and a reasonable model of change, evaluating and implementing outcome and process (Araujo-Soares, Hankonen, Presseau, Rodrigues, & Sniehotta, 2018).

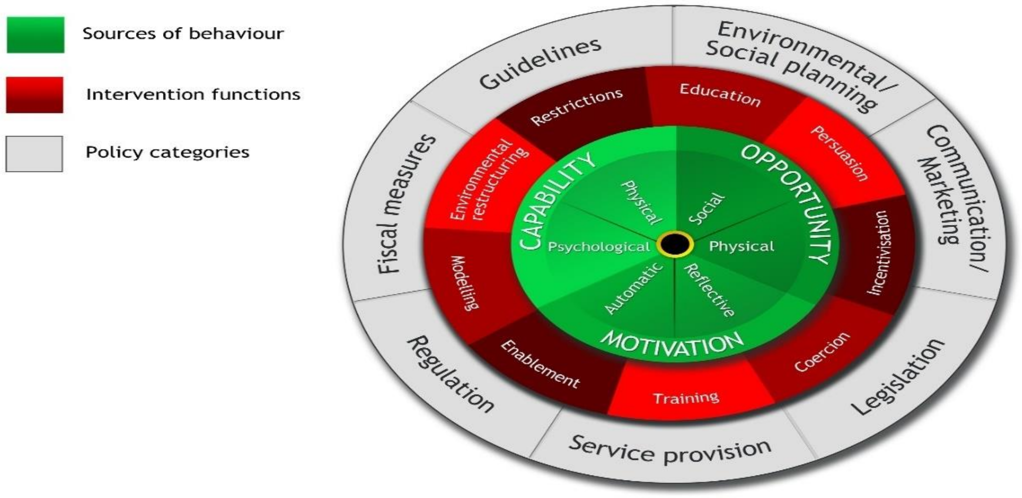
One common approach to addressing health behaviour change and informing the development of complex health behaviour change interventions is the BCW framework (Michie et al., 2011). BCW delivers a systematic and in-depth approach to choosing and applying behavioural constructs to the design of the intervention. BCW model is also expandable, which allows for the integration of behaviour change constructs and strategies from other models and theories. BCW offers systematic phases of development work preceding a full path of a complex intervention. It aims to improve the quality of intervention, increasing the probability of the intervention being implementable and effective, while also adding to a growing science of behaviour change (Bleijenberg et al., 2018). For the purpose of this thesis, the BCW model is briefly described below.

5.4.1 Behaviour Change Wheel (BCW)

The BCW (see Figure 5.1) is an overarching framework that provides a comprehensive fundamental analysis of behaviour and recognises three core areas for behaviour change, including capability (C), opportunity (O), and motivation (M), also known as the COM-B Model (see Figure 5.2) (Michie, Atkins, & West, 2014a).

Figure 5.1

The Behaviour Change Wheel

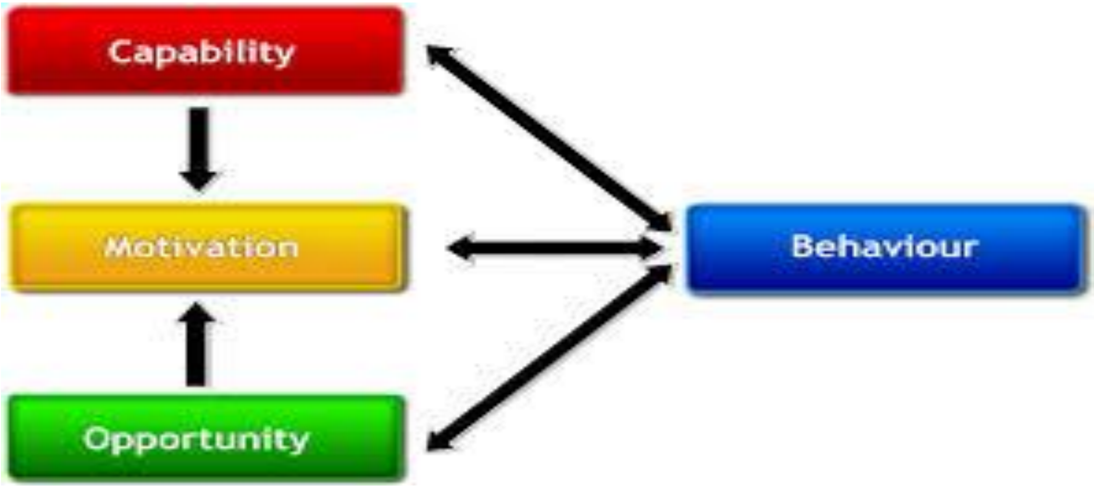


Retrieved from Michie et al., (2014a).

Capability refers to an individual's physical or psychological ability to engage in a specific activity, including understanding, knowledge, and mental and physical skills. Opportunity involves external factors that enable or prompt behaviour, such as the physical environment and availability of cues for healthy eating or physical activity. Motivation encompasses mental processes that drive behaviour, including goals, decision-making, emotions, impulses, habits, and desires (Michie et al., 2014). The COM-B model (see Figure 5.2 below) posits that modifying capability, opportunity, or motivation will change behaviour, with changes in capability and opportunity impacting motivation. This model helps identify barriers and enablers of behaviour to target in interventions (Phillips et al., 2015a).

Figure 5.2

COM-B Model



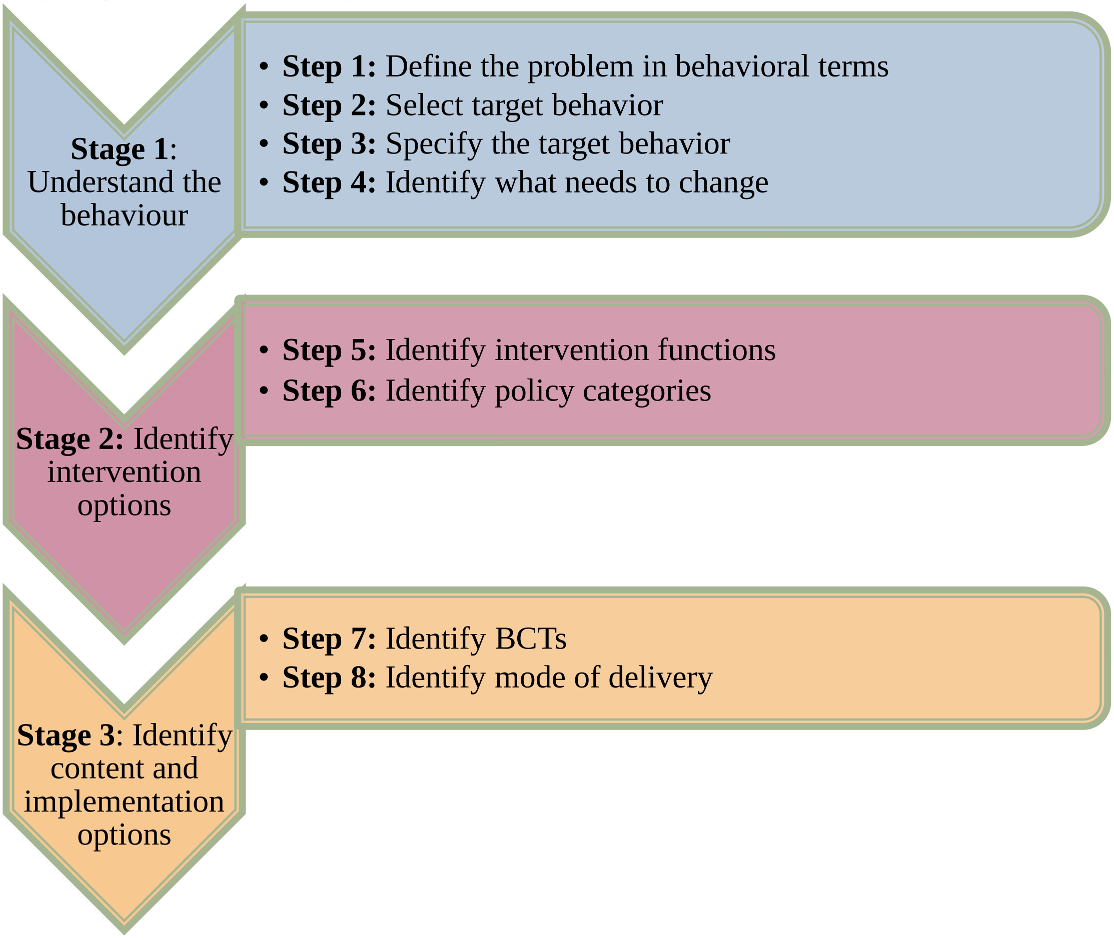
Retrieved from Michie et al., (2014a).

The BCW (Figure 5.1) further suggests that behaviour change results from an interaction of intervention functions and policy categories. Interventions can use multiple functions and policy categories to support and validate behaviour change efforts (Michie et al., 2014a).

Furthermore, according to the authors of the BCW guide, it involves three main stages of intervention design, which can be undertaken in sequence or parallel (Michie et al., 2011). Understanding the behaviour is key to bringing about the desired change. This involves defining who, what, when, where, how often and with whom the behaviour needs to change, as well as identifying any necessary changes within the person or environment (stage 1). Stage 2 involves identifying intervention options, including functions and policies, and stage 3, BCTs and implementation options for the intervention. These stages can be further subdivided into eight main steps as presented in Figure 5.3 below.

Figure 5.3

Stages of Intervention Design in the BCW



Adapted from Michie et al. (2011). *BCT* Behaviour Change Techniques; *BCW* Behaviour Change Wheel.

Studies have used the BCW guide in the development and implementation of interventions in many different healthcare settings (Alexander, Brijnath, & Mazza, 2014; Barker, Atkins, & de Lusignan, 2016), including the reduction of alcohol consumption (Michie et al., 2012), smoking cessation (Gould et al., 2017), sexual counselling (McSharry, Murphy, & Byrne, 2016), condom use (Webster et al., 2016), physical activity (Truelove, Vanderloo, Tucker, Di Sebastiano, & Faulkner, 2020), adherence to physical activity and diet (Kinnear et al., 2020), etcetera. The BCW associates with another model of behaviour known as TDF (Cane, O’Connor, & Michie, 2012) to enable decision-making in the design of the intervention. Overall, the COM-B model and BCW provide a framework for understanding the specific capabilities, opportunities, and motivations of YAs with CKD. This understanding is crucial for designing interventions that effectively target these factors, promoting optimal self-management behaviours. By utilising these models, the research can identify specific barriers and enablers for YAs with CKD and address the research questions by developing targeted, evidence-based interventions to improve their self-management and health outcomes.

5.4.2 Theoretical Domains Framework (TDF)

According to Michie and colleagues (2014a), linking broad categories of interventions, such as intervention functions from the BCW and TDF can aid in codeveloping the SMI strategy. TDF includes 84 constructs from several psychological theories (action, motivational, and organisational theories), and 14 theoretical domains (Atkins et al., 2017; Cane et al., 2012; Michie et al., 2005). TDF offers a valuable framework for a deeper understanding of the barriers and enablers that influence specific behaviours (Curtis, Lahiri, & Brown, 2015; Phillips et al., 2015b). It provides a comprehensive analysis of the potentially modifiable factors associated with the BCW (the components of COM-B in the central cog of the wheel) in order to target intervention. Research suggests that using TDF allows for a theory-based assessment of behaviour change as well as the identification of various potential targets for interventions (Huijg, Gebhardt, Crone, Dusseldorp, & Presseau, 2014; Michie et al., 2005; Webster et al., 2015).

Domains can be targeted using a taxonomy of BCTs (Michie et al., 2013). According to Abraham and Michie (2008), BCTs are standardised definitions of the techniques that are used in complex behaviour change interventions, which are suggested to be the active components of interventions. BCTs allow effective components to be recognised in reports of a person's interventions, aid in improving the understanding of how interventions may work, enable consistent implementation of interventions outside research settings, and offer a taxonomy of definitions, which may be used to describe interventions in detail (Michie et al., 2011). Table 5.1 presents links between the COM-B system and TDF (Michie et al., 2014a) and Figure 5.4 graphically illustrates the COM-B and TDF matrix (Michie et al., 2011).

Table 5.1

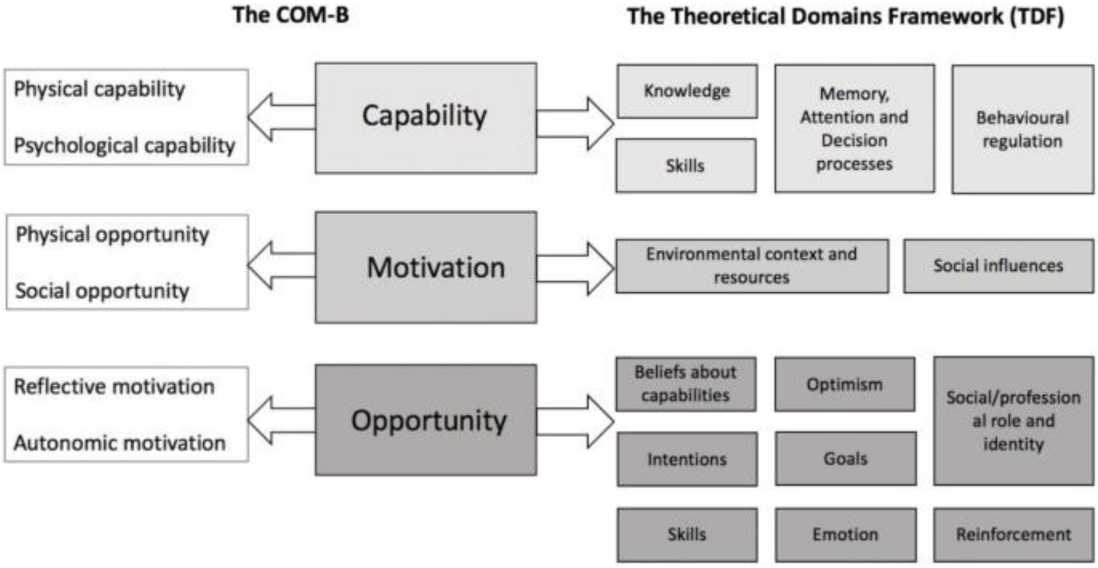
Links between the COM-B System and TDF

Component	Sub-component	Theoretical domains
Capability	Psychological capability	Knowledge Skills (cognitive and interpersonal) Memory, attention, and decision process Behavioural regulation
	Physical capability	Skills (physical)
Motivation	Reflective motivation	Social/professional role and identity Beliefs about capabilities Optimism Beliefs about consequences Goals Intentions
	Automatic motivation	Reinforcement Emotion
Opportunity	Social environment	Social influences
	Physical environment	Environmental context and resources

Adapted from Michie et al. (2014a).

Figure 5.4

The COM-B and TDF Matrix



Retrieved from (Michie et al., 2011).

Several survey and interview studies have effectively applied TDF to characterise the determinants of a variety of health behaviours, including smoking cessation, or lower back pain management (Beenstock et al., 2012). One study by Baay and colleagues (2019), applied a theory-based TDF approach to understand contributors which influence self-management behaviour in individuals with CKD and their caregivers, and to explore the associations between the 14 theoretical domains and CKD self-management. The researchers recognised from their findings five TDF domains that can influence CKD self-management behaviour (including environmental context and resources, knowledge, beliefs about capabilities and consequences, and social influences) and four potential intervention approaches to impact the behaviour change in individuals with CKD and their caregivers (including education, modelling, persuasion, and environmental restructuring). They concluded that these findings should inform the co-design of a behaviour change intervention to improve self-management in individuals with CKD (Baay et al., 2019).

Additionally, French and colleagues (2012), proposed a systematic approach using TDF to inform the development of complex implementation interventions (French et al., 2012). Implementation interventions are interventions that are intended to alter clinical practice behaviour and increase evidence uptake into practice. However, so far, the implementation interventions have had diverse and limited effects (Grimshaw et al., 2004), which could partially be a result of the absence of a clear rationale for choosing the intervention and the application of inapt methods in designing the intervention (Davies et al., 2010). Therefore, it is important to follow a systematic approach when designing an implementation intervention, including a robust rationale for the intervention design and clear reporting of its development (Baker, Brennan Ramirez, Claus, & Land, 2008; Boutron et al., 2008). One way to achieve this is to use theory to inform the intervention's design and development (Eccles, Grimshaw, Walker, Johnston, & Pitts, 2005). For instance, one useful approach to designing interventions is the above-mentioned UK MRC guide for developing complex implementation interventions, which is informed by theory (MRC, 2000; 2021), however, this approach lacks comprehensive guidance on how to accomplish this.

Conversely, the French et al. (2012) approach, built on the guidance from the UK MRC (2000) and previously recognised methods for the development of theory-based interventions (Foy et al., 2007; Hrisos et al., 2008), offers a four-step systematic approach to the development of an intervention based on a theoretical framework (French et al., 2012). According to Lennon and colleagues (2018), intervention is more likely to be effective if it targets causal determinants of behaviour and behaviour change (Lennon, Blake, Booth, Pollock, & Lawrence, 2018). Hence, the current study employed the French and colleagues' (2012) approach in the design and development of a novel intervention. Moreover, although their approach involves similar steps to intervention design as BCW (Michie et al., 2011), it was decided to employ a four-step systematic approach in the current study as it offers a more thorough method and it was deemed as a more appropriate approach for the current study design (e.g., the inclusion of employing the quantitative and qualitative methods to recognise barriers and enablers of behaviour change). The four steps of this approach to the development of theory-based intervention are presented in Table 5.2 below, and how these steps were applied in the current study is explored in more detail in Chapter 8.

Table 5.2

Four-Step Systematic Approach

	Description of tasks
Step 1: Who needs to do what, differently?	-to identify the evidence gap -to specify the behaviour change needed to reduce the evidence-practice gap -to specify the health professional group whose behaviour needs changing
Step 2: Using a theoretical framework, which barriers and enablers need to be addressed?	-to select (from the literature or experience of the development team) which theory(ies), or theoretical framework(s), are likely to inform the pathways of change -to use the chosen theory(ies), or theoretical framework(s), to identify the pathways(s) of change and the potential barriers and enablers to that pathway -to use qualitative and/or quantitative methods to identify barriers and enablers to behaviour change
Step 3: Which intervention components (BCTs and mode(s) of delivery) could overcome the modifiable barriers and enhance the enablers?	-to use the chosen theory(ies), or theoretical framework(s), to identify the possible BCTs to overcome the barriers and enhance the enablers -to identify evidence to inform the selection of potential BCTs and modes of delivery -to identify what is likely to be feasible, locally relevant, and acceptable and combine identified components into an acceptable intervention that can be delivered
Step 4: How can behaviour change be measured and understood?	-to identify mediators of change to investigate the proposed pathways of change -to select appropriate outcome measures -to determine the feasibility of outcomes to be measured

Adapted from French et al. (2012). *BCT* Behaviour Change Techniques.

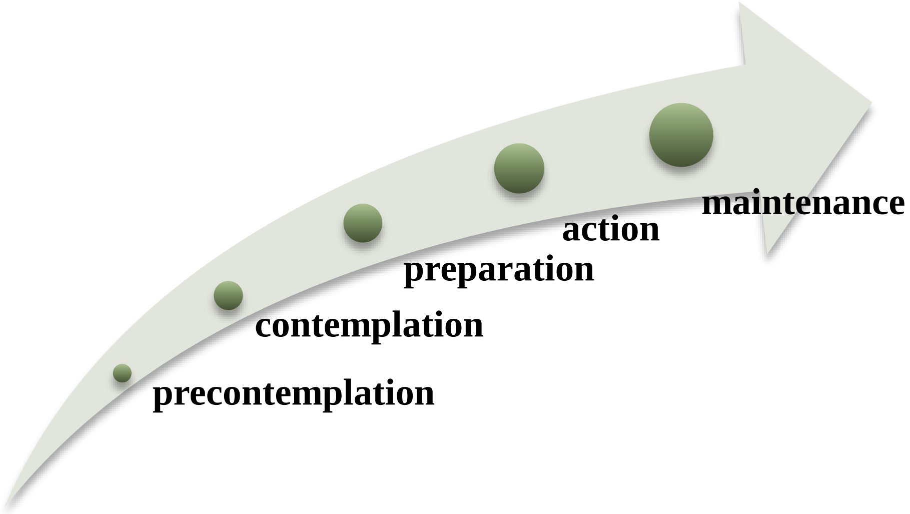
5.5 Brief Overview of Health Behaviour Models

There are several theoretical models recognised in health behaviour literature. The following briefly describes one particular model that is relevant to the current study, namely, the Transtheoretical Model (TTM; Prochaska & DiClemente, 1984; 1986; Prochaska, DiClemente, & Norcross, 1992), one of the most widely used models to understand and predict health-related behaviours.

The TTM, also known as the “stages of change” model, suggests that health behaviour change comprises progress through five stages (Prochaska et al., 1992). In particular, *pre-contemplation*, where a person does not intend to take action in the predictable future, nor are they aware that their behaviour is problematic or produces negative consequences. Next, is *contemplation*, where they intend to start healthy behaviour in the predictable future. The third stage involves *preparation*, where a person is ready to take action and starts taking small steps towards behaviour change. Next is the *action* stage, where they have recently changed their behaviour and intend to keep moving forward with that behaviour change. The final stage includes *maintenance*, where they have sustained their behaviour change for a while and intend to maintain it going forward (refer to Figure 5.5) (Prochaska et al., 1992). There is also a sixth stage known as *termination*, however, it should be noted that this stage was not part of the initial model and is less often applied in stages of change for health-related behaviours. Individuals are continuously moving from one stage to another; however, they can also move in the opposite direction and relapse (Prochaska &Velicer, 1997). Evidence supporting the TTM comes from cross-sectional studies, which report variances in variables from a variety of theoretical frameworks (e.g., self-efficacy), across the five stages of change (e.g., Armitage, Povey, & Arden, 2003).

Figure 5.5

The Transtheoretical Model



Adapted from Prochaska et al., (1992).

Nevertheless, several studies have reported some concerns regarding the staging process. For instance, Herzog and Blagg (2007), examined the stages of the change process in association with numerous measures of motivation to stop smoking and reported that the staging process underestimated motivation to stop smoking. Other critics argued that this model is restricted since it does not explain how people change their behaviour and why only a few do well (Munro, Lewin, Swart & Volmink, 2007). Moreover, it was hard to test this model because of the lack of well-developed instruments. To address this and to improve what was viewed as a promising model but with a few flaws, Hibbard and colleagues developed the PAM (Hibbard et al., 2004), discussed in the section below.

5.6 Patient Activation Measure (PAM)

As discussed in the introductory section of this Chapter, the shift from the paternalistic model to PCC in providing care for people with CKD has received increased attention in the past years and several benefits of PCC have been identified. However, from this, questions arise on whether patients are ready to take on this role. According to Hill, Richardson, and Skouteris (2015), it is not only a matter of education, and it might be important here to consider the significance of patient activation. For individuals with CKD to be ready to take on the ownership of their care, they have to understand what to do and how (knowledge), they have to be able to perform essential tasks or behaviours (skills), and they have to feel confident that they can do it.

Consistent with Remmers et al. (2009), individuals who suffer from chronic conditions need better interaction with health providers and evidence suggests that those who are more activated are more ready to engage in self-management over a long period. To learn how to manage their disease, individuals undergo the process known as activation (Audulv et al., 2012). The activation term has been used for decades to define the degree to which people are activated and engaged in their care (Snell, 2011). Patient activation is described as the knowledge, skills, and confidence that individuals require to manage their health and healthcare, and how likely is that they will do so (Hibbard, Greene, Shi, Mittler, & Scanlon, 2015). Hibbard and Mahoney (2010) defined patient activation as a comprehensive, multi-dimensional self-management self-concept.

The patient activation concept integrates components of self-efficacy and readiness to change and moderately incorporates health literacy (Hibbard & Guilburd, 2014; Do, Young, Barnason, & Tran, 2015). These concepts rely on less robust measurements which make it difficult to assess changes in score, however, the PAM has drawn on and captured these elements. Consequently, compared to concepts of self-efficacy, readiness to change, and health literacy, the PAM has been found as the greatest predictor of healthy behaviours over a broader series of outcomes (Rademakers, Nijman, Brabers, de Jong, & Hendriks, 2014; Serper et al., 2014).

Given the need for an overarching measure of self-management, Hibbard and colleagues (2004) recognised factors related to self-management capacity (e.g., Lorig & Holman's 2003 classification of the five main self-management skills discussed earlier), explained the concept of patient activation, and developed a 22 item PAM, and PAM-13 short version of the measure (Hibbard et al., 2005). According to research, reliable and valid instruments assist healthcare providers in understanding the discrepancy in self-management capability and recognise individuals who may benefit from improving their self-management skills (Ryvicker, Feldman, Chiu, & Gerber, 2013).

Contrary to the five stages of change of the TTM, the PAM involves four levels, including "disengaged and overwhelmed" (level 1), "becoming aware, but still struggling" (level 2), "taking action" (level 3), and level 4 "maintaining behaviours and pushing further" (Hibbard et al., 2004). Therefore, PAM examines some elements of general disease-related self-efficacy, but it also measures actions, coping, and attitudes. The four levels of PAM are indication points on a continuum. Individuals progress through these levels as they improve in self-management (Hibbard, Green, & Tusler, 2009; Hibbard & Guilburd, 2014). However, like in the TTM (Prochaska &Velicer, 1997), activation can also move in the opposite direction and deteriorate (Hibbard et al., 2009). Table 5.3 below illustrates the stages of change of the TTM (including the sixth *termination* stage) and corresponding PAM equivalents, including a description of stages/levels.

Table 5.3

Stages of Change and Corresponding PAM Equivalents

Stage of change	Description	PAM equivalent	Description
Pre-contemplation	Individual not planning to take action within the next 6 months	Disengaged and overwhelmed (*level 1*)	Individual is passive and lacks confidence. Their knowledge is low, adherence is poor, and goal-orientation is weak
Contemplation	Individual intending to take action in the next 6 months. Aware of the pros of behaviour change, but also acutely aware of the cons		
Preparation	Individual intending to act within the next month. Some actions have been undertaken, or plans made	Becoming aware, but still struggling (*level 2*)	Individual has some knowledge, but large gaps still remain. They can set simple goals; however, they still believe that health is largely out of their control
Action	Individual has made specific overt modifications to their lifestyle in the last 6 months. Must be a sufficient level of action to realistically achieve goals (e.g., weight loss)	Taking action (*level 3*)	Individual has the main facts and is building skills to self-manage their condition. The individual is goal-orientated and strives for best-practice behaviours
Maintenance	Individual is working to prevent relapse, but not applying change processes as frequently as individuals in the action stage	Maintaining behaviours and pushing further (*level 4)*	Individual has adopted new behaviours; however, they may still struggle in times of change or stress. The key focus is maintaining a healthy lifestyle
Relapse	(*Not part of the original model*) Individual has reverted to previous behaviour		

Adapted from: the TTM (Prochaska & DiClemente, 1984; 1986; Prochaska, et al., 1992) and PAM (Hibbard et al., 2004). *PAM* Patient Activation Measure.

It has been widely recognised that healthcare systems in the UK and globally are facing great challenges, and PCC continues to be a National Health Service (NHS) priority (De Silva, 2014). According to the English NHS Five Year Forward View (NHS England, 2014), because of a progressively ageing population (Barnett et al., 2012), the growing prevalence of multiple long-term conditions (LTCs) (Berzins, Reilly, Abell, Hughes, & Challis, 2009), and the confines to the existing financial resources (Mulley, Trimble, & Elwyn, 2012), there is a need for models of care to face demands of the current population in the UK. However, there is no single, clear definition of PCC (Brewster & Ramcharan, 2005), and a review by de Silva (2014) recognised 160 diverse tools trying to measure this notion. This indicates that there is a growing interest in this topic, however, also a lack of clarity about what is meant by PCC and how to examine the degree to which it is being delivered. The concept of patient activation has received increasing attention in the UK and worldwide and has been recognised as potentially most related to the principles of PCC and LTC management (Ahmad, Ellins, Krelle, & Lawrie, 2014).

The PAM can be used as an outcome measure (e.g., to evaluate interventions), as a tailoring tool (e.g., to design SMI tailored to patient activation level), and both, as an outcome measure and tailoring tool (e.g., using individual's activation score to tailor the delivery of treatment to person's specific needs, and using changes in PAM score across a group of individuals to evaluate the impact of treatment) (Roberts et al., 2016). The PAM can be applied to one or more levels of scale, including the population level (e.g., individuals with LTCs), service level (e.g., health coaching interventions), and individual level (e.g., service user). Previous studies successfully applied the PAM as a tailoring tool at the individual level (PCC, 2018; NHS England, 2018), service level (e.g., Health Foundation, 2018) and population level (e.g., Armstrong et al., 2017) with individuals with LTCs. Previous research also successfully applied PAM to measure outcomes in LTCs at the individual level (e.g., Armstrong et al., 2017), service level (e.g., Health Foundation, 2013), and population level (e.g., Barker, Steventon, Williamson, & Deeny, 2018).

Linden (2015) criticised the PAM for the possibility of scoring when responses are missing which may lead to considerable error in measurement.

However, this error is only significant when nine items of the PAM-13 (which constitute 69.2% of the measure) are missing, and in the research practice, this would be excluded (Tabachnic & Fidell, 2013), and in clinical practice, HCPs would follow-up with the patients to further assess their level of activation. In contrast to other methods of measuring activation (Kamajian, 2014) and self-efficacy (Greene & Hibbard, 2011), the PAM measures a wider range of dimensions of activation. The PAM-13 has been recently validated in the CKD population (Lightfoot, Wilkinson, Memory, Palmer, & Smith, 2021), and its psychometric properties, distribution of the survey in the current study, and scoring are further discussed in Chapter 2. Battersby et al. (2010), proposed that healthcare providers could set suitable goals associated with the individual’s baseline activation data, which would let them work thoroughly with individuals toward incremental improvements in their activation level by helping them to close the gaps that stop them from being entirely involved in their health and healthcare. The authors compared this development to the SCT concept of self-efficacy (Bandura, 1977) given that the small accomplishments resulting from such interventions can improve confidence and skills for self-management (Battersby et al., 2010).

According to Hibbard and Cunningham (2008), approximately 2-40 percent of the population has a low level of activation. In terms of those who live with CKD, between 43 and 50 percent show low activation levels, and they commonly report low or lack of knowledge and understanding of the importance of self-management, and they lack the necessary self-management skills (Griva et al., 2018; Wilkinson, Memory, Lightfoot, Palmer, & Smith, 2021). Improving patient activation in individuals with LTCs is important as more activated individuals are more likely to follow healthy behaviours, seek out and use health information, attain improved health-related outcomes, use healthcare services more appropriately, experience less hospitalisation, and avoid health-damaging behaviours (Begum, Donald, Ozolins, & Dower, 2011; Greene et al., 2015; Jacobson et al., 2018; Mosen et al., 2007; Lindsay, Hibbard, Boothroyd, Glaseroff, & Asch, 2018; Struwe, Schmaderer, & Zimmerman, 2020). Deeny, Thorlby and Stevenson (2018) established that in the UK, individuals with LTCs who had a higher level of activation, compared to those with lower activation, reported 32 percent fewer attendings to the emergency department, and 38 percent fewer emergency admissions (Deeny et al., 2018).

Additionally, it has been reported that a low level of activation is significantly related to a greater level of depression and anxiety, and a lower health literacy level (Cukor, Zelnick, Charytan, Shallcross, & Mehrotra, 2021), and contrary, a high level of activation is significantly related to improved health-related quality of life (HRQoL) and decreased symptom burden (Magadi et al., 2022). Many researchers concur that patient activation is vital to the development of successful self-management to improve health and chronic disease outcomes as well as to improve patient engagement in decision-making (Becker & Roblin, 2008; Deen, Lu, Rothstein, Santana, & Gold, 2011; Hibbard et al., 2004). However, it is the least well-developed intervention in chronic conditions (Hibbard et al., 2007). In the recent literature review (refer to Chapter 3), only one trial assessed patient activation. Donald and colleagues (2011) emphasised that activation is the core of self-management.

The evidence also established factors that may impact the degree to which the individual's activation improves, for instance, age, gender, ethnicity, educational level, HRQoL, depression, level of health-literacy, and multimorbidity (Blakemore et al., 2016; Eliacin et al., 2018; Gleason, Tanner, Boyd, Saczynski, & Szanton, 2016; Goodworth et al., 2016: Hendriks & Rademakers, 2014; Overbeek et al., 2018; Prey et al., 2014; Wetzstein, Shanta, & Chlan, 2020). Typically, individuals with chronic conditions attend primary care as their first point of contact, thus primary care setting may be the preferable setting in which to address the goal of improving activation (Mattei da Silva et al., 2020). Research suggests that interventions that support self-management, and consequently patient activation, in primary care settings are most effective when they are participative, structured, and delivered one-to-one (Dineen-Griffin, Garcia-Cardenas, Williams, & Benrimoj, 2019), when they are tailored to the individual (Hibbard & Greene, 2013), addressing multimorbidity (Smith, Wallace, O'Dowd, & Fortin, 2016), and focusing on physical health but also emotional dimensions (Menichetti, Graffigna, & Steinsbekk, 2018).

One approach that can address these necessities is health coaching (Hill et al., 2015). Health coaching is an intervention based on PCC principles, which activates individuals to change their behaviours (Bennett, Coleman, Parry, Bodenheimer, &

Chen, 2010; Lin, Weng, Apriliyasari, Truong, & Tsai, 2020; Olsen, 2014), by setting personal goals and improving their skills and confidence in managing their health (Kivela, Elo, Kyngas, & Kaariainen, 2014). It differs from counselling, which delivers health education by applying rigid instructions, without taking into account the individual's goals and desires to change (Singh, Kennedy, & Stupans, 2020). Health coaching aims to motivate individuals to take action and thrive (Hibbard & Greene, 2013), which in turn motivates them to take more actions and ownership, improving their activation level. Evidence suggests that coaching can improve patient activation (Nouri et al., 2019), HRQoL (Benzo et al., 2016), self-efficacy (Tuluce & Kultuturkan, 2018), and medication adherence (Wolever & Dreusicke, 2016).

In CKD, SMIs that emphasise problem-solving, skill development, and peer support appear to improve the patients' activation levels, behaviour modifications, and self-efficacy to effectively self-manage their condition (Greene & Hibbard, 2012; Lin et al., 2020; Nguyen et al., 2019). Strategies that are typically used in patient activation interventions comprise personalised care plans, problem-solving, peer support, feedback, lay health providers, skill-building, and theory-based counselling (Bolen et al., 2014). Further support for SMIs and health coaching to improve patient activation is presented below.

5.6.1 Enhancing Patient Activation through Health Coaching and Self-Management

Empirical evidence advocates that patient activation is a factor that can predict the health status of individuals who suffer from chronic illnesses (Hibbard & Greene, 2013). It has been established that CKD individuals have lower activation compared to those who suffer from other chronic conditions, such as multiple sclerosis (Stepleman et al., 2010), HIV (Kendall et al., 2018), and inflammatory bowel disease (Barnes, Long, Kappelman, Martin, & Sandler, 2019), with those receiving in-centre haemodialysis having the lowest activation (van Bulck et al., 2018; Gair et al., 2019). CKD studies reported that poor engagement with self-management behaviours is related to lower levels of poor clinical outcomes, including cardiovascular disease, progression to end-stage kidney disease (ESKD), and adverse events, such as death (Schrauben et al., 2018). However, according to Nair and Cavanaugh (2020), only a limited number of studies have administered PAM to individuals with CKD and more information concerning the factors and outcomes associated with patient activation in this population is scant. Thus, there is a necessity to examine the factors that impact or are impacted by patient activation in the CKD population.

Health coaching and educational programmes that are targeted according to the PAM score may help healthcare providers to interact more efficiently to strengthen the individual’s role in managing their healthcare (Reistroffer, Hearld, & Szychowski, 2017). Studies reported that when tailoring coaching to the patient activation level as opposed to the usual way of coaching, there is a noticeable improvement in outcomes (Lawson et al., 2013). One of the frequently implemented health coaching techniques is motivational interviewing (MI) (Miller and Rollnick, 2013) which assists patients in finding a resolution to uncertain feelings toward change (Hill et al., 2015). According to researchers, health coaching and MI enable behaviour change by motivating people to establish attainable individual goals and promote self-efficacy (Wong-Rieger & Rieger, 2013). During coaching, the person’s readiness to change is assessed, and then their fundamental motivation to change is elicited. Coaching involves a sequence of setting and applying an action plan, assessment, and building the individual’s confidence each time the goal is accomplished (Crown, Vogel, & Hurlock-Chorostecki, 2017). According to Mukoro (2012), integrating tailored coaching and MI may improve behaviour and health outcomes.

Recent studies, such as Lin et al. (2020), demonstrate that health coaching improves patient activation, self-efficacy, self-management, and QoL in early-stage CKD, highlighting the importance of these strategies in self-management programs. Further supporting evidence comes from nurse-led, individually tailored interventions that show improvements in patient activation and secondary outcomes (Moreno-Chico et al., 2021). However, maintaining these improvements post-intervention remains a challenge, suggesting a need for ongoing support to sustain patient activation levels (Greene, Hibbard, Alvarez, & Overton., 2016). Thus, incorporating continuous support and maintenance activities into health coaching interventions is essential for long-term success in self-management for individuals with CKD.

In terms of self-management, there are numerous associations between self-management behaviours and patient activation in chronic disease (Graffigna, Barello, & Bonanomi, 2017). For instance, adhering to a healthy diet, physical activity, and attending healthcare appointments were linked to improved patient activation (Wong, Peterson, & Black, 2011). LTC literature established the positive changes in a number of different self-management skills as a result of improving patient activation, for example in individuals with diabetes (Hibbard et al., 2007), and cardiovascular illness (Hibbard & Tusler, 2007). However, in CKD, the relationship between levels of patient activation and CKD-specific self-management behaviours is not well recognised, and as recently suggested by researchers (Nair & Cavanaugh, 2020; Lightfoot et al., 2021), it should be explored further. Nevertheless, the lesson can be learned from other LTCs, and as mentioned earlier, PAM can be applied in three ways (tailoring tool, outcome measure, or both) and some examples of the measure being applied in these ways are briefly discussed below.

Assessing patient activation for self-management is just the first step in the process of meeting individual self-management needs (Rodriguez, Poon, Wang, & Shortell, 2019). The critical component in improving overall health and HRQoL is activating people to take control over their health and healthcare and engaging them in self-management skills (Newland, Lorenz & Oliver, 2021). Provided that the questions related to PAM offer a structure for discussions about health behaviours, the PAM can be used to inform conversation between the patient and HCP, and as a guide to discovering how the individual copes and manages their condition and how they feel about making lifestyle modifications to improve their health (Hibbard & Guilburd, 2014). If the individual is motivated and confident to self-manage their condition, the HCP may provide them with more thorough information and/or assist them in creating a structured plan (e.g., an exercise and diet plan). Conversely, if they report being overwhelmed, the HCP can then take some time to understand why they feel this way and assist them in setting simple and achievable tasks, which can decrease their risk level and increase their confidence (Gibert, DeGrazia, & Danis, 2017).

Previous studies used the results of the PAM to tailor care for individuals with LTCs in the clinical setting by employing various interventions, including already discussed MI and health coaching, as well as goal-setting (e.g., Houlihan et al., 2017), delivery of health information (e.g., Hibbard, 2017), the transition from hospital to home, coordination of care, self-management and prevention interventions (e.g., Roeper et al., 2018; Young, Hertzog, Barnason, 2016), and care and self-management plans development (e.g., Kidd, Lawrence, Booth, Rowat, & Russell, 2015). For instance, Kidd and colleagues (2015) used the PAM’s results to identify and discuss goals with stroke patients and develop a self-management action plan in a nurse-led SMI. In this study, nurses employed MI and advised patients on self-management, which was tailored to the individual’s level of activation (Kidd et al., 2015).

Recently, Kearns and colleagues (2020) reviewed these studies that used PAM to tailor treatment for individuals with LTCs and recognised several enablers and barriers that affect the implementation of the PAM to tailor care. The authors concluded from their scoping review that to allow the successful implementation of the PAM to tailored care in clinical settings, HCPs should consider an enhanced understanding of the value and purpose of using the PAM as a tailoring tool, in conjunction with a distinct and flexible administration approaches to inform patient care (Kearns et al., 2020).

In terms of the PAM as an outcome measure to evaluate intervention or patient activation over time, it can be employed for interventions that are intended to enhance health outcomes or to improve self-management behaviours (Armstrong, Tarrant, Martin, Manktelow, Brewster, 2015). A limited number of studies (mainly, cross-sectional studies) have applied PAM in CKD. Recently, Nair and Cavanaugh (2022) reviewed these studies and made some important conclusions. For instance, the authors reported that low activation level is related to the presence of CKD (e.g., Bos-Touwen et al., 2015), lower eGFR (e.g., Johnson et al., 2016), older age (e.g., Zimbudzi et al., 2017), decreased medication obedience (e.g., Hamilton et al., 2018), a higher number of comorbidities (e.g., Wilkinson et al., 2021), increased symptom burden (e.g., Gair et al., 2019), worse HRQoL (e.g., Magadi et al., 2022), and being uncertain about which treatment option to choose (e.g., Velez-Bermudez, Christensen, Kinner, Roche, & Fraer, 2019). The authors agreed with other researchers (e.g., Mitchell et al., 2014) who suggested that including PAM in chronic conditions like CKD has a great potential to identify those individuals who are at greatest risk for poor health outcomes and increased healthcare utilisation and those who will most benefit from tailored interventions to enhance activation level and disease self-management (Nair & Cavanaugh, 2022).

Another important finding documented in the studies that employed PAM as an outcome measure is that those individuals who are in the lowest levels of activation experience better improvements in their activation level following the intervention, whereas those in the highest levels of activation do not experience as much improvement (Miller et al., 2020; Shah et al., 2015). Lightfoot et al. (2021) suggested that this may partially be due to the ceiling effect present in the PAM and it is an important consideration in the design of RCTs.

Additional considerations of the measure involve its use as a tailoring tool, which due to the wide-ranging nature of the measure (e.g., PAM can be administered across diverse patient groups and it is not a disease-specific measure) it tends to be more complex and not as understood as when applied as an outcome measure. According to research, this can limit the significance and feasibility of the PAM’s results because they are not explicit enough to the individual’s needs and desires (Kidd et al., 2015). The measure does not query if the person really engages in preventive or self-management behaviours (Hibbard et al., 2005). Therefore, individuals may be fully activated without actually improving their health (Gibert et al., 2017). As stated by Armstrong and colleagues (2015), the PAM can serve as an outcome in itself combined with other outcomes and using PAM on its own can enhance outcomes by promoting patient engagement and PCC. Moreover, administering PAM in the clinical setting to tailor treatment might require more flexibility than applying it as an outcome measure to assess the intervention (Kearns et al., 2020). Given that the PAM is embodied into a meaningful metric in CKD treatment and service, more research is needed to recognise its usefulness and relationship to health outcomes in this population (Cukor et al., 2021).

5.6.2 Brief Action Planning (BAP)

We have seen that various approaches have been used to offer improved guidance for both, healthcare providers and recipients, including MI (Miller and Rollnick, 2013) and self-management programmes for chronic conditions (Lorig et al., 2001). However, the feasibility of these approaches has been criticised. For instance, while the latter has been found to be effective when delivered by peers in community settings (Lorig et al., 2001), findings from the studies conducted in primary care are not well recognised. Moreover, MI, which has been established as a more effective technique compared to traditional "advice-giving", in interventions of a wide range of behaviours and chronic diseases (Heckman, Egleston, & Hofmann, 2010; Lundahl et al., 2013), has been questioned for its fidelity as it comprises numerous training sessions and practices as well as feedback to attain competency (Resnicow et al., 2002).

Recognising the challenges that healthcare providers face, it is important to consider an appropriate approach to support individuals with chronic conditions in changing behaviours, which could be implemented in primary care settings. One evidence-based approach that can potentially address these challenges is a BAP approach (Cole, Davis, Cole, & Gutnick, 2010; Cole, Cole, Gutnick, & Davis, 2014; Gutnick et al., 2014; Reims, Gutnick, Davis, & Cole, 2012), which can be employed regularly by both healthcare teams and individual healthcare providers to enable PCC goal setting and action planning, in collaboration with the patients. Both MI and BAP offer structured procedures that encourage patients to actively engage in healthcare decisions (Knight, McGowan, Dickens, & Bundy, 2006). However, the BAP is a more concise tool that assists patients in producing and tracking personal achievable goals and plans for behaviour change, and importantly, it may be an ideal self-management tool for busy practitioners (Bussieres et al., 2015). The BAP has been successfully applied in several self-management programmes to improve self-efficacy and adherence to exercise (Koka & Hagger, 2017).

Research reported that an individual's self-management goals, values, and preferences (that overlap with the principles of PCC) may improve a patient's self-efficacy, health-related outcomes, and treatment adherence (Stilwell & Harman, 2017). Strategies including empathy and active listening have been found to encourage the relationship between patients and healthcare providers and may be beneficial for active planning and shared decision-making (Barry and Edgman-Levitan, 2012). Previous studies (e.g., Bean, Biskobing, Francis, & Wickham, 2012) that involved patients in action planning, reported improvement in self-efficacy in SMIs of chronic conditions. The BAP is a collaborative, self-management technique to support goal setting and action planning (Cole et al., 2010; 2014; Gutnick et al., 2014; Reims et al., 2012). According to the authors of BAP, this self-management support method may be used to enable goal setting and action planning to improve self-efficacy in the management and prevention of chronic illnesses. This is further supported by Lorig and colleagues (2014), who established that the process of action planning per se can improve self-efficacy (Lorig, Laurent, Plant, Krishnan, & Ritter, 2014). Indeed, the BAP complements the self-management skills (Lorig & Holman, 2003) discussed in section 4.2.

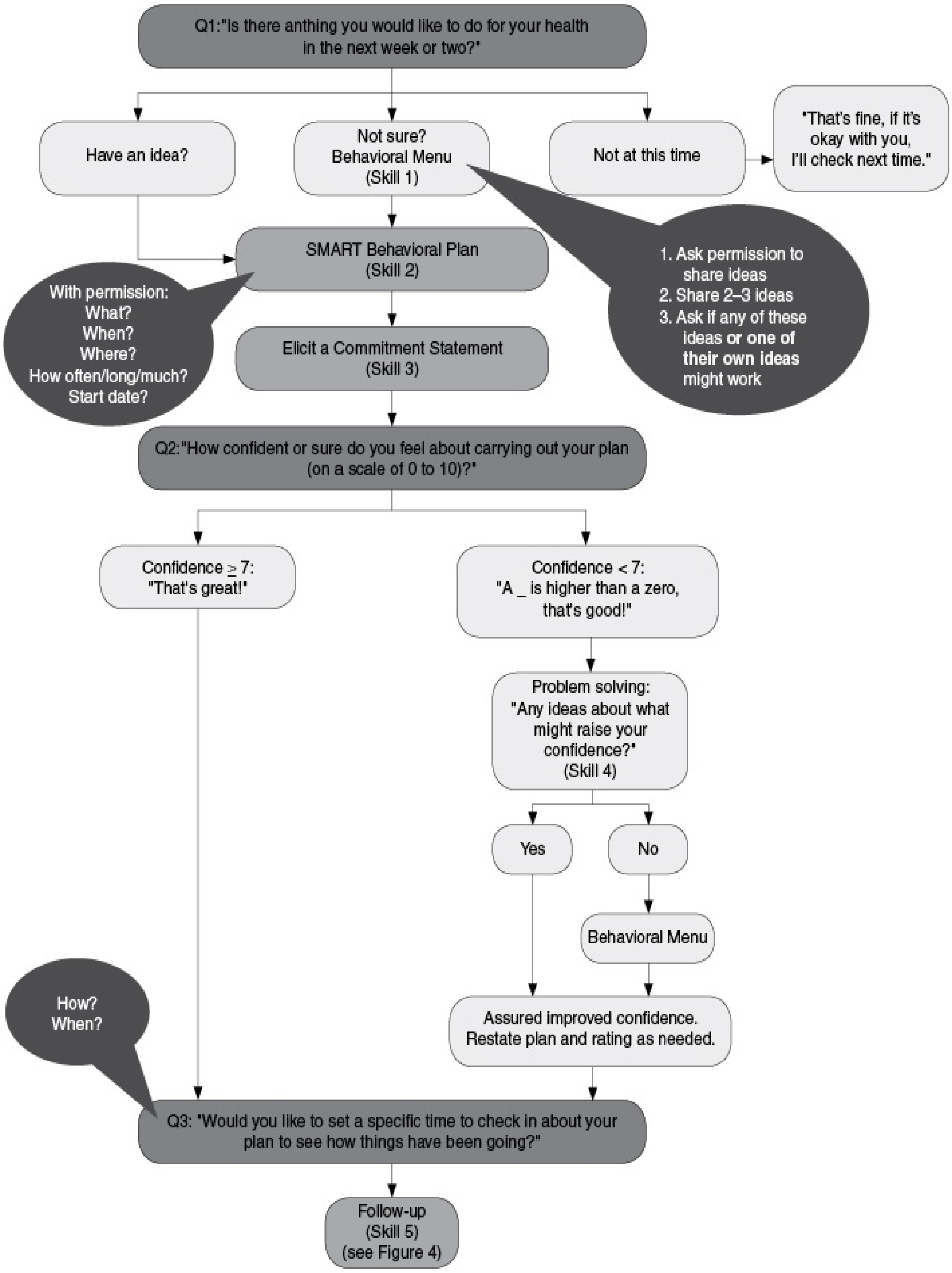
The BAP technique integrates the principle and practice of behaviour change (such as self-efficacy, and the concepts from self-management support, including action planning) (Bodenheimer et al., 2002; MacGregor et al., 2006), and the “spirit of MI” (Compassion, Acceptance, Partnership, and Evocation; Miller & Rollnick, 2013). The “MI spirit” is a fundamental element of BAP, and research suggests that the “spirit of MI” itself is related to positive patient behaviour change outcomes (Del Canale et al., 2012; Hojat et al., 2011; Miller & Rollnick, 2009). Similarly, action planning has been established to mediate the intention-behaviour association thus making it more likely that a person’s intentions will result in behaviour change (Gollwitzer & Sheeran, 2006). We have seen that this is consistent with the HAPA model discussed in the previous Chapter. BAP aims to help patients to set small, realistic goals, and plan action, while the practitioners’ role is to enable and simplify this process. Individuals setting achievable goals, contrasted with ambiguous and hard-to-accomplish goals, are more likely to realise these goals (Locke & Latham, 2002). In order for the process of goal setting and action planning to be effective, the healthcare providers have to establish rapport with patients prior to action planning, and the patient must be an active participant during the whole process.

The BAP, composed of three questions and five skills, involves establishing an agenda, setting SMART (Specific, Measurable, Achievable, Realistic, and Timely) goals, fostering confidence if required, as well as following up on the employed plans and repetitively establishing the plan development to encourage self-efficacy and self-management (Howcroft, Walters, Wood-Baker, & Walters, 2016). If the individual indicates that they need more support or their confidence is low, healthcare providers can then employ a patient-approved behavioural menu that allows them to share ideas with healthcare recipients (Gutnick et al., 2014; Miller, Rollnick, & Butler, 2008). The behavioural menu strategy involves suggesting two or three ideas (e.g., using visual prompts) to assist the person in determining their personal goals, which as a result may enable the patient’s process of own decision-making. These strategies of BAP allow for taking into account and respecting recipients’ individual preferences while considering environmental requirements, endorsing access to care, and offering emotional support by evaluating patients’ confidence in their ability to follow through with the newly established plans (Bean et al., 2012), and this follow-up process also builds trust (Artinian et al., 2010). Previous studies reported that individuals are more likely to follow these plans if they regularly check-in, especially when it is done earlier in the process (Cialdini, 2008).

Finally, as established earlier, improving self-efficacy to self-manage is vital in chronic illness self-management programmes, MI, and behaviour change interventions (Lorig, Homan, Sobel, & Laurent, 2012). According to Lorig and colleagues (2014), low confidence predicts non-completion of the action plan, and effectively applying the action plan improves confidence and self-efficacy for engaging in the behaviour (Lorig et al., 2014). Researchers suggest that the process of building self-efficacy (which may involve further health action planning), is more significant than the successful completion of the action plan (Bodenheimer & Handley, 2009). Figure 5.6 below, schematically represents the flowchart of BAP implementation in clinical practice.

Figure 5.6

Brief Action Planning Flowchart



Retrieved from Gutnick et al (2014).

5.7 Summary of the Rationale for the Current Research

The rationale for the current study has been provided in the introductory Chapter of this thesis. Throughout this thesis, additional justifications for conducting current research have been recognised. It has become more apparent that there is an emerging need for an appropriate SMI for YAs with CKD in the UK. The increasing prevalence of CKD demands that healthcare professionals support and empower patients with the skills, knowledge, and confidence to manage their condition. Current evidence indicates that CKD management is particularly challenging for YAs, who face additional psychological and physical changes, underscoring the need for tailored interventions. There is a noticeable gap in research regarding effective strategies for this age group, with evidence from the current systematic review suggesting that theory-based interventions that enhance self-efficacy through goal setting, barrier identification, problem-solving, and social support can improve outcomes. PCC is crucial but underused, necessitating further research to implement it effectively. Assessing and improving patient activation and self-efficacy, essential for successful self-management, is also lacking in current studies. This study aims to develop a theory- and PCC-based SMI, incorporating relevant theoretical concepts to enhance self-efficacy, patient activation, and other modifiable risk factors for YAs with CKD. The steps applied to achieve this are briefly described in the section below which summarises a theoretical framework for the present research.

5.8 Theoretical Framework of the Current Study

Despite mixed evidence on the effectiveness of theory-based interventions, employing a robust empirical and theoretical framework remains essential for developing health behaviour interventions. This study focuses on self-efficacy and patient activation, core components for successful self-management, providing both, practical and theoretical reasons to examine these in YAs with CKD and focus the treatment on enhancing their knowledge, skills, and confidence in SMIs. Additionally, given that interventions that implement both motivational and volitional factors are more effective in changing health-related behaviours as opposed to those that adopt motivational or volitional factors alone (Hagger et al., 2012), the current study considered the importance of the Health Action Process Approach (HAPA)’s motivational and volitional factors. Particularly, this study has adopted Schwarzer and colleagues’ (2011) recommendations to integrate both continuum and stage models. Much of the literature related to self-management has been constructed on SCT, particularly self-efficacy, and the stages of change model (more frequently operationalised as patient activation). The present research will employ the continuum model as a theoretical template (namely, self-efficacy), and it will consider different stages of change by offering the possibility of splitting the participants into stage groups to allow for stage-matched intervention (stage model), tailored to their mindset (Schwarzer et al., 2011). Thus, in the current study, the self-efficacy theory has been adopted as a theoretical foundation for explaining and predicting behaviour, whereas the concept of readiness to change (Transtheoretical model; TTM/ patient activation) was considered as theoretical support for guiding intervention.

Furthermore, having considered a variety of the theoretical frameworks discussed in the literature, the most recent relevant study employed the previously discussed self-efficacy model (refer to Figure 4.4 in Chapter) as a theoretical framework to design a theory-based, person-centred SMI for adults (between 25 and 84 years old) who suffer from CKD stages 1-4 (Havas et al., 2018). In their single-sample, pre-post study of a personalised, 12-week intervention based on principles of SCT, the authors included self-efficacy and self-management as their primary outcomes. The secondary outcomes encompassed CKD knowledge, health-related quality of life (HRQoL), emotional distress, physical activity, diet, alcohol consumption, communication with HCPs, comorbidity, as well as descriptive statistics and clinical information. Their previous studies exploring self-management support (SMS) desires of individuals with CKD (Bonner et al., 2014; Havas et al., 2016; Havas et al., 2017a) informed their intervention design and development. Their former work also emphasised a lack of individualisation in the interventions as a vast gap, which they aimed to address in their proposed CKD-SMS. The researchers reported from their study improved behavioural and patient outcomes among the CKD population. Their CKD-SMS led to significant improvement in self-efficacy and knowledge (through several sources, including education, vicarious experience, self-appraisal, performance accomplishment, and verbal persuasion), which in consequence led to improvement in behaviour and outcomes (Havas et al., 2018).

Additionally, their study contributed to knowledge concerning CKD self-management by highlighting that a person-centred, theory-based approach to CKD self-management can improve behavioural and patient outcomes. Given that individuals with CKD have varied needs and related compound comorbidities, the researchers concluded from their study that it is significant to consider individual needs, circumstances, goals, as well as the current level of activation, however, patient activation was not examined in their study (Havas et al., 2018). In their previous study, they recommended the inclusion of PAM at the beginning of the intervention to tailor support in future studies (Havas, Douglas, & Bonner, 2017b). In their qualitative study, the authors examined the participants' perceptions and experiences of the proposed CKD-SMS programme and reported that participants felt that CKD-SMS helped them to understand their CKD (improved knowledge) and build confidence to self-manage their disease. Participants also stated that CKD-SMS helped them to develop several practical skills necessary to engage in CKD self-management behaviours (Havas et al., 2017b).

Therefore, the current study builds on Havas and colleagues' (2018) study by assessing similar outcomes (refer to Chapter 2 for the overview of included outcomes), however, with the addition of the important measure of patient activation and PCC principles, emphasising collaboration between healthcare providers and YA patients. The innovative SMI will consider HCPs as experts in CKD treatment, and YAs as experts on their lives, bodies, and experiences (Sanderson & Angouri, 2014). By applying the HAPA, particularly in the planning phase, the study aims to bridge the intention-behaviour gap, ensuring sustained behaviour change.

Additionally, strategies such as those from the BAP and factors influencing self-management, such as those recognised in Chapter 1 (e.g., age, gender, level of education, CKD stages and time since diagnosis, and emotional state), will inform the intervention development, guided by the French et al.’ (2012) four-steps systematic approach. Employing the COM-B and TDF matrix aims to better understand barriers and enablers that influence CKD self-management behaviours in YAs and to inform the development of a complex intervention to lessen the burden of their disease. This will allow for a theory-based assessment of behaviour change, and the identification of various potential targets for the novel SMI to address the current study research question on the most optimal intervention for YAs with CKD. All included strategies and the process employed to develop the novel intervention are detailed in Chapter 8.

5.9 Chapter Summary

The literature identified self-management as a term for behaviours intended to promote health, and it is often incorporated into the SCT, the HAPA, and patient activation, all of which overlap to some extent. Further, self-management as a set of behaviours is frequently combined with self-efficacy and patient activation, and both have been established as variables that predict and/or mediate self-management behaviours. The theoretical framework presented for this study captured the theoretical relationships between these concepts and concludes that to effectively improve self-efficacy and patient activation in YAs with CKD to better self-manage their condition, the novel intervention will employ the HAPA model to explain and predict behaviour in this population and to guide the intervention. Moreover, the novel study focuses on the YA population (18-35 years old) with all stages of CKD. Although recent studies have looked at this framework in relation to CKD SMI, they have not specifically considered this with the YA population. To our knowledge, this is the first study developing SMI based on theory and tailored to YAs with CKD stages 1-5. The idea of this novel intervention is to increase YAs' confidence to self-manage their CKD, which should lead to improved participation in self-management behaviours, and hence lead to enhanced clinical outcomes.

This Chapter aimed to explore the relevant concepts used to elicit health behaviour change and review the relevant approaches for developing behaviour change interventions. This and the previous Chapter discovered theories, models, frameworks, and approaches relevant to the current study. We have seen that the concepts discussed in the previous Chapters complement each other. Although the use of theory in the design and development of health behaviour change intervention is recommended, theory alone is often not enough to inform all aspects of the intervention. By combining all relevant theoretical concepts, we presented the theoretical framework that was used to inform the design and development of the novel SMI for YAs with CKD. The next Chapters present results from statistical analysis (Chapter 6) and findings from thematic analysis (Chapter 7). Then Chapter 8 proposes the novel intervention and Chapter 9 discusses and concludes the overall research.

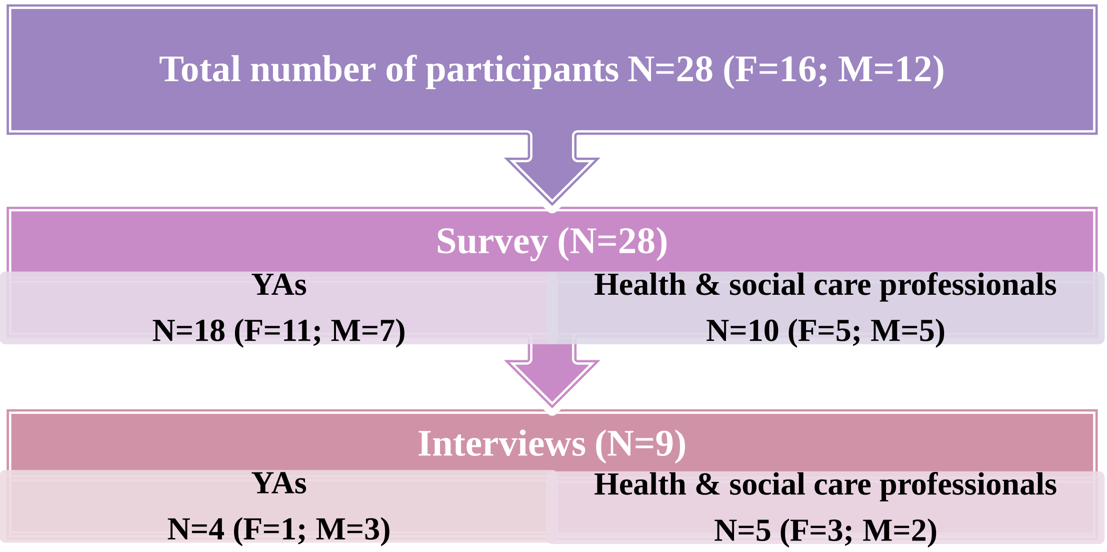
Chapter 6: Phase 2 - Quantitative Results

6.1 Overall Sample for Phase 2

A total of 28 participants met the inclusion criteria for the questionnaire-based study, including 18 young adults (YAs) and 10 health and social care professionals (no participants were excluded). Out of all 28 participants, nine further participated in the second part of phase 2, semi-structured interviews. Thus, the actual size of the sample recruited for the individual interviews was nine, including four YAs, and five professionals (see Figure 6.1).

Figure 6.1

Sample Size: Survey and Interviews



F Female; *M* Male; *N* Number; *YA* Young Adult.

6.2 Part 1 - Quantitative Results

The results from the quantitative study are reported in line with the STROBE checklist (refer to Appendix A).

Descriptive statistics:

Descriptive statistics for the YA sample (N=18) can be seen in Table 6.1 below. YA participants were located in Wales (N=11, 61.1%) and England (N=7, 38.9%), and no participants responded to take part in the study from Scotland or Northern Ireland. The sample involved seven males (38.9%) and 11 females (61.1%), aged 20 to 35 years old (29.72±5.22 years). All participants had formal education, most holding a Bachelor's degree (N=10, 55.6%), followed by diplomas (N= 5, 27.8%), one doctorate, and two with "access to HE" and "Youth Work Practices level 2" qualifications. Most were employed (N=11, 61.1%), and the estimated monthly household income (with 1-6 people per household) ranged between £500 and £80,000 (£12,560.63±£21,674.65).

Table 6.1

Descriptive Statistics of Sample

	Value
Total N	18
Place of residence	
Wales [a]	11 (61.11)
England [a]	7 (38.89)
Age (years) [b]	29.72(5.22)
Gender	
Male [a]	7 (38.89)
Female [a]	11 (61.11)
Highest level of education	
Diploma [a]	5 (27.78)
Bachelor's degree [a]	10 (55.56)
Doctorate [a]	1 (5.56)
Other [a]	2 (11.11)
Employment status	
Unemployed [a]	7 (38.89)
Employed/self-employed [a]	11 (61.11)
Estimated household income (per month) [b]	£12,560.63(£21,674.65)
<£10, 000 [a]	12 (66.67)
£10, 000 - £19, 999 [a]	0
£20, 000 - £29, 999 [a]	1 (5.56)
£30, 000 - £49, 999 [a]	2 (11.11)
>£50, 000 [a]	1 (5.56)
Did not respond [a]	2 (11.11)
Number of people living in the household [b]	2.78(1.43)

[a] Results presented as N(%). [b] Results presented as M(SD).

Clinical characteristics:

According to the validated scale’s descriptions (refer to Chapter 2, section 2.4.5), the participants’ clinical characteristics presented in Table 6.2 below revealed that YAs’ time since diagnosis ranged between the last two years and 35 years (diagnosed at birth) (*Mdn*=12.50 years), with most participants in chronic kidney disease (CKD) stages 3b (N=5, 27.8%) and 3a (N=4, 22.2%). Additionally, 66.7% (N=12) reported comorbidities.

The descriptive statistics of the sample revealed important information regarding YA’s health-related behaviours. Particularly, the majority of YAs were non-smokers (N=5, 83.33%), while three (16.67%) smoked up to 10 cigarettes a day or only in social situations. Most YAs were at low risk of drinking or alcohol use disorders (N=13, 72.22%), though four (22.22%) had moderate risk, and one (5.56%) was at severe risk, potentially indicating that drinking is affecting their health and safety. Eating behaviour self-regulation varied, with four YA's (22.22%) scoring low, eight (44.44%) medium, and six (33.33%) high. Physical activity levels were low in four participants (22.22%), moderate in eight (44.44%) indicating doing some activity, and high in six (33.33%).

Furthermore, the assessment of psychological distress indicated that YAs' level of depression ranged between 3 and 19 (*Mdn*=8.00), while almost half of the responders (N=8, 44.44%) showed no symptoms. However, five YAs (27.77%) indicated borderline abnormal cases showing the occurrence of depressive symptoms, however to a moderate degree, whereas the other five (27.77%) showed a significant number of depression symptoms indicating abnormal cases. Moreover, YAs' level of anxiety ranged between 0 and 18 (*Mdn*=12.00), indicating worrying findings with the majority of YAs (N= 10, 55.55%) showing a significant number of the presence of anxiety symptomology, and four (22.22%) indicated borderline abnormal cases showing some symptoms of anxiety but to a moderate degree. Only the remaining four participants (22.22%) reported the absence of anxiety symptoms. These findings further support the discussion in the introduction chapter on the need for psychological interventions.

In addition, the measure of general health and well-being or health-related quality of life (HRQoL) revealed that YAs' physical component score (PCS) ranged between 26.87 and 57.73 (*Mdn*=40.07) and their mental component score (MCS) ranged between 19.35 and 55.77 (*Mdn*=32.39) with higher scores representing better health. Self-management knowledge was generally high, with 66.67% (N=12) responding correctly to all CKD self-management knowledge items. Moreover, the descriptive statistics from standardised measures (particularly those employed in statistical analyses) exposed that YAs' self-care behaviours score ranged between 3.58 and 7.75 (*Mdn*=6.50) with a higher score indicating better self-management behaviour and knowledge, and self-efficacy ranged from 1.83 to 8.83 (*Mdn*=6.00) with a higher score signifying higher self-efficacy.

Finally, half of the YA participants (50%) were at a higher level of activation (level 3), followed by low activation (levels 1 and 2; 38.89%), and two YAs were at the highest level of activation (level 4; 11.11%). These findings suggest that those at the highest level of activation may have adopted several behaviour changes required to support their health, but may need support to ensure that they will maintain their behaviours when faced with life stressors. Those who were at a higher level of activation appear to start acting but may still lack the confidence and skills to support their behaviour. Whereas those YAs who indicated low activation levels (1 and 2) might be passive, not believing that their role is important, and may feel overwhelmed with the management of CKD, lacking the necessary knowledge and confidence to self-manage their condition (Hibbard et al., 2004).

Note that, given the small sample size, interpretations of the psychological characteristics should be approached with caution. The limited number of participants, may not fully represent the broader YA population with CKD, and the variability in individual responses suggests that further research with larger samples is necessary to confirm these findings and better understand the psychological dimensions of self-management in this demographic.

Table 6.2

Clinical Characteristics of Sample

	Value
Total N	18
Time since diagnoses (years) [b]	*12.50[8.00-23.25]*
≤ 2 years [a]	1 (5.56)
2 years 1 month - 10 years [a]	7 (38.89)
10 years 1 month - 20 years [a]	6 (33.33)
≥ 20 years [a]	4 (22.22)
Stage of CKD	
1 [a]	1 (5.6)
2 [a]	2 (11.1)
3a [a]	4 (22.2)
3b [a]	5 (27.8)
4 [a]	3 (16.7)
5 [a]	3 (16.7)
Comorbidity reported	
Yes [a]	12 (66.7)

	Value
No[a]	6 (33.3)
PIH[b]	*6.50[5.81-6.98]*
SEMCD[b]	*6.00[3.29-7.67]*
Health-related behaviours	
Smoking status	
Non-smokers[a]	15 (83.33)
Smokers[a]	3 (16.67)
Alcohol consumption- AUDIT-C[b]	*1.50[0.75-4.00]*
Low risk[a]	13 (72.22)
Moderate risk[a]	4 (22.22)
High risk[a]	0
Severe risk[a]	1 (5.56)
SREBQ[b]	*3.30[2.70-3.85]*
Low[a]	4 (22.22)
Medium[a]	8 (44.44)
High[a]	6 (33.33)
IPAQ[b]	1401.00[717.75-3744.00]
Low[a]	4 (22.22)
Moderate[a]	8 (44.44)
High[a]	6 (33.33)
HADS Depression[b]	*8.00[3.75-11.25]*
HADS Anxiety[b]	*12.00[7.75-15.00]*
SF-12-PCS (physical)[b]	*40.07[31.92-52.28]*
SF-12-MCS (mental)[b]	*32.39[24.86-48.98]*
CKD-SMKT Section A[b]	*100.00[85.71-100.00]*
CKD-SMKT Section B (n=2)[b]	*16.67[0.00-33.33]*
CKD-SMKT Section C (overall knowledge)[b]	*2.00[2.00-3.00]*
PAM[b]	*59.35[50.00-65.50]*
Low activation (levels 1 and 2)[a]	7 (38.89)
Higher activation (level 3)[a]	9 (50)
Highest activation (level 4)[a]	2 (11.11)

[a] Results presented as N(%); [b] Results presented as *Mdn[IQR]; AUDIT-C* Alcohol Use Disorders Test Consumption; *CKD-SMKT* Chronic Kidney Disease Self-Management Knowledge Tool; *HADS* Hospital Anxiety and Depression Scale; *IPAQ* International Physical Activity Questionnaire; *IQR* Interquartile Range; *Mdn* Median; *N* Number; *PAM* Patient Activation Measure; *PIH* Partners in Health; *SEMCD* Self-Efficacy for Managing Chronic Disease; *SF* Short Form*; SREBQ* Self-Regulation of Eating Behaviour Questionnaire; *YA* Young Adult.

Results from some textual qualitative data concerning YAs’ preferences for support delivery are presented in Table 6.3 below. These findings show some variability in preferences for delivery and delivery times, suggesting that it is important to engage in individual discussions with patients to tailor these aspects according to their unique preferences and needs.

Table 6.3

Preferences for Support Delivery

Question	Response (N)	Frequency (%)
How would you like to receive self-management support?		
Multiple options	*8*	*44.44*
Face-to-face	12	41.38
Telephone	6	20.69
Email	5	17.24
Video call (e.g., Zoom or Teams)	4	13.79
Leaflets	1	3.45
Online learning	1	3.45
When in the week could you attend sessions?		
Flexible (multiple options)	*5*	*27.78*
Weekends	3	16.67
No preference	5	27.78
Specific day in the week:		
Monday	3	12.5
Tuesday	2	8.33
Friday	1	4.17
During dialysis	1	4.17
Evenings	5	20.83
Mornings	3	12.5
Afternoons	1	4.17
Where could you attend the session?		
Hospital Clinic	8	44.44
Home or online*	5	27.78
“Locally”	5	27.78
Would you prefer group/face-to-face/phone call sessions?		
Face-to-face	6	33.33
Phone call	4	22.22
Online	1	5.56
Group	1	5.56
“Any”	6	33.33
Would you like to bring a friend/family member?		
Yes	6	33.33
No	10	55.56
Not sure	2	11.11
Who would you like to receive support from?		
Multiple options	*6*	*33.33*

Question	Response (N)	Frequency (%)
Doctor (Nephrologist)/Renal team	9	37.5
Nurse	5	20.83
Self-management expert	3	12.5
External expert	2	8.33
Counsellor	2	8.33
Social Worker	1	4.17
Menhal health support	1	4.17
Unsure	1	4.17

*Two of these participants highlighted this option as “depending on COVID.”

Results for main analyses:

In this section, results for each main analysis are reported, including the results from post-hoc tests. Refer to Appendices DD-GG for SPSS data output for all four analyses. Following this, the responses from both groups of participants regarding person-centred care (PCC) plans as well as the level of interest in receiving CKD SMS are discussed, and then a summary of the quantitative study is provided in section 6.3.

Analysis 1:

Research question: Will the YAs’ levels of self-efficacy and patient activation be significant predictors of their level of self-management behaviours, while controlling for time since diagnosis?

The overall model was significant, F(3, 14)= 6.03, *p*= .007, explaining 47% (adjusted R^2= .47) of the variance in the outcome variable. The self-efficacy variable (B= .22, t(15)= 2.2, *p*= .045) contributed significantly to the model, however, the patient activation variable (B= .03, t(15)= 1.56, *p*= .142) showed a positive non-significant correlation. Additionally, time since diagnosis as the covariate variable showed a negative non-significant correlation (B= .00, t(15)= -.11, *p*= .916) (refer to summary Table 6.4 below for analysis 1, and Appendix DD). These results indicate that higher levels of self-efficacy were associated with greater self-management behaviours among YAs with CKD. This association remained significant when accounting for time since diagnosis.

Table 6.4

Summary Table - Analysis 1

			95% CI				
Variable	B	SE	LL	LU	Beta	t	p
(Constant)	3.2	1.05	.95	5.44		3.06	.009
Time since diagnosis	.00	.02	-.04	.03	-.02	-.11	.916
Self-efficacy	.22	.1	.01	.43	.49	2.2	.045
Patient activation	.03	.02	-.01	.08	.35	1.56	.142

Dependent variable: Self-management behaviours

Note: R^2adj=.47 (N=18, *p*=.007). CI=Confidence Interval for B; LL=Lower Bound; LU=Upper Bound; SE=Standard Error.

Post-hoc analysis: Achieved power= .84, with effect size= .89 (based on adjusted R^2=.47), alpha= .05, total sample size= 18, and 3 predictors.

Analysis 2:

Research question: Will YA's time since diagnosis significantly impact their mean responses across all 10 CKD SMS areas, while controlling for self-efficacy?

The results of the second analysis exposed non-significant results, (F(2, 15)= 1.14, *p*= .346) (refer to Table 6.5 below and Appendix EE). These non-significant results suggest that YAs' time since diagnosis and the confounding effect of level of self-efficacy were not predictors of YAs' level of interest in receiving CKD SMS across all 10 areas.

Table 6.5

Summary Table - Analysis 2

			95% CI				
Variable	B	SE	LL	LU	Beta	t	p
(Constant)	8.88	1.72	5.22	12.54		5.18	<.001
Time since diagnosis	.02	.05	-.09	.14	.11	.44	.665
Self-efficacy	-.36	.25	-.9	.17	-.35	-1.46	.164

Dependent variable: SMS CKD areas

Note: R^2adj=.01 (N=18, *p*=.346). CI=Confidence Interval for B; LL=Lower Bound; LU=Upper Bound; SE=Standard Error.

Post-hoc analysis: Achieved power= .07, with effect size= .02 (based on adjusted R^2=.02), alpha= .05, total sample size= 18, and 2 predictors.

Analysis 3:

Research question: Will there be a significant difference between the level of interest in receiving CKD SMS across all 10 areas based on the stage of CKD (early-CKD stages: 1-3a/b - Group 1, versus late-CKD stages: 4-5 - Group 2)?

Analysis 3 revealed no significant differences (t(16)= .89, *p*= .387, d= .45) in mean scores for group 1 (early-CKD stage) (M= 7.57, SD= 2.25) and group 2 (late-CKD stage) (M= 6.55, SD= 2.41). The magnitude of the differences in the means (mean difference= 1.02, 95% *CI*: -1.41 to 3.46) was very small (see Table 6.6 below and Appendix FF), suggesting that both groups have similar perceptions and evaluations in the context of CKD SMS.

Table 6.6

Summary Table - Analysis 3

t-test for Equality of Means			
Mean Difference	SE Difference	95% *CI* of the Difference	
		LL	LU
1.02	1.15	-1.41	3.46

Note: t(16)= .89, *p*= .387, d=.45. CI=Confidence Interval; LL=Lower Bound; LU=Upper Bound; SE=Standard Error.

Post-hoc analysis: Achieved power= .13, based on two-tailed, effect size= .44 [based on Mean=7.57 and SD=2.25 for group 1 (G1; early-CKD-stage) and Mean=6.55 and SD=2.41 for group 2 (G2; late-CKD-stage)], alpha= .05, and total sample size= 18 (G1=12; G2=6).

Analysis 4:

Research question: Will there be a significant difference in mean responses across all 10 CKD SMS areas between YAs (Group 1) and their health and social care professionals (or staff; Group 2)?

The final statistical analysis 4 showed no significant differences (t(26)= -1.65, *p*= .110, d=-.65) in mean scores for group 1 (YAs) (M= 7.23, SD= 2.28) and group 2 (professionals) (M= 8.53, SD= 1.28). The magnitude of the differences in the means (mean difference= -1.30, 95% *CI*: -2.92 to .32) was very small. Refer to the summary Table 6.7 below for analysis 4 and Appendix GG for SPSS output. These findings suggest that these two groups also have similar perceptions and evaluations of CKD SMS.

Table 6.7

Summary Table - Analysis 4

t-test for Equality of Means			
Mean Difference	SE Difference	95% *CI* of the Difference	
		LL	LU
-1.3	.79	-2.92	.32

Note: t(26)= -1.65, *p*= .110, d=-.65. CI=Confidence Interval; LL=Lower Bound; LU=Upper Bound; SE=Standard Error.

Post-hoc analysis: Achieved power= .40, based on two-tailed, effect size= .70 [based on Mean=7.23 and SD=2.28 for group 1 (G1; YAs), and Mean=8.53 and SD=1.28 for group 2 (G2; staff)], alpha= .05, and total sample size= 28 (G1=18; G2=10).

Overall, given the threshold of .8 (Cohen, 1988), only analysis 1 indicated sufficient power to support its results, thus one should be mindful when considering results from analyses 2, 3, and 4.

Questions related to the PCC plan (YAs and HCPs):

When asked whether they have a CKD care plan, eight YA participants (44.44%) responded “yes”, and the majority (N=10; 55.56%) answered “no”. However, of the eight who had a care plan in place, only three YAs (37.5%) actually saw their care plan and worked together with healthcare professionals (HCPs) on their development. These three participants also claimed that their care plan was personalised to their needs and wants, and included agreed goals and actions. However, only two out of these three YAs reported that their care plan was used and updated during the transition from paediatric to adult services.

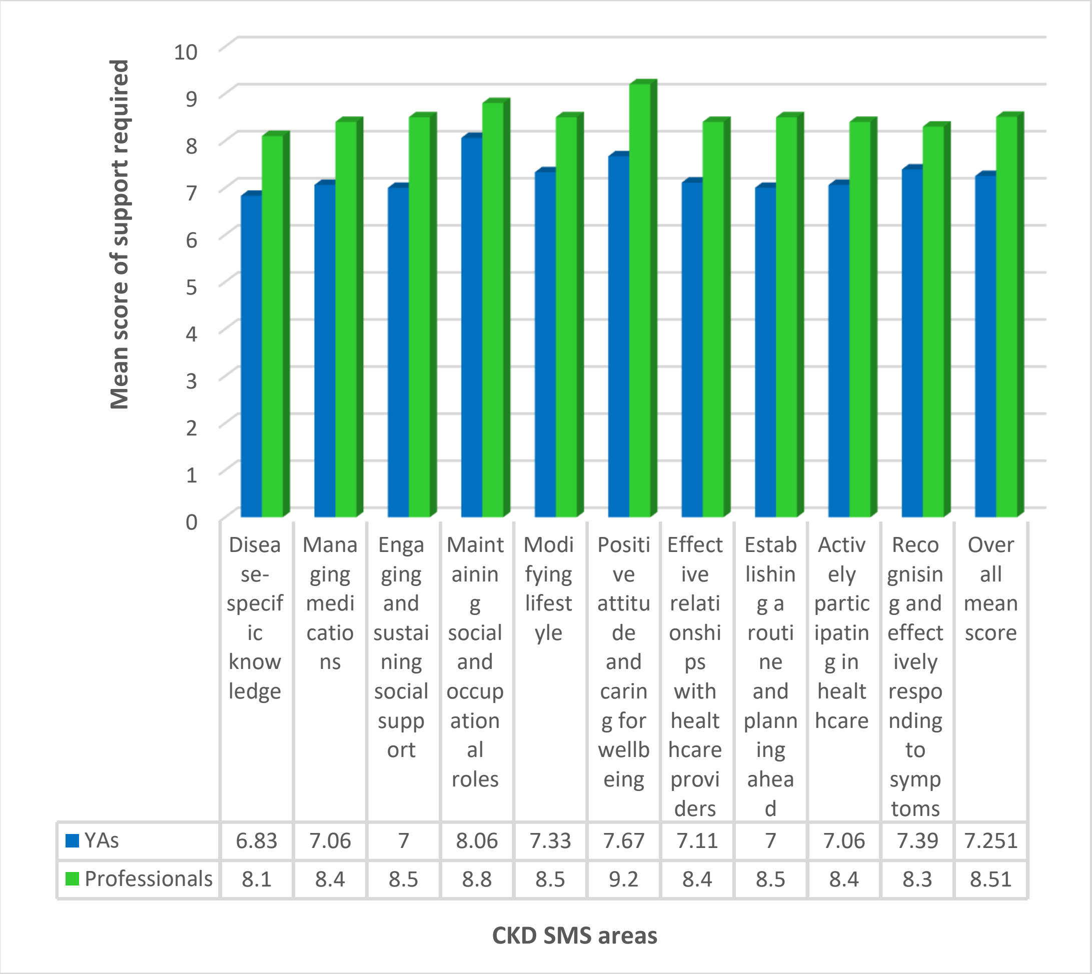
Furthermore, in group 2, 10 health and social care professionals (5 males and 5 females) were also asked similar questions regarding PCC plans and their use with YAs. Out of 10, only three (30%) claimed that there are care plans in place but they are not used regularly. Out of these three, only one participant (33.33%) claimed that they are updated regularly “following contact or communication”, however when asked if they are developed and updated together with the patient, they replied “no”, while the other two participants (66.67%) claimed that they are. Further, all three professionals agreed that the care plans are personalised to YAs’ needs and desires, they include their agreed goals and actions and are updated during the transition process. However, when asked if the care plans are available to patients and their guardians and shared across the multidisciplinary team (MDT), only 2/3 said “yes”.

Questions related to the CKD SMS areas (YAs and HCPs):

Overall, participants in both groups reported interest in more support with all 10 areas of CKD SMS. Particularly, the “maintaining social and occupational roles” domain had the highest mean response as reported by YAs. Havas and colleagues (2016) defined this domain as “continuing to work, sustaining hobbies, maintaining relationships and home roles”. Whereas, for professionals, the “developing and sustaining a positive attitude and caring for mental and physical well-being” area of CKD SMS was reported as the highest mean response, described as “avoiding anxiety and depression, staying positive, staying generally physically healthy” (Havas et al., 2016). The additional suggestions regarding what they want more support with were provided by only one YA (5.56%) who stated that it would be beneficial to receive support on “future problems” (for example, considering “a high risk of heart disease and certain cancers”) and how to prevent them. Finally, additional suggestions regarding what YAs need more support with were provided by half of the professionals. These included: “knowing how and who to contact about any issues or changes” (N=4; 40%), “being routinely involved in strategic service planning and co-production in developing improved service provision” (N=2; 20%), and four professionals (N=4; 40%) highlighted the importance of mental wellbeing, and suggested support (in form of, e.g., education) on how to deal with distress, self-harm, as well as considering YA population and the impact of their disease on their “sense of self, identity, and mood”. Figure 6.2 below represents a bar chart with mean responses to each area of CKD SMS across YAs and their professionals, including the overall average for both groups.

Figure 6.2

Mean Responses to Each Area Across Both Groups



CKD Chronic Kidney Disease; *SMS* Self-Management Support; *YAs* Young Adults.

6.3 Quantitative Study - Discussion

The findings of the current quantitative study align with previous research, such as the studies by Havas et al. (2016; 2017a), which established that individuals with CKD perceive self-management as complex, and both YAs and their professionals in the current study acknowledged all 10 areas of CKD SMS as important. The presence of comorbidities among most YA participants in the current study further adds to the complexity of disease management. The results of this study also support previous studies (e.g., Chuang et al., 2020) reporting self-efficacy as a predictor of CKD self-management behaviours, suggesting the need to enhance YAs' levels of self-efficacy to improve their self-management of CKD.

Nonetheless, the current results regarding patient activation as a predictor of self-management behaviours in YAs with CKD and the impact of time since diagnosis (as the covariate), did not support former studies suggesting an association between patient activation and self-care practices (e.g., Zimbudzi et al., 2017). Although, to our knowledge, the direct assessment of patient activation as a predictor of self-management was not conducted in previous studies involving CKD individuals, a recent cross-sectional study by Meraz, Caldwell, and McGee (2023) examining patients with heart failure reported similar results, indicating that patient activation was not a reliable predictor of self-care behaviours. We have learnt from previous research that low activation level is associated with older age. The current study employed younger individuals, resulting in higher activation levels: 3 and 4 (50% and 11.11% respectively) in YAs, which may explain why patient activation did not significantly predict their self-management behaviours.

Furthermore, the current results showing that time since diagnosis has no impact on the level of interest in receiving 10 CKD SMS areas (while controlling for self-efficacy) are inconsistent with previous studies (e.g., Harwood et al., 2005; Havas et al. 2017a) which reported that those CKD individuals who live with the disease longer show a greater desire for support compared to those who live with CKD for a shorter period. Additionally, in the current study, there was no evidence to support differences between the mean ratings of CKD SMS of different groups (early-stage vs. late-stage CKD, as well as, groups 1 and 2). Although no previous studies directly investigated the difference between these groups in 10 aspects of CKD SMS needing more support, Wu and colleagues (2022) study compared similar groups by their CKD stage (early and end-stage CKD) and reported significant differences between these two groups (e.g., in age or self-care knowledge). The authors also concluded that individuals with early-stage CKD reported lower self-care knowledge and depression levels than those with ESKD, suggesting different patient needs based on disease stage, and that self-efficacy is the most significant predictor of self-management for individuals with all CKD stages (Wu et al., 2020).

The latter is consistent with our statistically significant results from quantitative analysis 1.

These inconsistencies with the previous research may be attributed to factors such as age, gender, and socioeconomic status. Studies have shown (e.g., Williams et al., 2010) that younger individuals, females, with higher socioeconomic status are more likely to be actively involved in their healthcare. As the current study predominantly recruited a younger population with a majority of females, it is possible that they were already actively engaged in their healthcare. Though the current study showed non-significant results regarding associations with CKD SMS, considering that all participants expressed interest in all 10 areas of CKD SMS, these areas can still serve as a checklist to ensure that YAs are receiving the comprehensive support they desire and require.

In addition, there is a lack of previous studies examining the differences in responses to the 10 recognised areas of receiving SMS between individuals with CKD and their professionals, making it difficult to compare the current non-significant results with existing evidence. However, it is important to note that only quantitative analysis 1 achieved sufficient statistical power and the results from analyses 2, 3, and 4 did not, and as such, it may contribute to the discrepancies with previous findings. Insufficient statistical power may impact the reliability of research findings, and it may be challenging to compare results with previous studies and determine whether the discrepancies are due to true differences or simply the result of low power.

Additionally, the YAs' cross-sectional characteristics in the survey study revealed some concerning findings. Particularly, 5/18 YAs showed borderline abnormal cases of moderate depressive symptoms, and another five displayed a significant number of depression symptoms, indicating abnormal cases. The majority of participants also had symptoms of anxiety, and four displayed borderline abnormal cases of moderate anxiety symptoms. These findings are consistent with the discussion on factors influencing CKD SMI in Chapter 1, which acknowledged that psychological disorders, particularly anxiety and depression are common in CKD individuals, highlighting the importance of the emotional impact of the disease. More recent studies (e.g., Alshelleh et al., 2022; Cogley et al., 2023) established that

CKD is strongly associated with increased social and psychological issues, suggesting the need for interventions to improve psychosocial well-being in the CKD population. This is particularly observed in YAs with CKD, for instance in a cross-sectional study examining psychosocial health and lifestyle behaviours in YAs (16-30 years old) receiving kidney replacement therapy (KRT), the authors reported worse psychosocial health among YAs in the United Kingdom (UK) compared to general, same age population (Hamilton, Caskey, Casula, Ben-Shlomo, & Inward, 2019).

Psychological distress is closely associated with adopting and sustaining health behaviours in chronic diseases, including smoking, poor diet, alcohol consumption and/or insufficient physical activity (Choi, Sullivan, DiNitto, & Kunik, 2019; Hoang, Kristoffersen, & Li, 2019; Paine et al., 2019). This may explain the findings from the current survey study reporting that 4/18 responders showed signs of moderate drinking risk, and one displayed severe risk, suggesting that their health and safety may be affected by their drinking habits. Similarly, 4/18 YAs had trouble controlling their eating behaviour and were not very physically active, while 8/18 had moderate self-regulatory skills when it came to eating and were moderately active. Finally, although most participants were at higher levels (3 and 4) of patient activation, some indicated to be at levels 1 and 2. These findings indicate that YAs are at different stages of activation which further highlights the importance of the assessment of the patient activation, and the need for appropriate support according to their activation level. These various cross-sectional findings further indicate the importance of the holistic approach.

Strengths and limitations:

One of the strengths of the current study is the inclusion of the unique cohort of YAs with CKD and those who look after them to address the overall research question for phase 2 on what aspects of the existing CKD SMIs need improvement and what aspects YAs can benefit from. This inclusion provided preliminary insights and contributed to the understanding of CKD self-management in this particular group. It provided a more holistic understanding of the challenges and needs faced by YAs and shed light on the role of professionals in supporting this population.

However, it is important to acknowledge some limitations of this quantitative study, such as the small sample size.

Employing a larger sample size would allow for more robust statistical analyses while maintaining good statistical power to support the findings. For instance, in the current study, the inspection of the mediation between self-efficacy, patient activation, and self-management behaviours was considered, however, the insufficient sample size did not allow for this examination. Moreover, although the process of recalculating the sample size for the revised study design was necessary to ensure sufficient statistical power, the insufficient resulting sample size meant limiting the number of variables that could be included in the analyses. As a result, the assessment of certain sub-scales had to be omitted, which may have led to the exclusion of potentially important information within the data. By focusing on a reduced set of variables, capturing the full complexity of the relationships and interactions among different factors may have been missed.

Similarly, as per the post-hoc power examination, analyses 2, 3, and 4 had low statistical power. This indicates that the sample size or other factors related to the study design may have limited the ability to detect significant associations or variances between variables. Thus, the non-significant results obtained in these analyses should be interpreted with caution, and preferably examined again in a larger sample study. Equally, given the small sample size and variability in responses, interpretations of the psychological characteristics should be cautious, and further research with a larger sample is needed to confirm these findings and understand the psychological scopes of self-management in YAs with CKD. Finally, another limitation involves the use of a cross-sectional, single-time-point study design, which did not allow us to make assumptions about causation.

Implications for practice and future research:

It is recommended for future research to employ a greater sample size and optimise the study design to achieve sufficient statistical power. By doing so, researchers can increase the robustness of findings and provide more reliable insights into the relationships and differences between studied variables. A larger sample size would also increase the representativeness of the study population, improving the external validity and generalisability of the findings to the broader target population.

Additionally, future research would benefit from a different study design, for example, a longitudinal study to enable the assessment of the longitudinal association between variables assessed in the current study, and the inclusion of those demographic and clinical variables which were not explored in more detail in this study. For instance, given the concerning findings indicating the presence of depression and anxiety symptoms in YAs, it is crucial to investigate further the assessment and understanding of psychological distress in this population. Targeted interventions and support programmes for YAs with CKD should be developed collaboratively by MDTs to address their psychological well-being, provide comprehensive support, and facilitate early intervention for YAs’ mental health concerns. A different study design would also allow for a better understanding of the dynamics and causal relationship between variables of interest over time. In-depth analyses of measured variables, including demographic and clinical characteristics, may provide valuable information about potential moderating or mediating factors that influence the outcomes of interest, and increased understanding of the relationship between different factors in relation to the study topic.

The current findings highlight the importance of addressing the lack of PCC plans and the utilisation of person-centred approaches in the management of CKD among YAs. Future research should investigate this concern further to understand the barriers and facilitators to implementing individual care plans and explore strategies to improve their use in clinical practice. Additionally, the 10 areas of CKD SMS identified by Havas et al.’ (2016) can serve as a valuable checklist for HCPs to ensure that YAs are provided with all the support they require, and YAs’ preferences for support delivery identified in the current study could be employed to promote PCC in CKD self-management. Particular attention may be needed to support YAs in maintaining their social and occupational roles, as this aspect appeared to be significant for participants in the current study.

Finally, considering the variations in levels of activation observed in the present study, future practice should continue to assess the activation levels of YAs with CKD to tailor treatments and interventions accordingly. For individuals with higher activation levels, HCPs should focus on providing appropriate strategies to help them maintain their positive self-management behaviours. This may involve providing ongoing support and resources and empowering them to take an active role in their care.

6.4 Chapter Summary

In this Chapter, the results from the quantitative study (phase 2, part 1) were presented. The next Chapter presents the findings from part 2 of phase 2, the qualitative study.

Chapter 7: Phase 2 - Qualitative Findings

7.1 Part 2 - Qualitative Findings

The findings from the analytic process together with a discussion confirming and comparing examined evidence with relevant literature are presented below, reported in line with the COREQ checklist (refer to Appendix B).

Thematic synthesis:

Following the interviews with YAs (group 1) and their health and social care professionals (group 2, also referred to as staff members and/or ST in the below synthesis), five main themes and one sub-theme emerged from the data, and these serve to answer the research questions further (refer to the Figure 7.1 below for a revised thematic map). The aim was to add to knowledge about the existing self-management behaviours among young patients with CKD and highlight the challenges they face associated with the complex nature of their disease, based on their (and those who look after them) views, opinions, and experiences. In the following paragraphs, first, the participants' characteristics are described, and then each theme is presented as an illustration of thematic analysis (TA) from both groups of participants.

Participants' characteristics:

Overall, all four YAs recruited in this study (group 1; one female and three males) completed semi-structured interviews and their demographic information is provided in Table 7.1 below. Whereas, data from group 2, namely five health and social care professionals (three females and two males; no drop-outs), is presented in Table 7.2 below.

Table 7.1

Participants' Characteristics (Group 1)

Participant ID	Age	Gender	Stage of CKD	Time since diagnoses
1	24	Female	3	5 years
2	20	Male	5	11 years
3	35	Male	5	35 years
4	34	Male	3	13 years

CKD Chronic Kidney Disease.

Table 7.2

Participants' Characteristics (Group 2)

Participant ID	Age	Gender	Current role	Duration of the current role
5	58	Female	Specialist Renal Social Worker	11 months
6	46	Male	Renal Social Worker	9 years
7	52	Female	Dedicated Renal Social Worker	24 years
8	34	Female	Renal Social Worker	4 years
9	32	Male	Youth Worker	6 years

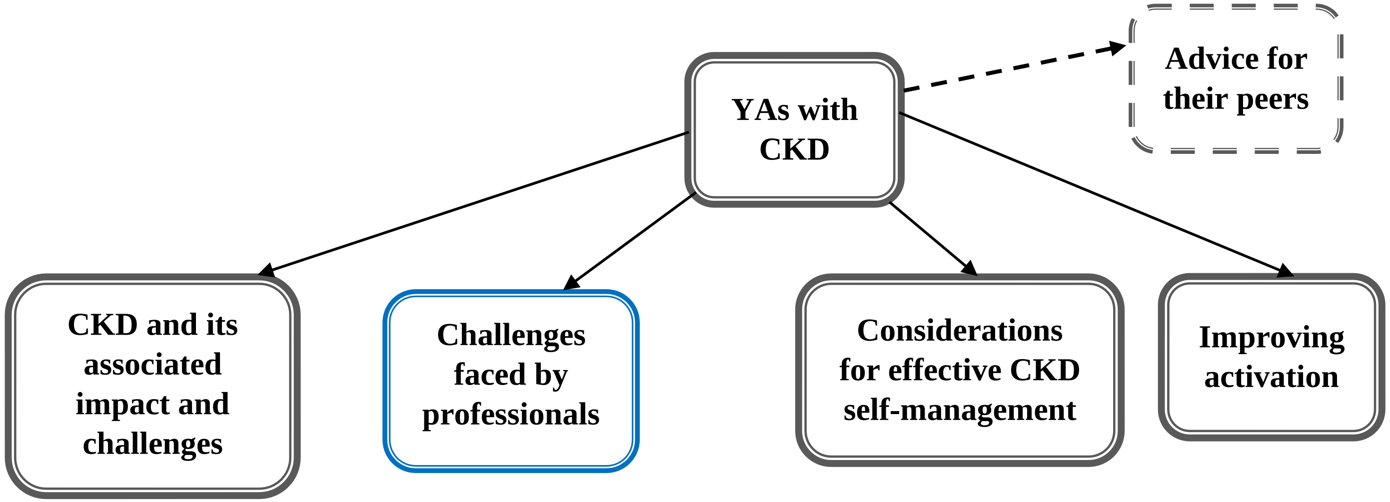
Data from Table 7.1 above revealed that half of the YA participants were in CKD stage 3, while the other half had stage 5, and they ranged between 20 and 35 years old at the time of the interviews. Thus, the ages of the YA participants in the current interview study covered a broad spectrum of young adulthood. While this age range encompasses the target demographic of 18 to 35 years old for developing a self-management intervention for YAs with CKD, the sample is relatively small and may not fully represent the diversity of experiences within this age group. The inclusion of participants aged 34 and 35, for example, may provide insights into the later stages of young adulthood, which might differ significantly from those in their early twenties. This variability could impact the generalisability of the findings and the relevance of the intervention across all YA age subgroups. The majority of YAs were diagnosed before 18 years of age, apart from one who was diagnosed at the age of 19. The average time of these four interviews was around 45 minutes.

Whereas, data from Table 7.2 showed that one youth worker and four renal social workers, aged between 32 and 58 years old, had extensive experience in their current role, ranging between 11 months and 24 years. Interviews with this group of participants lasted an average of 35 minutes. Participants’ feedback (from both groups) is described in the text and presented visually in Figure 7.1 below and Tables in relevant Appendices (see Appendix II and **Error! Reference source not found.** for examples of data extract). This interview study aimed to address the overall research question for phase 2 on what aspects of the existing CKD SMIs need improvement and what aspects YAs can benefit from, and explicit questions for this part of phase 2 (see Figure 7.1).

Figure 7.1

Revised Thematic Map

Research questions: *Among YAs living with CKD (stages 1-5), what aspects of the existing CKD SMIs need improvement and what additional aspects may they benefit from? / How does CKD affect YAs and what do they require to effectively self-manage their condition?*



CKD Chronic Kidney Disease; *SMI* Self-Management Intervention; *YA* Young Adult.

━━━ -Theme derived from interviews with staff only

╍╍╍ -Sub-theme

Theme 1 - YAs with CKD:

This theme served to describe the specific YA (18-35 years old) population who suffer from CKD. This inductive theme also comprised a brief inductive sub-theme which was included to convey YAs' advice, based on their experiences, to their peers. First, codes that produce an essence of theme 1 are described, and then codes included in the sub-theme are presented.

Invincible and naïve:

One YA and three staff members referred to YAs as "invincible", for instance, participant 1 described YAs as "invincible" based on her experience.

"*I think when you're young, you think you're invincible" "When you're young, you get told all this stuff like: just live your life, do whatever you want, you are invincible*" (P1, YA, female).

She has also added that YAs tend to be naïve as it was in her case when she was first diagnosed.

"I was really naïve: my friends are right, I will be fine in a few months. And then it hit me.." (P1, YA, female).

Health and social care professionals confirmed this account by describing the risky behaviours and need for a sense of freedom associated with the young age.

“Risky behaviour at that age when you're pushing boundaries” and *“Some YAs rebel against it or not wanting to fit into the treatment”* (P6, ST, male).

“Younger people need that sense of freedom” (P7, ST, female).

The introductory Chapter of this thesis acknowledged that young adulthood is a distinct period identified by impulsive and risk-taking behaviours. This leads to non-compliance problems, which makes it difficult for both YAs and HCPs, thus, it is important to consider the characteristics of this specific cohort when developing SMI.

“We are more than our condition”:

Although this code was generated based on data from only two YAs, it was decided to include this code and use the YA participant’s quote for this code as it powerfully conveys the message (P3, YA, male). YAs talked about the support they require, and one particularly highlighted the mental health, and social and youth work as being important for them, to stress that it is not just the physical aspects of the condition that they struggle and need support with. He further stated that YAs want to be heard.

“They (doctors) *were talking at me rather than with me and I think they need to learn the difference between listening to me and hearing me. If you hear me, you’re going to take action on what I said, if you're listening, you're just ticking boxes: yes, we listened to the patient. I'm not a box.. and I think those are big points that should and can and do make a difference in people's lives”* (P3, YA, male).

YAs also expressed wanting to be treated like adult patients and be informed about their condition, even if it is a “hard truth.” One interviewee talked about her struggle with doctors being “vague” and not wanting to tell her everything she should know.

“*It was my dad who came with me and actually sat down with the doctor and said: no, you need to tell us the facts now, you can't hide this stuff from her” “I'm glad that I knew this is my condition, this is what my prospects are as best they* (doctors) *could tell me. I just want adults to be honest. I think when you get told this stuff, you just want all the facts, you just want to be told.”* (P1, YA, female).

“Want to live a normal life”:

Another semantic code was generated to highlight the importance of the message conveyed by the majority of YAs who expressed wanting to live a normal life.

“There's a side of me where I want to live my normal life” (P1, YA, female).

“Our aim at the end of the day is to lead as normal life as possible.. we still have to navigate all that stuff whilst still trying to be normal. And it's a lot” (P3, YA, male).

“It (CKD) *stopped me from doing more things that I’d like to do”* (P4, YA, male).

All staff members also reiterated this statement. For example:

"They'll just want to be able to lead that kind of the same lifestyle as their peers that can be really difficult" "We've had some young people who maybe haven't taken their medications as they should, because they just want to lead that: normal life.. and then that's cause difficulties down the line for them" (P8, ST, female).

In a recent interview study examining YAs (same age group as in the present study) from across six different countries (three from the UK), diagnosed with CKD since childhood, six main themes emerged from their perspective on life participation, some of which reflected themes identified in the current analysis (Kerklaan et al., 2020). Their thematic synthesis revealed that YAs who grew up with CKD had to give up activities they valued and enjoyed which consequently incapacitated them from living "normal life" as their peers. This is consistent with our study where participants reported having had to stop certain activities they enjoy, for example, contact sports. In other qualitative research (e.g., Lewis & Arber, 2015), being able to participate in sports was viewed as particularly important to "living a normal life".

Furthermore, studies on CKD-childhood-onset have reported that CKD is related to increased mortality in children and may impair their social, physical, and cognitive functioning (Hooper et al., 2016; Thys et al., 2015). These challenges hinder their abilities to achieve developmental milestones, autonomy, and independence, and ultimately restrict their ability to fully participate in society as adults (Rocha et al., 2011). Others added (e.g., Tjaden, Grootenhuis, Noordzij, & Groothoff, 2016) that YAs with CKD-childhood-onset face challenges and delays in accomplishing education, employment, and relationships compared to the general population in this age group. In studies on life participation (e.g., Logeman et al., 2020), it was established that for children with CKD, meaningful activities, which bring enjoyment, fulfilment, hope, and control (Ju et al., 2019), include sports, study, leisure and social activities. However, life participation is often limited by CKD treatment, symptoms, and side effects burdens, leading to longstanding consequences in young adulthood (Tjaden et al., 2014).

Sub-theme - Advice for their peers:

This sub-theme was generated based on interviews with YAs only. Out of four, three YA participants conveyed different advice for other YAs with CKD, therefore it was decided to generate a semantic code for each piece of advice resulting in three codes. Particularly, based on YAs' experiences, the suggestions for their peers were to:

"Be brave" One YA expressed that if she had to advise someone newly diagnosed with CKD, she would tell them to be brave and not take things personally. She further stated to be patient with people (e.g., friends) as they will not understand, and consequently, they may feel let down (P1, YA, female).

"Keep going and keep on track" For another participant, the most important piece of advice was to carry on going and focus on everyday self-management activities to ensure keeping routine (P2, YA, male).

Whereas one advised other YAs with CKD to: *"Get support and take one step at a time"* (P3, YA, male). He talked about the importance of finding the right support system, such as charities or peer support (depending on individual needs), and he warned that there will be many ups and downs so it is important to take one step at a time.

Theme 2 - CKD and its associated impact and challenges:

This theme included a family of codes describing YAs and their professionals' perception of living with CKD, its impact, and associated challenges specific to YAs with CKD.

Invisible and misjudged disability:

All YA participants recognised the challenges of living with CKD, particularly in terms of its hidden nature. YAs talked about CKD as a silent, invisible condition.

"It's a silent disease. That's a big part of it that is the challenging part to be fair" (P2, YA, male).

"Just because you can't see it, it doesn't mean it's not happening internally" (P3, YA, male).

One staff member confirmed this based on her experience of working with YAs.

"Lots of them (YAs) *talked about it being an invisible illness"* (P8, ST, female).

Other qualitative researchers also recognised similar interpretations of CKD. For instance, in a secondary analysis of qualitative interviews with CKD individuals, the researchers recognised and included an "invisibility" theme to portray the perception of CKD in their thematic synthesis (Bristowe, Selman, Higginson, & Murtagh, 2019). Additionally, because of the hidden nature of CKD, the condition was also recognised by YAs as misjudged as people often assume that it is an old person's disease. One YA stressed that:

“The fact that it's seen as an old person illness, I think that kind of mental shift needs to change” “I understand that the majority of CKD patients are probably older than we are but we still do exist and we still do need support and we still are trying to live a life” (P3, YA, male).

Daunting and lonely illness:

Both groups of participants agreed that CKD is a daunting condition. One YA particularly described her frightening experience:

“They (doctors*) said that I could die younger, and they said that is indefinite if I’ll ever come off my medication and I’ll quite possibly need a transplant because of how young I am, which yeah it was all very daunting, it wasn't the best appointment I could have in the world”* (P1, YA, female).

She also talked about being judged by friends and family as they don’t understand CKD and make their own assumptions and added:

“When you're going through something like that and not having your friends and family for you, that is probably the biggest hurdle that you will ever face because you do feel like you're alone. So yeah, that's what I went through, and I won’t wish it on anyone” (P1, YA, female).

Other YA stated:

“You do feel down, and you can feel very isolated and alone” (P3, YA, male).

Staff members added to it by describing CKD as an unpredictable and complicated condition, making its management complex and overwhelming for YAs.

Lack of CKD awareness and understanding:

The challenges of CKD being invisible and misjudged condition associated with other challenges of living with this illness, namely the lack of CKD awareness and understanding, particularly from teachers and employers. YAs found it important to make people aware of their condition:

"I find it important to tell someone that I have CKD because I have to carry a card around with me just in case I have to get any medication that needs to not interfere with mine" (P1, YA, female).

They also found it important to increase CKD awareness to allow for an early diagnosis:

"I feel like actually if you educate people then in a way that self-help because some person could early identify themselves to maybe having kidney disease" (P1, YA, female).

However, they agreed that while other conditions like cancer or heart disease are well-known, there is a lack of CKD awareness. This often links to the lack of support and understanding from employers and teachers. For example, YA stated that:

“It would be nice if employers understood that chronic illnesses like CKD affect similarly as it would affect other serious illnesses like cancer or heart problems” (P3, YA, male).

He also associated this lack of CKD awareness with being bullied at school:

“When you're a little kid and you look different because of drug side effects, people just see that as bullying and normal kids can be bullied, yeah fair enough, but that's just one layer and then, when they see another thing that's another layer” (P3, YA, male).

Bullying by peers because of physical differences caused by CKD was also reported in other qualitative studies (e.g., Kim & Choi, 2016).

A good example of how misconceptions of CKD and the YA population link to the challenges in school and employment, was provided by a YA participant who talked about employers judging YA as “skivers” who are just making excuses to get time off work.

“Because we have this image in our society as a whole that young people are kind of like skivers and don't want to work and are happy to sit at home and do nothing and don't want to contribute to society which is far from the truth. If anything, we want to be more involved, we want to be more engaged, we want to be out there, talking to people, interacting with new members of staff that we've met gaining into a role. That stuff kind of motivates us” (P3, YA, male).

Such tendencies were also identified in former studies (e.g., Tsutsui et al., 2017) that reported a lack of acceptance and understanding by employers and work colleagues because of frequent absence and physical symptoms.

Most of the professionals also acknowledged the lack of CKD awareness and understanding.

"Sometimes their peers can't understand if they're really tired and trying to explain to their work that although they look well, they're actually not feeling that well" (P8, ST, female).

We have seen that CKD and its management are complex, especially for YAs who experience other psychological, sexual, and physical modifications of development and the challenging demands of everyday life. However, the current analysis revealed that YAs' requirements to effectively self-manage their condition are not met by their employers or teachers. Indeed, YAs talked about the lack of understanding of their needs, for example, employers not understanding that they had to drink loads of fluids and consequently needed more bathroom breaks, or when they did not feel well and had to take time off work or school. Taking time off work can also lead to a financial burden:

"If you've had times where you've been unwell, or you've got quite a lot of health checks, or you might get an infection that again impacts on, how you can work, and some employees have sick pay, some don't, so you have to rely on statutory sick pay, which is considerably less, so there can be a financial burden" (P8, ST, female).

YAs also found the need to constantly explain their condition and its consequences burdening:

"It can be hard to try and explain that, and it seems as well that the burden and the explanation is kind of put on the person to explain to the employer and you almost feel like you're defending yourself, for being ill. When you shouldn't really have to" (P3, YA, male).

The staff member also confirmed this by adding:

"But it also makes it very hard for them to be able to explain to other people and to feel that they really understand it" (P9, ST, male).

These reflected findings of other qualitative studies (e.g., Ekuma, 2018) where CKD participants expressed that the constant need to explain their situation to employers and colleagues led them to feel a loss of privacy. The issues related to lack of disease awareness and understanding from teachers and employers affect YAs from early childhood. A recent thematic synthesis exposed that YAs with childhood-onset CKD who shared their childhood experience also struggled with attending school or work due to treatment regimes, fatigue, and being self-conscious or unwell, which often left them behind their peers and consequently made them feel lacking in skills and knowledge (Kerklaan et al., 2020). This indicates that YAs should be supported from early childhood in their careers to enable them to reach their potential.

Physical and mental well-being:

When asked about the impact of CKD on YAs' lives, most staff members agreed that:

"It just impacts every area of life" (P5, ST, female).

Others added:

“I think there is an impact on everything, it is so holistic” (P6, ST, male).

“Because of how complicated kidney disease is and all of the various treatments, medications, and diet, the impact it can have on their physical appearance, their sexual relationships, all different matters of things, it’s really quite a complicated thing for them to wrap their head around” (P9, ST, male).

YAs detailed it further and most YAs highlighted the importance of mental health. They talked about struggling with their mental well-being, particularly anxiety:

“I mean on the anxiety side of it, which is a big part of my problems, with the kidney disease, you know, to treat anxiety. I think the biggest thing is to help me to live with it, live my life” (P2, YA, male).

When asked, what is the most challenging in managing CKD, YA responded:

“The mental side of it, managing your own mental state, because obviously when I was coming towards a transplant, it was very much playing in my mind on, you know, what's life, going to be like afterwards, and just feeling horrible all the time, and then post-transplant,

again it's sort of the mental side of it: great I've had a transplant, it's not functioning as I'd like and I can't do the contact sports that I love to do, so I probably say the mental side of it really" (P4, YA, male).

Staff added:

"I think that mental health is really precarious so as well as going through all the normal developmental problems that kind of teenagers and young adults do, on top of that they've got to deal with the confinements of treatments" (P7, ST, female).

Throughout this thesis, we have seen that psychological disorders (particularly anxiety and depression) are common in people with CKD, and emotional management is an important task for those who suffer from chronic conditions. Our findings are consistent with Havas et al. (2017a)' study which established that CKD individuals show a high demand for mental health support.

Furthermore, when discussing the physical aspect of their condition, fatigue was the most recurring concern highlighted by both groups of participants. This reflected the findings from another qualitative study on YAs who identified fatigue as the most debilitating symptom disabling them from performing simple activities like getting up from bed (Kerklaan et al., 2020). YAs talked about their struggle with tiredness as one of the biggest impacts of CKD:

"I think the main thing that affected me is tiredness, that's the biggest part" (P2, YA, male).

"Once I remember, I had one week off work because I just couldn't get out of bed. I was that lethargic and I couldn't drive, because I *couldn't actually focus and see straight" "It's rare that I get days like that now, but when I do, I find it really hard to function"* (P1, YA, female).

She also added about medication side effects:
"It (medication) *makes my blood pressure drop so much that I end up having really bad days, where I can't actually function"* (P1, YA, female). She also stressed that medication should be free.

Staff members also added that*: "Medication is a big impact"* (P6, ST, male).

YAs talked about the strategies they use to manage their medication. These included setting reminders on the phone, writing notes and sticking them in visible places, using a pillbox to organise and control their daily doses, planning ahead and stocking medication to ensure they do not run out and to ensure they drink enough liquid. One YA also used a bottle with times on it, which as she claims motivated her to drink water at certain times. Although they expressed forgetting to take their medication on occasion, these strategies worked well for them, however, they acknowledged that more support with diet and exercise from professionals would be beneficial. YAs revealed that skills which helped them manage their medication, diet and exercise involved being organised and resilient.

One staff also talked about effective strategies like the visual prompts mentioned above but also highlighted that:

"Sometimes it's about working with the person to find out what works for you" (P8, ST, female).

Our findings further confirm that effective CKD SMI should consider both, YAs' physical and mental well-being, and given that individuals with CKD often struggle to discuss their psychological stress (de Sousa, 2008), HCPs should encourage YAs to talk about it.

The transition process and taking ownership:

Another challenge that YAs face, which was highlighted by all staff and one YA, is the transition process from paediatric to adult services and taking ownership of own health. Professionals talked about the difficulties that YAs face when transitioning and how it can be an overwhelming and frightening experience. YA participants described the challenge of taking responsibility for their own health:

"When you are in paediatrics, generally, your parents take a lot of the brunt of the responsibilities because obviously they are your parents and you're under their care. But I think when you hit that kind of threshold and you have to move on and then, you kind of understand all the stuff your parents were dealing with and how to deal with and that can be a really big change for a young person" (P3, YA, male).

He also talked about how different paediatric and adult services are and how this transition process could be improved:

"I think attitudes with paediatrics and adults are very different. Paediatrics seem to be a lot more nurturing and understanding, and they seem to talk to us at our level, they tend not to use as much jargon. They try to explain things in more accessible ways, they could use toys, like Lego or drawing. Whereas with adults, I find they don't really consider the language, you kind of get a leaflet about something and that's it" "*Having someone there helps a lot"* (P3, YA, male).

Many staff concurred that the transition process should start at a much earlier age. One supported this claim by adding:

“From experience, we found that when we do that, people then manage much better as they get older if they’ve been doing it for since they were as young as sort of 11, 13” (P9, ST, male).

They also discussed that some YAs want to take over the management of their disease from their parents but do not know how to, and some are not ready to take this ownership. They talked about the appropriate support that YAs require to ease this process for them, and some suggested the importance of YAs’ feedback:

“I think one of the big things is making sure that we're rightly speaking to YAs who have been through the transition process and getting feedback: was this helpful, was there anything you felt we could be doing better?” (P8, ST, female).

Transitioning from paediatric to adult services was discussed in the introductory Chapter of this thesis as a challenging period for YAs with CKD (who also go through a major life transition), which often is managed poorly. This is consistent with the findings from our qualitative study which further confirms that more research in this area is required. An improved transition process could lead to fewer transplant failures, and we agree with Viner’s (1999) account provided in Chapter 1 which suggests that YAs should not transition to adult services until they have been provided with the necessary skills to successfully function once in the adult centre.

Socialising and peer pressure:

This code was generated based on YAs' feedback only. They talked about the challenge of peer pressure and social life. A good example was provided by YA who talked about being diagnosed with CKD while studying at university, and consequently, how her condition impacted her social life. She spoke about having to be careful with alcohol consumption while on medication and the pressure that she felt from her peers who did not understand her condition.

"Them not understanding was really difficult. Because it is that sort of culture. So that was quite difficult when I was younger" (P1, YA, female).

In Chapter 1, we established that when compared to older adults, the challenges of CKD and its treatment and management disengage YAs from their social life, and also delay their developmental path of individualisation, independence, and maturation (Ferris et al., 2006). Peer pressure, to some extent, links back to the lack of CKD awareness. If people were more aware of the condition and what it means for YAs, perhaps they would understand their situation, which hopefully would lead to more peer support rather than peer pressure. In a recent qualitative study that employed a similar cohort, interviews with YAs (aged 18-25, with CKD stages 3-5), exposed alike experiences when disclosing their condition to their friends. One participant even claimed that on two occasions when explaining their condition to peers, they just walked away, leaving them anxious to form future friendships and relationships (Coyne et al., 2019). In another study on the experiences of children and adolescents with ESKD, interview data revealed an entire theme dedicated to this issue (Nicholas, Picone, & Selkirk, 2011), where participants echoed similar challenges to participants in the current study. The current study strengthens the findings from the previous studies by highlighting the challenges faced by YAs and the support they require. This could involve raising awareness of CKD and helping YAs develop or improve their social and communication skills.

Acceptance of CKD:

Whereas, this code was produced based on the feedback of those who look after YAs with CKD. In their opinion, many YAs struggle with accepting their diagnosis and treatment.

"It's about acceptance, coming to terms with the fact that you've got this condition and this condition will remain for life" (P7, ST, female).

According to staff, individuals who accept their health condition, tend to manage it well. The acceptance of health problems and the development of an identity separate from their condition may lead to feeling a better sense of normality as reported in an interview study with adolescents and YAs (Tong et al., 2013).

Having children:

Finally, although only one YA participant talked about the concern of having children, it was decided to include this code in the current analysis as it highlights an important struggle that YAs (chiefly women) with CKD face. When interviewing a young female participant, she talked about her experience of being told when she was 19 years old that if she wanted to have children, she would have to start considering it as soon as possible and let doctors know six months in advance as she would have to come off her medication and ensure that she maintains her kidney function to reduce the risk associated with being pregnant. She added:

"It's kind of been a ticking time bomb in the back of my head, every day, especially being a woman, we don't really have that much time anyways. So, my specialist said: you kind of got to find the right time, where your kidneys are in a good position and you're not too old

as they put it, which always makes you feel great when you're 19 (laughs)" "*That's kind of always on my mind, even though, I don't talk about it, it's always on my mind because yeah I'm 24 now, I'm still young, but I know lots of people my age, my friends, who got kids and getting married"* (P1, YA, female).

Although having children was mentioned only by one YA in the current interviews, it could be because there was only one YA female participant. However, in a recent study examining the same age group of YAs with CKD, males also raised their concerns regarding planning parenthood (Kerklaan et al., 2020). For instance, one male stated that to become a father, he would have to do in vitro fertilisation. Other participants had similar concerns to those that emerged from the current analysis, for example, feeling pressure to start planning parenthood early, fearing that their condition will worsen or fail during pregnancy or the possibility of passing the disease to their child (Kerklaan et al., 2020). Moreover, in a systematic review of qualitative studies on YAs' perspectives on living with kidney failure, fertility and parenthood theme was also identified when participants, particularly young women expressed their concerns (Bailey et al., 2018). There is a gap in the areas of reproductive and sexual health and more research is required (National Health Service; NHS Kidney Care, 2013) to support and engage YAs to talk about this sensitive, yet important topic.

Theme 3 - challenges faced by professionals:

Note that, this theme was generated to reflect only the staff's views, YA participants did not talk about the challenges faced by their professionals. Two main codes emerged from the data from professionals, mainly engagement, and limited time and resources. The majority of staff discoursed the challenge of engaging and connecting with YAs, highlighting the lived difficulties of creating relationships and bonds with them. They talked about the balance between giving YAs advice and allowing them to make their own choices and being dictatorial, telling them what to do. Additionally, staff also voiced their concerns regarding time constraints and limited resources as a barrier to providing YAs with the appropriate support they require. One described feeling “deflating” because of letting YAs down and not being able to help. Some examples of the extracts for these two inductive codes are presented below.

Engagement:

“Getting their engagement and getting them on the side, getting them to feel like you're an ally, rather than just another sort of health professional” (P6, ST, male).

“I find it really difficult to engage people” (P7, ST, female).

“Probably when they're not ready to accept help or they don't know what they need, which is very often, and part of our role is helping people understand that and building up a relationship with somebody to be able to give them that support and identify things they're needing, what treatment would help, but when people put up a barrier because they don't want to even engage with the idea of learning about their condition” (P9, ST, male).

Limited time and resources:

“We tend to have caseload, so I’ve got about three or four young people to get in touch with, to check whether they are doing all right, but it's quite hard to do regularly, and whereas if somebody had that sort of specific role and training the skills, more specific than I’ve got, to be able to work with them, I think that could be beneficial” “Problem is, because it is a really small cohort, you don't use those skills quite as much” (P6, ST, male).

“We've got a caseload of kind of 30/40 patients, working part-time, and I think YAs need intense support.. I think they need accessibility to staff and we're not able to give that, so the work we do, therefore, is crisis management with them” “I find it really tricky because we don't have the time as social workers to commit” (P7, ST, female).

“There are good resources there but the barriers of the time to fill it out and maybe some young people don't want to have to go through it” (P8, ST, female).

A previous study examining CKD management in the UK reported similar findings where lack of time caused by excessive workload was identified as a barrier for HCPs to effective patient counselling, however, the study was limited as it did not include HCPs’ views and opinions, and thus could not conclude the reasons for not communicating with patients their treatment regimes and potential outcomes of their condition (Ahmad, 2006). The present study adds to knowledge by recognising particular challenges that should be considered for providing effective CKD SMI. Our findings resonate with a previous qualitative study on HCPs’ perspectives, where similar barriers to CKD management in primary care were reported (Ramakrishnan et al., 2022). We postulate that future CKD SMI should consider equipping staff with appropriate tools to help them support YAs as efficiently as possible. For instance, professionals claimed the availability of “good resources,” however, when discussing Lorig and Holman’s (2003) five self-management skills, particularly the resources-utilisation skill in Chapter 5, we learnt that just providing individuals with appropriate resources is not sufficient, professionals must also teach them how to seek and use these resources (Lorig and Holman, 2003), preferably accessing numerous potential resources at the same time to further enhance their knowledge and skills (Gucciardi et al., 2006). Similarly, to tackle the issue of time constraints, future SMI could perhaps consider the Brief Action Planning (BAP) tool, discussed in Chapter 5, as an ideal self-management tool for busy practitioners (Gutnick et al., 2014).

Theme 4 - Considerations for effective CKD self-management:

This theme assisted in identifying aspects of CKD self-management that YAs recognise as important to effectively self-manage their condition. Both YAs and staff shared their experience with self-management strategies that work well and suggested areas that require improvement.

Family and peer support:

The importance of family and peer support was discussed by all participants across both groups. YAs talked about their family, especially their mothers, and how they supported them physically and mentally throughout their illness. One YA even held that his mom saved his life by encouraging him to go out and do something with his life. This encouragement led him to obtain a youth worker qualification and opened up the doors in the volunteering sector.

"It was my mom who kind of encouraged me to go in the daylight and do something and stop moping around" (P3, YA, male).

One staff member held a similar view on the importance of family support and further suggested that parental education could help YAs with managing CKD and becoming more independent. While family support is valued by YAs, there is a risk that overprotectiveness by parents may impede their ability to live independently and with confidence. In the current interviews, one YA disclosed that her mum was very protective over her as she was "*a really ill baby*" and her mum "*went into mum mode and researched everything*" (P1, YA, female). In Kerklaan et al.'s (2020) study, overprotectiveness by adults was also discussed by young patients and some claimed that teachers and doctors also kept them "in a bubble" by suggesting to avoid travelling or sports.

Furthermore, peer support was viewed as vital by all YA and staff participants. YAs acknowledged the advantages of peer support through, for example, focus groups, sports activities, open days, peer or “champion patients”, and even participating in sharing their experiences on blogs and forums for YAs, and some wished they had the opportunity to participate in these.

“I've not really had any of that and I think I’d be one of these people who, if I knew there was a focus group, at my local hospital or even anywhere really, where there are young people with the same condition or even old, I would go along once in a while and just say: yeah I need help with this, could anyone help? And just be a community” (P1, YA, female).

Some even valued peer support over family support as they could share their lived experience with people in a similar situation.

“As much as family and loved ones care for us and try to look after us, I think there's a different aspect when you meet people who are like you. We all have our individual stories and journeys of where we are in that kind of chronic illness but I think we can relate more to each other because we've lived it” (P3, YA, male).

However, although all interviewed staff members confirmed that some of these significant opportunities (e.g., an “activity day”, social media groups, and peers from the charitable sector) are available for YAs, they also claimed that it is dependent on the area where they live.

“Living in rural areas, as we do in North Wales, it's harder” (P6, ST, male).

"Depending on where you are, depends on what support is available in your hospital, not every hospital has a social or youth worker, or access to psychology counselling or different charities" (P8, ST, female).

YA participant also expressed this concern.

"I'm based over in North Wales so it's pretty sort of rural and we don't have much of that around here" (P4, YA, male).

The current literature review also identified social and peer support as well as family involvement as effective strategies for improving self-efficacy, and consequently CKD self-management (refer to Chapter 3). Further, the introductory Chapter discussed studies on YAs which established that peer support has a positive influence on their self-management and everyday lives. The challenge of implementing peer support was also discussed, with YAs constituting a small portion of the CKD population and many healthcare services lacking access to appropriate peer mentors to support patients in this age group. This was reflected in our findings where participants acknowledged that peer support is available, but dependent on the location. This link to our next recognised consideration for effective CKD self-management - "consistency in care".

Consistency in care:

The importance of consistency in care was acknowledged by all staff members and one YA. The YA participant talked about his experience with different hospitals which he described as:

"One not so successful, and one absolutely amazing. I've kind of seen how it should be and how horribly it can make you feel" He further reiterated: *"A renal social worker would be great and again some areas have these, some areas don't, which is why I think it needs to be nationalised. At the moment, it's a very postcode lottery, if you live in one area and they have it, you're lucky, if you live in the other area and you don't have it, you're buggered"* (P3, YA, male).

He articulated that the appropriate care that he was provided with by one hospital (consisting of, for example, "*co-production and self-care, confidence building and equal partnership"*) should be consistent across all hospitals and YAs should not suffer "*more than they need to*" (P3, YA, male). A similar experience was described in another qualitative study by a participant with ESKD who expressed "disgust" at the way that some nurses communicated with him, while also expressing being treated with respect and dignity by other nurses (Ekuma, 2018).

Additionally, staff postulated that everyone should have the same opportunities, and suggested picking one resource or standardised approach and using it consistently by all team members. One professional added:

"It (talking about the ready-steady-go programme) *has the potential to be a really good programme if used correctly, but it also has to be implemented by every member of the team, and it has to be consistent"* (P9, ST, male).

Note that programmes like ready-steady-go (mentioned in Chapter 1) have been discussed by almost all staff members throughout the interviews (typically when discussing patient activation), as well as the study stakeholders (Kidney Wales Foundation). Thus, to gain more insight into the programme, the researcher attended the "*Renal conditions: Moving on up together. Working together to manage paediatric onset renal conditions moving into adult services*" online study where the ready-steady-go programme was included and debated (see

Appendix YY for the certificate of attendance). The researcher also volunteered and got involved in translating the ready-steady-go resources from English to Polish language. This familiarisation with the programme allowed for a better understanding of what is currently in place and what can be improved. The ready-steady-go programme is further discussed later on in this synthesis.

Effective communication and relationship with HCPs:

The efficiency of care for CKD individuals strongly depends on the quality of the communication and therapeutic relationship between patients and HCPs, comprising all professionals involved in patient care (Checton, Greene, Magsamen-Conrad, & Ventis, 2012). Effective communication with HCPs as well as within the multidisciplinary team (MDT) was crucial in YAs and staff's view. One YA participant talked about the importance of effective communication highlighting that each patient should be talked to their level, considering their needs, learning capabilities, and language barrier. In his opinion, YAs must feel confident and empowered to talk to their professionals. He further reiterated that once a person gains this effective communication, they will be able to self-advocate which consequently will reduce the burden on the renal team. The importance of being able to self-advocate was expressed by almost all YAs.

"I think giving those tools to a patient and potentially even their carers and their families, those tools to self-advocate and the tools to have co-production with your renal team so you're working together as opposed to kind of being talked down to and being told what to do" (P3, YA, male).

Others were concerned that "*people don't fight their thrones*" (P1, YA, female) and take professionals' "*words as Gospel*" (P4, YA, male).

YAs also expressed their frustration regarding poor communication within MDT, particularly when a person has comorbidities and their care involves several different professionals and different services like GP and pharmacy.

"*I don't want to be the middleman, I'm living with this, it's bad enough living with it*". "*Just talk to each other, like it's 2021, how hard is it to send an email*" (P3, YA, male).

Staff also confirmed these accounts and concurred that for the communication to be effective, it has to be on an individual level, with consideration to YAs' needs and abilities, which links to our next consideration for effective CKD self-management, namely PCC.

Finally, to develop effective communication, professionals need to have good relationships with patients, which according to YAs starts with an initial consultation.

"It goes to that first appointment. That first time you see someone and then the initial first building blocks are basically going to be the foundation of that relationship with that patient. If you don't put down the right foundations it's never going to work.. Those initial steps, consultations, and conversations need to be appropriate for each patient for that foundation to set and be strong" (P3, YA, male).

Most staff reiterated this further by stating that the relationship between professionals and YAs is crucial and fundamental and that staff should spend more time getting to know the person and building a relationship, which consequently will help YAs trust their professionals when they reach a crisis. Our findings reflect those of previous studies, for instance, Stomer, Wahl, Goransson, and Urstad (2022) found that patients' relationship with their HCPs was crucial for effective CKD self-management. The significance of HCP interactions was extended by another study (Sakraida & Robinson, 2009) which reported that patients relied on input from their HPCs for the clarification of information. This reflects the interviewees' statements in the current study who expressed the need for reassurance from professionals. This may support YAs in making informed health decisions and in gaining confidence in asking further questions regarding the management of CKD as it was perceived by participants in the Warner et al. (2019)' study.

PCC approach:

The significance of the PCC approach appeared across all interviews when discussing several diverse topics. Both groups of participants acknowledged that "*every person is different*" (P1, YA, female) and "*the illness is so individual to each person*" (P3, YA, male) that "*professionals should have a full understanding of how best to meet their needs*" (P5, ST, female). Findings from this analysis confirmed our extensive discussion on the importance of PCC throughout this thesis, including the findings from the current literature review. We have seen several benefits of taking this holistic approach, however, as recognised in our narrative synthesis (refer to Chapter 3), tailoring interventions to individuals may be challenging to compromise an individual approach with the needs of healthcare services. The current thematic synthesis adds to knowledge by highlighting not only that every person is different though they share the same condition, but also that YAs constitute a small cohort which is often neglected, particularly when they join adult services.

"Although they are at an early stage, they're in an adult clinic and they are kind of treated like everybody else which works for some people but doesn't work for everybody" (P6, ST, male).

Others added:

"They're coming into this environment which is structured, there's not much flexibility to it and they've just got to fit into a system.. I don't think we're flexible enough.. there's only a small number of YAs who attend our clinics and then there's nothing specific put together for them" (P7, ST, female).

All staff were congruent that "*one size doesn't fit all*" (P8, ST, female) and that "*person-centred care is the way forward*" (P7, ST, female).

Some YAs and staff further reiterated this by discussing the importance of considering the YA cohort and gaining their perspective by engaging them in research, which linked to and collapsed with the PCC approach code. YA participant stated:

"The more research is done, the more it can make easier for YAs, YAs more than older generations.. encouraging each hospital to promote kidney research itself" (P2, YA, male).

YAs acknowledged that their lived experience can help future generations and they encourage other YAs to participate in research:

"I think a lot of patients, if they feel empowered and listened to, a lot of us are willing to give back also to the community because we understand this can help future generations and future children who will have to go through similar things to what I went through" (P3, YA, male).

Staff echoed this by stating that gaining YAs' perspective would aid in supporting them more effectively.

"It has to be led by young people themselves.. I think any research that looks at that's co-production, that's working with YAs that have been through it or going through it to try and help us to figure out what we can do to change is really helpful" (P8, ST, female).

Staff also pointed out that in addition to gaining YAs' perspectives, regular check-ins and reviews are equally important to support YAs the best they can, particularly constantly evaluating to see how are they doing and adapting to their needs.

"Having evaluation processes can help us to adapt and change for not doing something well or to celebrate what we are doing and put more of that into the light" (P8, ST, female).

One YA further confirmed this by highlighting that regular reviews would reassure them whether what they are doing is correct.

"It'd be great if they almost sort of quiz you at appointments so have asked me whether I'm doing, you know X, Y Z and then just asking me: do I know what I should be doing" (P4, YA, male).

Theme 5 - Improving activation:

This final theme was generated to highlight YA's areas of knowledge, skills, and confidence necessary to improve their activation levels. The importance of patient activation was discussed throughout the whole thesis, mainly in Chapter 5, which was consistent with findings from our qualitative analysis. Both groups of participants acknowledged the importance of activation, and they raised their concerns and suggestions for improving the activation level. Consequently, several codes, described below, were derived from interview data.

Adequate information:

Although some YAs claimed the availability of unofficial resources (e.g., websites, social media, charities, and peer groups), many concurred that getting information is "*really down to you*" (P2, YA, male), and they also acknowledged that some of these resources may be confusing and misleading and researching information (e.g., on the Internet) may cause stress and panic. One YA also communicated that in his opinion, not only YAs should be educated but also the staff members. He told a story of his auntie's experience who was provided with misleading information from the nurse who shared her preconceived ideas based on culture, rather than professional advice. Similar comments were identified in other studies on ESKD patients (e.g., de Brito-Ashurst et al., 2010) who expressed their preference for receiving information (e.g., on diet) from experts, such as renal dietitians, as they believe that experts' advice will be adequate and constructive, suggesting that all professional involved in renal care should possess relevant knowledge and skills to provide YAs with effective support.

Almost all YA participants agreed that they do not have enough information they require to effectively self-manage their condition and that they were not provided with much knowledge, indeed most searched for information themselves or through their parents. They claimed that they were provided with a leaflet at most and would appreciate more support from professionals to increase their CKD knowledge (e.g., in the form of trustworthy resources). For instance:

"I think this (being provided with CKD knowledge) *would do a massive thing to actually get to acceptance of it and, yeah, I definitely not got enough information in my book".* She also added: *"I just think, you get told this news and then it's like: oh bye bye, you out the door, next person. I've done a lot of my own research to get the basics. But no, no one's ever really sat me down and said: okay, this is how it works, this is why you have it, this is how it affects everything"* (P1, YA, female).

Further, a staff member confirmed this by adding:

"It would just be the educational materials we have.. we've got a welcome booklet to support younger people to access things to self-manage their condition, to access charities, peer support.. but that is not accessible through units, that is something we would work on with people on an individual basis, and again that's, not to say that every young adult is referred to us, it's only when another professional finds that they might need support, so it's not routine" (P7, ST, female).

This indicates that potentially appropriate resources might be available, however, it goes back to the issue of "consistency in care" discussed earlier. The knowledge gap theme also emerged in other qualitative studies as a major issue. For instance, in the study by Ekuma (2018), individuals with ESKD claimed being provided with contradictory information and lack of adequate CKD information (including its causes, treatment and potential outcomes), which consequently increased their level of uncertainty and made them feel disempowered to make informed decisions on simple tasks, such as deciding on an appropriate diet.

Moreover, in a systematic review of patients' information needs, CKD individuals recognised 13 topics which are important to them, however, the prioritisation of these information topics and the best time to provide the corresponding information is not yet clear (Ormandy, 2008). The findings from the current interviews are limited to some extent in answering the questions of what, when and how much information should be provided to YAs with CKD. However, as per opinions communicated by YAs, we can conclude that they should be provided with adequate information right from the time of diagnosis to enable them to "accept" their condition, make informed decisions, and consequently improve patient outcomes. Given the knowledge gap, future studies should look into assessing and developing appropriate guidelines and resources (and later evaluating them), considering the diverse populations varying in gender, age, beliefs, preferences, language, and skills, while also acknowledging that patients' needs tend to change during an illness (Coulter, Parsons, & Askham, 2008).

In addition, two professionals suggested platforms, like mobile phone apps, to increase YAs' knowledge. For instance, one gave an example of her teenage daughter being constantly on her phone suggesting that the YA cohort would respond positively to an app to help them self-manage CKD (P5, ST, female). Another professional (P9, ST, male) talked about his plan to develop such an app based on self-management specific to YAs. Indeed, he claimed that the app is in development (but, postponed due to the COVID outbreak) and described some of its features. He conveyed that the idea was to comprise learning and education with an element of fun by including a gaming element (e.g., employing Avatar characters) where YAs will be able to learn about their condition through games and videos.

A few mobile apps aimed at facilitating CKD self-management have been recently developed, for instance, the "Stay Strong app" developed and qualitatively evaluated by Nagel et al. (2022), or MiKidney app by Doyle et al. (2019), or "My Kidneys & Me" (MK&M) a digital CKD self-management programme co-developed by Lightfoot et al. (2022). These apps showed promising potential to improve CKD self-management. For instance, MK&M is a theory-based and evidence-driven app for non-dialysis CKD individuals in the UK aimed to enhance CKD knowledge and important patient activation by incorporating Behaviour Change techniques (BCTs). The researchers claimed that the MK&M app is a successful holistic CKD self-management programme which provides tailored, accessible, and interactive support to enhance patients' knowledge, awareness and understanding of their condition and confidence in managing it. They also projected that in the next stage of their research, they will evaluate the effectiveness of MK&M in improving patient activation (Lightfoot et al., 2022).

One study employed Avatar characters in the development of virtual reality counselling for YAs affected by (their own or a family member's) cancer diagnosis (Phelps et al., 2017). The authors acknowledged the importance of psychosocial support in this population and by gaining insight from the intended users, they proposed highly tailored, to YAs, online counselling intervention. However, despite positive developmental outcomes, the researchers have also experienced difficulties recruiting young people, leading to a temporary pause in the study. This highlights the complex nature of involving, developing, and evaluating interventions for YAs, further emphasising the difficulties in aligning clinical practice and research. Nevertheless, this Avatar-based, virtual reality counselling intervention holds promise as it signifies an apt approach to addressing the unique YAs' needs in facing cancer-related psychosocial challenges (Phelps et al., 2017).

However, as far as we are aware, there are no such platforms specific to the YA population with CKD, and as per the interviewed staff who is currently working on a digital app specific to YAs (P9, ST, male), it is intended that the findings of the current research will aid in the development of this app by recognising YAs' requirements to effectively self-manage their condition.

“Being born with it is better than being diagnosed later on”:

When discussing the necessary skills to self-manage CKD, one YA and three staff members expressed surprising views that being born with CKD is better than being diagnosed with it later in life. YA participant even said that he feels lucky to be born with it as he learned through life how to manage it. Through several transplants, he learned about diverse dialyses, diets, fluid management, etcetera. In contrast, he emphasised that a person diagnosed later in their life, like while they are at university and/or when they starting their career and settling down, the CKD diagnosis "*will hit them and then: like crap, what do I do with my life*" (P3, YA, male). Most professionals echoed his statement by agreeing that individuals diagnosed in childhood have more skills and are more informed, whereas later-onset diagnosis can be a real shock to them. They added that YAs may become overwhelmed and even rebel against it due to a lack of knowledge and skills to self-manage CKD. These findings add important information to existing knowledge highlighting the importance of considering the time since diagnosis when supporting YAs with CKD.

Furthermore, when discussing CKD self-management skills with staff, some mentioned programmes like ready-steady-go again, claiming that they use this and similar programmes (e.g., "patient view") to support YAs and give them appropriate tools to improve their self-management skills. However, as per the staff's statement: *"It's been well received by some and not as well received by others"* (P9, ST, male).

Confident "now" but not "then":

Through a discussion with YAs about confidence in CKD self-management, it became apparent that most YAs feel fairly confident now, however, they were *"nowhere near confident"* when first diagnosed:

"But certainly, when I first was diagnosed, I was nowhere near confident, particularly with the exercise, and because I was unsure about what I could do and what I couldn't do, so, in the end, I just thought I just almost do what I want to do, which is what I did" (P4, YA, male).

Those who went through transplant added that sometimes they struggle with taking transplant medication, and for others, it is the uncertainty about the future where they lack confidence. For example:

"I'm not so confident in the reality of living with CKD, sounds really silly because I am living with it, but the future is quite daunting and that's what I'm not confident with. It's those little questions that I get in my head now and again, and I don't have the answers, and therefore I don't feel confident about my future in a sense" (P1, YA, female).

Additionally, although this code was derived from YAs' interviews only, the staff talked about the importance of considering each person as an individual (across all interviews) as they may be at different stages of their activation. One staff member suggested improving YAs' confidence by employing a more formalised system where they can grade patients to see how is it going for them and what can be done to support them better (P6, ST, male). This led to the final topic, discussed with professionals only, on the use of the patient activation measure (PAM) to assess YAs' activation level and the practice of BCTs to improve their activation.

Empowerment, partnership, and respect:

One YA expressed that being informed, listened to, spoken to with respect, and having a relationship and partnership with HCPs, would help YAs develop the necessary confidence to self-manage their condition, which would benefit both patients and the system.

"We will have the confidence to reach out to you and you will have that confidence to reach out to us". He added: *"It empowers us because then we feel we have more control over our condition. And I think is about partnership and empowerment and having that independence and knowledge"* (P3, YA, male).

Staff echoed this by stating that empowering YAs will build their confidence to self-manage, ask for help, come to terms with their condition, and take on some challenges.

Use of PAM and BCTs:

This code emerged from interviews with professionals only. Unfortunately, when asked about the use of both PAM and BCTs, all staff concurred that both are not utilised in the current care and some were not even aware of either. However, they all acknowledged the importance of examining YAs' activation level and using BCTs to enhance it. Most staff concurred that the "ready-steady-go" programme mentioned earlier, is probably the closest to PAM which includes some BCTs as tools to improve the level of activation. They expressed that it incorporates the assessment of patient activation to some extent by using a traffic light system for different stages of readiness. This provides staff with prompts to engage in the appropriate topics or to signpost the individual to the most appropriate professional. Overall, staff praised this and similar programmes, however, they acknowledged that it requires improvement and reminded once more about the issue of consistency in care when utilising such resources.

Furthermore, in terms of the utilisation of tools to enhance YAs' activation, including BCTs, few claimed to be trained in techniques like motivational interviewing (MI) and/or coaching, and those acknowledged its many benefits. One particularly claimed to be trained and have experience (from previous work) in MI and health and wellness coaching and was very passionate and enthusiastic about those skills she learned. She stated:

"I'm a strong believer in coaching, I think it's very much about empowering and helping to guide and working with someone at their own pace, and MI, the chase cycle of change, trying to find out where someone's at and helping them to move through that but not trying to jump too far.. It's really strength-based and empowerment focus and that's why I'm really passionate about it" (P8, ST, female).

She held an opinion that behaviour change training can make a difference as it puts a person at the centre and MI or coaching is not about telling a person what to do but rather finding out where they at and what they know and guiding them to where they need to be by setting clear goals and providing them with appropriate tools to achieve these goals, while considering their needs and wants. She and other staff stressed the significance of knowing at which stage of readiness YAs are to effectively support them by tailoring support to their level of activation. However, although all agreed that these approaches are very important and transferable, yet again the issue of consistency and limited time and resources was echoed as barriers when supporting YAs. The importance of both PAM and BCTs was discussed throughout this thesis, particularly in Chapter 5, and the current synthesis confirms further that considering different stages of readiness and employing BCTs while tailoring the intervention to the appropriate level of activation is vital to enhance YAs CKD self-management.

Overall, effective CKD self-management depends on identifying the patient as the main manager of their illness. Yet, to date, only a few qualitative studies explored how YAs perceive their condition and what influences their everyday self-management behaviours. Most previous literature focused on older adults with CKD, but we know, that the younger population face different challenges and unique barriers. Thus, this qualitative study aimed to fill a gap in the current knowledge and explore patient-centred perspectives, particularly YAs' and their health and social care professionals' views, opinions, and experiences on CKD and its associated challenges and self-management. Both groups of participants conveyed varied experiences and perceptions, and through our systematic and comprehensive TA, we identified five major themes and one sub-theme that answered our research questions (refer to Figure 7.1).

Although the interviews revealed some positive accounts, there were many cases where the participants expressed their concerns regarding CKD and its management and discussed its associated challenges and barriers. Our findings strengthen the growing evidence that the management of CKD is complex and individual-based. The findings of the current TA also add to the existing knowledge by highlighting the various challenges and considerations for effective CKD self-management specific to YAs between 18 and 35 years old and suggesting potential strategies to support this unique cohort and those who look after them. It should be noted that the current qualitative data was further analysed in phase 3 (Chapter 8) to recognise barriers and enablers specific to the identified target behaviour. Below, we discuss the strengths and limitations of the current analysis and then conclude with recommendations for future practice and research.

Strengths and limitations:

One of the strengths of this TA was its flexibility. The researcher had no previous experience in conducting qualitative studies, thus Braun and Clarke's (2006) reflexive TA was an appropriate choice given that this method is foundational to several other methods of qualitative analysis. The flexibility of TA allowed, for example, the application of a hybrid approach which led to a balanced and comprehensive view of the overall data. Nevertheless, while the flexibility of the TA is seen as an advantage, it can also be viewed as a disadvantage that lacks rigorous methods. However, rigour was safeguarded in the methods by ensuring consistency and completeness by carefully following each step of TA and identifying the assumptions that underline the analysis.

The current qualitative semi-structured interviews allowed for the exploration of individual viewpoints (Flick, 2009) and the collection of in-depth individual experiences while allowing for the flexibility to examine certain issues with more open and follow-up questions (Cohen, Manion, & Morrison, 2011; Robson, 2011). TA approach to qualitative data analysis aided in identifying commonly recognised themes and patterns of meanings across a dataset, produced in and by people, events, and situations, concerning specific research questions (Clarke, Braun, Terry, & Hayfield, 2019; Gerritse et al., 2018; Roberts, Dowell, & Nie, 2019; Vaismoradi, Turunen, & Bondas, 2013). The TA's iterative and reflexive process allowed us to expand on our quantitative investigation and explore in more detail what it means to be a YA living with CKD and what it means to look after this specific cohort. It enabled the identification of areas in CKD self-management that work well and those that require improvement.

The inclusion of professionals' views and opinions, alongside YAs, allowed for a deeper understanding of the current care and challenges that professionals face when supporting this cohort. Their extensive experience, ranging from 11 months to 24 years, offered a depth of insight into the practical challenges associated with managing CKD in YAs. This breadth of experience is particularly beneficial for understanding the long-term trends and shifts in care practices, as well as the evolving needs of YA patients over time. However, there are some limitations to this inclusion. For instance, professionals may focus on clinical priorities, and their views might introduce bias, potentially overlooking personal experiences and challenges faced by YAs with CKD. This could lead to an intervention that, while practical and implementable, might not fully resonate with the target demographic's specific needs and preferences. Moreover, the inclusion of professionals with such varied lengths of experience could result in a wide range of viewpoints, potentially complicating the synthesis of the data. Those with shorter tenure might offer fresh perspectives and highlight current challenges, while those with more extensive experience might provide historical context and long-term insights. Balancing these different perspectives is crucial but also challenging, as it requires careful consideration to ensure that the final intervention is informed by both current and long-standing issues in CKD management. Thus, to develop a truly YA-centred and effective SMI, the researcher had to critically balance the invaluable professionals' insights with the direct experiences of YAs with CKD. The potential discrepancies between professional priorities and YAs' needs underscore the importance of integrating diverse perspectives while maintaining a clear focus on the intervention users.

Additionally, while the age distribution of YA participants in the current interview study (ranging from 20 to 35 years old) covered the target demographic for developing a novel CKD SMI, it presents some limitations. The small sample size and the significant age range may not fully represent the diverse experiences and needs within this group, particularly the differences between those in their early twenties and those in their thirties. Similarly, although the findings of the current analysis contributed new knowledge to the understanding of this specific population, these findings may not be transferable or generalisable to other age groups as this small cohort may not be representative of a whole population. Moreover, our relatively small sample included a higher number of males than females with CKD stages 3 and 5, which also limits generalisability.

Another limitation is due to the nature of a doctoral study. This TA was conducted by one person and reviewed and discussed with the research supervisors.

This allowed for consistency in the methods but failed to offer several perspectives from various individuals with differing expertise. Moreover, although the researcher engaged in reflective exercise throughout all aspects of the research, it is uncertain whether the interpretations of findings may still have been influenced by the researcher's knowledge of the topic obtained through the literature review (phase 1).

Implications for practice:

Findings from the current synthesis recognise several areas in which YAs with CKD should be supported to effectively self-manage their disease and identify areas to improve to help HCPs successfully support this specific cohort. Through the interviews with both groups of participants, the researcher was able to describe the specific YA (18-35 years old) population who suffer from CKD. Future practice should address non-compliance problems in YAs by acknowledging that they often engage in impulsive and risk-taking behaviours. Professionals should consider that YAs' goal is to live as normally as possible and want to be viewed as more than just their condition.

Several challenges that YAs with CKD face were identified. Through the analysis of all interview data, it became apparent that participants view CKD as an invisible, misjudged, and lonely illness and there is an emerging need for increasing awareness of CKD. Particularly, employers and teachers are invited to increase CKD awareness, provide YAs with appropriate support, and protect the rights of this vulnerable cohort. Increasing CKD awareness and understanding may potentially decrease peer pressure and discrimination, improve social skills, and ease the acceptance of CKD.

In addition, HCPs should pay equal attention to YAs' physical and mental well-being, and encourage them to talk about their psychological issues, and other sensitive subjects important to them (e.g., having children). The findings also demonstrated the importance of assisting YAs in the transition process from an early age and empowering them to take ownership of their health. HCPs must ensure that YAs possess the necessary skills to function in adult services.

Furthermore, the current analysis established important considerations for effective CKD self-management, suggesting areas that work well and those that require improvement. Based on the current findings, we suggest that to successfully support YAs with CKD, HCPs should effectively communicate with patients and within MDT, and although YAs share similar characteristics, every person is different and thus a PCC approach should be adopted in the current practice. To enhance this effective communication, HCPs should build a relationship with YAs from the start. HCPs would benefit from additional training to advance skills in effective communication to develop collaborative partnerships with YAs patients, thus acknowledging YAs' role in their healthcare (Lawn et al., 2009). We also recognised the significance of family and peer support and concluded that opportunities to engage, especially with other YAs who go through similar issues, should be given to all young patients, regardless of where they live.

Additionally, probably one of the most imperative considerations for CKD self-management for YAs that adds to current knowledge is the lack of consistency in care. The current TA revealed that several self-management strategies work well and many YAs experienced valuable support from HCPs, but they also voiced “bad” experiences. Therefore, HCPs must ensure consistency of “good” practice and we believe that the agreed standardised approach to support YAs should be employed consistently by all professionals. The current findings will aid in the development of appropriate interventions for YAs with CKD (phase 3), which may form a reliable resource to support HCPs in helping YAs and ensure consistency in care.

Further, our in-depth analysis revealed areas of improvement to enhance YAs' knowledge, skills, and confidence. The most recurring issue highlighted by interviews was the knowledge deficit, suggesting that HCPs must provide YAs with appropriate CKD knowledge from the very beginning to empower them to make informed health decisions. To improve healthcare services, all professionals should be educated in CKD self-management to avoid providing contradictory and misleading information. Additionally, while promoting PCC, CKD onset and time since diagnosis should be considered. As per interview data, YAs with later-onset diagnoses need further support in developing the necessary self-management skills. Similarly, given that YA participants expressed feeling confident now, but not when first diagnosed, the extra focus should be given right from the initial consultation. To enhance their confidence in self-management further, as per interviews' suggestions, HCPs must empower YAs, be respectful and promote partnership.

Finally, discussions with professionals about the use of PAM and BCTs revealed worrying findings. Although all interviews acknowledged the importance of both, they claimed patient activation is not directly considered in YAs' care and BCTs are not utilised, indeed only a few were aware of both. Interviews discovered surprising findings showing that only one professional interview was trained (prior to her current post) in some BCTs. This reflected other studies which established that HCPs are not provided with formal training in delivering SMIs (Lake & Staiger, 2010). Thus, we strongly recommend that all staff should undergo formal training compromising BCTs and support should be provided to YAs with consideration of their level of activation.

Implications for research:

The current qualitative study highlights several areas for further inquiry. For instance, when employing this method of analysis, the process, such as coding the data, could include several individuals with codes and themes being generated using discussions with other experts or researchers, and/or the participants themselves, and perhaps the literature review should be conducted following the interviews. Additionally, future interview studies should include a more representative age range to better inform the development of SMIs for YAs (aged 18-35) with CKD. Similarly, future work would benefit from employing more females, and although we reached content saturation in the current study, future studies should involve a larger sample, including participants with different CKD stages (both dialysis and non-dialysis patients), and consider other demographic variables, such as ethnicity, income and employment status. Future research would also benefit from the inclusion of perspectives from YAs with lower CKD stages who require less contact with HCPs and tend to be less engaged in their health and consequently may have lower health literacy because of this lack of communication. Similarly, self-management has been recently explored during COVID-19 (e.g., Okoro, 2021; Mayes et al., 2021), however, these studies were also limited to participants with advanced CKD stages. Future studies could investigate CKD self-management before and during COVID-19 to establish whether CKD individuals have adapted their self-management strategies and used alternative resources, such as technology utilisation, to gain information as a result of the pandemic.

Furthermore, the current TA identified important information concerning barriers to effectively supporting YAs with CKD. HCPs voiced their concerns about engaging YAs and limited time and resources. Future studies should further explore these issues and identify strategies to help HCPs in assisting YAs with CKD more effectively. Moreover, we recognised several under-searched areas in CKD self-management topics and recommend future investigation. For instance, we established that more research is required on reproductive and sexual health and studies should focus on gaining a better understanding of the topic from both, male and female YAs. More research needs to be conducted to answer questions of what, when and how much CKD information should be provided to YAs, and to examine digital platforms as they may be valuable tools to enhance their self-management knowledge. Finally, as we saw discrepancies in the current YA’s care, future studies should recruit and interview geographically disadvantaged YAs to improve support in rural areas. The opening Chapter of this thesis also noted that YAs living in rural areas and managing chronic conditions face additional challenges such as accessing services, receiving appropriate care, ensuring convenience, and fostering engagement (Robards et al., 2019).

To conclude, we believe that, despite some limitations, the insights provided by the current analysis have significant implications for the current care of YA patients with CKD and stimulate future research in several overlooked areas. By identifying challenges faced by YAs, considerations for effective CKD self-management, and areas of improving the important patient activation, our study offers answers to the under-searched questions of how the condition affects this specific population and what they require to effectively self-manage their condition and improve their overall well-being. However, due to the small and heterogeneous sample, these findings need to be interpreted with caution. Based on these findings and results from the quantitative study, as well as the literature review, in the next Chapter, we propose effective strategies to support YAs with CKD in the form of person-centred and theory-based intervention.

7.2 Overall Discussion and Conclusion for Phase 2

7.2.1 Synthesis of Quantitative Results and Qualitative Findings

Some similarities and differences were identified from the findings of both parts of phase 2. The findings of quantitative and qualitative data analyses exposed that YAs' requirements to effectively self-manage their CKD are not met. For instance, in the survey study, several areas of SMS were acknowledged by both groups of participants (YAs and HCPs) as significant, suggesting interest in more support. This aligns with the qualitative findings that also identified various areas for improvement in CKD self-management. In both studies, YAs acknowledged the need for support in maintaining social and occupational roles. In the survey study, this domain was highlighted as the most important for YAs, and in the qualitative study, both YAs and their professionals recognised that YAs with CKD desire to maintain a normal lifestyle, engage in hobbies, sustain social life and careers, and develop and nurture relationships.

Additionally, both quantitative and qualitative syntheses revealed that YAs are affected by psychological disorders. Particularly, professionals participating in the survey study expressed that, in their opinion, YAs need more support with the "developing and sustaining a positive attitude and caring for mental and physical well-being" area of CKD SMS, and some retaliated this further in additional suggestions. This domain was also rated as the most important aspect of CKD self-management in Havas et al.' (2017a) study. Descriptive analysis of psychological disorders also revealed that many YAs reported symptoms of depression and anxiety. Data from interviews with YAs further echoed this by highlighting that YAs struggle with their mental well-being, with anxiety being a particularly prominent concern. These findings from both studies suggest the potential significance of psychosocial support for YAs, addressing social factors, mental well-being, and fostering a positive mindset in YAs for effective CKD self-management.

Furthermore, qualitative data revealed an important issue of inconsistency in care, which was highlighted by most participants. This was also reflected in some responses from the survey study, where participants reported mixed experiences with individualised PCC plans. These findings emphasise the need for a standardised and consistent approach to supporting YAs with CKD in their self-management efforts. The convergence of findings from both methods reinforces the results and suggests the importance of addressing these areas of need.

On the other hand, the results of the current quantitative study and the findings of the current qualitative study are not consistent concerning the importance of the age at diagnosis and time since diagnosis. The interview data with YAs and their professionals regarding the necessary skills to self-manage CKD revealed that *"being born with it* (CKD) *is better than being diagnosed later on"*, highlighting the significance of early diagnosis and the need for appropriate support for those diagnosed later on in their lives. In terms of the time since diagnosis, the quantitative results showed no impact of this variable on self-management and the level of interest in CKD SMS.

As established earlier, YAs often wished they were more involved in self-management and received more support when first diagnosed. The current study adds to this by acknowledging that those who were diagnosed later on in their lives, may require more support. All YAs participants in the current qualitative study were at later-CKD stages (3 and 5) and most were diagnosed before 18 years of age, thus their experiences may vary from those at earlier stages, and all interviewees highlighted the significance of support from an initial consultation. Previous research (Jacobson Vann et al., 2015) revealed that SMS is crucial in early-stage CKD, and future research should investigate how to motivate and encourage those at earlier CKD stages to effectively self-manage their condition. These varied findings indicate that time since diagnosis and CKD stages should be considered in CKD self-management with different strategies for those diagnosed earlier and later in their lives.

7.2.2 Phase 2 - Conclusion

To conclude, a mixture of quantitative and qualitative studies allowed us to identify how YAs manage their health condition based on their, and those who look after them, perspectives. Particularly, findings from phase 2 recognised YAs' existing self-management behaviours and suggested factors the interventions need to address to improve their CKD self-management. Thus, both studies contributed to new knowledge about how to best support this particular cohort. The similarities in the findings between the quantitative and qualitative analyses suggest a clear consensus concerning the unmet need, the role of social factors, the presence of psychological disorders, and inconsistent care experienced by YAs with CKD. Whereas, the discrepancies between the findings from the two analyses highlight the complexity of CKD self-management and the need for a comprehensive understanding of the factors that influence it. Addressing these issues and providing personalised and consistent support is crucial in improving the CKD SMI of YAs. However, the findings from both quantitative and qualitative studies should be interpreted with caution due to the small and diverse sample size, while considering the challenge of balancing the health and social care professionals' views with YAs' lived experiences. Overall, this study contributes to a better understanding of the research topic and aids in the development of evidence-based interventions, research, and practices. The findings from this Phase and Phase 1 (literature review) are summarised in the next Chapter and are utilised to inform the intervention development.

7.3 Chapter Summary

In this Chapter, the findings from the qualitative study (phase 2, part 2) were presented. The next Chapter combines these with findings from phase 1 (literature review), and based on both phases, it proposes a novel intervention for YAs with CKD.

Chapter 8: Phase 3 - Intervention Development

8.1 Phase 3 - Introduction

Throughout this thesis, the development of a tailored, theory-based self-management intervention (SMI) for young adults (YAs) with chronic kidney disease (CKD) has been emphasised as important for improving and promoting optimal health outcomes and empowering this specific population to take an active role in their disease management. YAs with CKD face unique challenges during a critical phase of life, thus addressing their specific needs through effective intervention is necessary. While addressing the research question for phase 3 on the most optimal intervention for YAs with CKD, the current interview study revealed that when it comes to typical CKD self-management behaviours (such as medication management, diet, or fluid intake), YAs are currently self-managing these well. However, YAs and their professionals noted that psychosocial issues (including mental well-being such as anxiety, and particularly a lack of social connections and support) pose unique challenges for YAs, impacting their daily lives and self-management. Thus, the revised aim of this research is to develop a novel SMI, founded on health behaviour change methodology, for YAs with CKD, targeting their participation in social activities, while considering their unique challenges and needs.

The summary of the main findings for each phase of the work conducted to inform the intervention development, highlighting knowledge gaps, YAs and their professionals' experiences, barriers to self-management, and desired support, can be accessed in

Appendix ZZ. Briefly, these findings outline the importance of a person-centred approach in developing an effective SMI for YAs with CKD. This approach considers the unique needs, preferences, and challenges recognised in the previous phases of the current research, and aided in identifying the target behaviour described below. The methods employed to design the novel SMI are detailed in section 8.2, and the results of each step are outlined in section 8.3, followed by the proposal of the intervention in section 8.4.

The rationale, aims, and objectives for intervention development:

The novel intervention aims to target YAs' participation in social activities in the context of CKD. This selection of target behaviour was based on previous studies examining young populations with CKD, and findings from both quantitative and qualitative studies (phase 2), which suggested that YAs struggle with, and lack, confidence and skills to successfully participate in social interactions, sustain interpersonal relationships, and engage in work, school, and everyday activities. These social abilities broadly describe the concept of social functioning, which is often used reciprocally with several similar overlapping concepts, such as "social performance," "social adaptation," "social competence" or "social adjustment" (Brissos, Molodynski, Dias, & Figueira, 2011).

Previous studies (e.g., Francis et al., 2019; Hamilton et al., 2019) established that CKD negatively impacts the mental health and quality of life (QoL) of children and YAs. This impact is observed in various aspects of their well-being and functioning, including their social, emotional, physical, and educational aspects (Rupp, Fair, Korcycinski, & Ferris, 2021), and as in older adults with CKD, there is evidence suggesting that psychosocial issues negatively impact YAs' medical outcomes (Clementi & Zimmerman, 2020). Former research (e.g., Carter et al., 2020; Gonzalez et al., 2020; Hanson et al., 2020) established that psychosocial outcomes are regularly rated as a high priority by children, young people, and adults with CKD, and life participation was established as particularly important in patient-reported outcome for children and YAs with CKD (Hanson et al., 2019).

In the previously-mentioned interview study on life participation by YAs (also aged 18-35 years old), six themes related to YAs' psychosocial well-being were identified (Kerklaan et al., 2020), reflecting findings from the current interview study, particularly the aspect of social well-being and functioning. While some of these themes are relevant for older adults, others are unique to the younger population, and thus it is important to consider YAs’ distinct challenges, needs and preferences, to ensure they receive appropriate support (Kula & Somers, 2021). Psychosocial support for YAs with CKD is particularly important during the transition from paediatric to adult services tailored to their diverse developmental stages. Considering the characteristics of this specific cohort, participating in social activities can play an important role in navigating their social environment more effectively, shaping behaviours, and adhering to recommended behaviours.

Furthermore, previous qualitative studies have identified "managing relationships and social networks" (Coyne et al., 2019) and "social isolation and intimate relationships" (Bailey et al., 2018) as major challenges faced by YAs with CKD. Similarly, the findings from the present interview study identified a code of "socialising and peer pressure" within the theme of "CKD and its associated impact and challenges." YAs expressed how their condition affects their social life and the pressures they face from peers who do not understand their condition. This further indicates that social factors play a significant role in these individuals' lives and can substantially impact their well-being and QoL.

Finally, in the current quantitative study, YAs recognised the "maintaining social and occupational roles" domain (including aspects, such as continuing to work, sustaining hobbies, and maintaining relationships and home roles) as requiring the most support across various pre-identified areas of CKD self-management support (SMS) (Havas et al., 2016; 2018). All these aspects were also acknowledged as important across all current interviews, which further highlights the importance of targeting YAs’ participation in social activities and addressing these significant aspects of their lives. Interventions that consider social factors, such as peer support programs or educational campaigns aimed at changing social norms, may effectively promote healthy behaviours in YAs and overcome social barriers to behaviour change. By enhancing YAs’ participation in social activities, the intervention can help them build and maintain relationships and social networks, mitigate social isolation and intimate relationships more effectively, and equip them with strategies to manage social challenges and peer pressure efficiently, fostering their social well-being.

8.2 Phase 3 - Methods

Phase 3 was conducted to develop a person-centred, theory-based SMI specifically tailored to YAs with CKD stages 1-5, drawing upon findings from previous phases (literature review and participants' feedback). The primary goal of this intervention was to empower YAs to actively manage their condition and enhance their overall well-being by providing them with the necessary support and strategies to improve their confidence in navigating their social environments. While the initial design of the current study was influenced by the work of Havas et al. (2018), the chosen theoretical framework for the current intervention development incorporated self-efficacy from the Social Cognitive Theory (SCT; Bandura, 1989) and Health Action Process Approach (HAPA; Schwarzer (1992), as well as behaviour change theories and approaches (specifically the Theoretical Domains Framework; TDF and Capability, Opportunity, Motivation-Behaviour; COM-B matrix; Cane et al., 2012; Michie et al., 2014a; refer to Chapters 4-5). Additionally, in line with the United Kingdom Medical Research Council recommendations (UK MRC 2000; 2021) and other advocates of theory-based interventions, the current intervention development followed French and colleagues (2012) systematic four-step approach for intervention development (refer to Chapter 5), presented in Table 8.1, while the results of each step are described in section 8.3.

Table 8.1

Four Steps to Intervention Development

	Description of steps employed in the current study
Step 1: Who needs to do what, differently?	✓ This question was initially addressed during the informal meeting with YAs with CKD, and meetings with the study stakeholders and research supervisors, where the potential needs for the appropriate intervention specific to YAs (age 18-35) with CKD were identified ✓ This was further addressed in the systematic literature review (***phase 1***) which established the current evidence-practice gap in CKD SMIs ✓ To further specify the behaviour change needed to reduce the evidence-practice gap and whose behaviour needs changing, a mixture of quantitative and qualitative studies were conducted (***phase 2, parts 1 and 2***)
Step 2: Using a theoretical framework, which barriers and enablers need to be addressed?	✓ ***Phase 2, part 2:*** The qualitative approach aimed to identify behavioural determinants (by identifying areas of SMIs that work and those that require improvement), which were likely to influence target behaviour ✓ The theoretical framework chosen for the current study, particularly the HAPA, was considered as most likely to inform the pathways of behaviour change and as theoretical support for guiding intervention, and TDF and COM-B matrix was employed to identify barriers/enablers
Step 3: Which intervention components could overcome the modifiable barriers and enhance the enablers?	✓ Informed by the effectiveness of BCTs from the empirical evidence, and selected theoretical frameworks, BCTs were mapped to the relevant barriers/enablers identified in previous phases (***phase 2, part 2***) ✓ The preferred mode(s) of delivery were identified in the questionnaire-based study (***phase 2, part 1***) ✓ The final selection of BCTs and mode(s) of delivery was based on their relevance to the local context, feasibility, and ability to be implemented as a cohesive intervention
Step 4: How can behaviour change be measured and understood?	✓ The predictors and mediators of change, particularly self-efficacy, were identified from the previous literature in advance, and quantitative analysis in ***phase 2*** examined it further as a predictor of change ✓ For the assessment of behaviour change, we recommend the adaptation of a questionnaire developed by Schwarzer (2008)

Adapted from French et al. (2012). *BCT* Behaviour Change Technique; *CKD* Chronic Kidney Disease; *COM-B* Capability, Opportunity, Motivation-Behaviour*; SCT* Social Cognitive Theory; *SMI* Self-Management Intervention; *TDF* Theoretical Domains Framework; *YA* Young Adult.

To achieve the optimal intervention for YAs with CKD and the most appropriate logic model of change, the researcher systematically navigated through each step. To ensure feasibility in the current intervention development the entire process was guided by the Acceptability, Practicability, Effectiveness, Affordability, Side-Effects, and Equity (APEASE) criteria for assessing intervention and its components (see Michie, Atkins, & West, 2014b). These criteria were used to resolve disagreements, reach team consensus, and guide the decisions on the selection of TDF domains, intervention functions, Behaviour Change Techniques (BCTs), and mode(s) of delivery. Moreover, the researcher completed online training and achieved “coding competence in the use of the BCT Taxonomy version 1 (BCTTv1) to specify the content of complex behaviour change interventions” (see Appendix AAA for the certificate of completion). The researcher supported their analysis by using the BCT-Taxonomy mobile app, which compromises 93 behaviour change theories as published by Michie et al. (2013) in BCTv1.

Further, to identify appropriate BCTs, while ensuring a comprehensive understanding of the links between BCTs and their mechanisms of action (MoAs), a free online Theory and Techniques Tool (TATT) developed by Johnston et al. (2021) was employed. This tool explores the links between 74 BCTs and 26 MoAs (e.g., the process through which they change behaviour). The strength of these links is determined based on published literature (Carey et al., 2019) and expert consensus (Connell et al., 2019). Considering and understanding these MoAs by which interventions work is crucial as they serve as the mediating factors between the intervention itself and behaviour change (Carey et al., 2019). By understanding these mechanisms, necessary adaptations can be made to tailor interventions to specific contexts, ultimately leading to the effective design of the novel intervention.

Additionally, studies that have combined BCTs and MoAs often lack the reporting of the explicit theoretical foundation for their integration (Michie et al., 2021). The current intervention development considered strategies within a larger theoretical framework to enable the identification of BCTs and MoAs that can be integrated to construct a comprehensive and effective complex intervention. As outlined in previous Chapters of this thesis, in the current study, self-efficacy theory from SCT was initially considered as most likely to inform the pathways of behaviour change. For instance, theoretically, YAs with high self-efficacy concerning their capacity to actively participate in social activities are more likely to initiate an increase in participation and maintain attempts to sustain this increase when faced with barriers to change. SCT acknowledges the importance of self-efficacy, risk perception, and outcome expectancies in forming intentions to change behaviour, however, it does not explain how to turn those intentions into action. To address this gap between intention and actual performance of new behaviour, the HAPA was considered the most appropriate model of health behaviour change in the current study. The HAPA was employed to model behaviour change in two stages, particularly the motivational stage aimed for YAs to develop intentions to engage in behaviour, and then a volitional stage aimed for YAs to translate these intentions into behaviour.

8.3 Phase 3 - Results of Each Step to Intervention Development

Step 1 (identification of the problem):

<u>What is the behaviour (or series of associated behaviours) that needs to change:</u>

The complexity of CKD self-management means that there are several individual interconnected behaviours involved. The current study considers a person-based approach to intervention development, which aims to firmly root behaviour change interventions in a profound understanding of the perspective and psychosocial context of those who will ultimately utilise them (Yardley et al., 2015). By prioritising YAs' unique needs and experiences, this approach ensures interventions are more relevant, effective, and resonate better with the intended users. While seeking to answer the questions of "who needs to do what, differently?", it was recognised that to improve YAs' management of CKD and overall well-being, it is important to enhance their participation in social activities. The chosen target behaviour, guided by the APEASE criteria, had strong supporting evidence, is potentially modifiable at the YAs' level, and is to be performed by YAs regularly, in social settings.

Step 2 (assessment of the problem):

Theory of change:

The assessment of the problem involved consideration of the theory of change (HAPA) and the TDFv2 and COM-B matrix (Cane et al., 2012; Michie et al., 2014a) diagnosis employed to deductively identify TDF domains relevant to barriers and enablers to the target behaviour, which were inductively identified from qualitative synthesis. Note that, the initial assessment of the problem identified 9 barriers and 7 enablers to the pathways of change (see Appendix BBB for a detailed description of all potential determinants, relevance to the TDF domains, examples of extracts, and definitions of TDF domains/constructs and corresponding COM-B components/sub-components). However, given that the novel intervention aimed to target YAs' behaviour, these potential barriers/enablers were further analysed, and based on the APEASE criteria, 2 barriers and 2 enablers within the TDF framework, to participating in social activities, modifiable at YAs' level, were considered and targeted in the current intervention. These are briefly described below.

Selected barriers and enablers to the pathways of change:

It was recognised that to address YAs' initially selected barriers/enablers and improve their social participation, they require effective communication and self-advocacy skills in three areas. Namely, YAs need to develop/improve these skills to 1) communicate their individual needs, preferences, and worries associated with CKD, 2) deal with social perception and influence, and 3) seek emotional support.

Effective communication and self-advocacy skills (identified as enablers in the current analysis; refer to Appendix BBB) are crucial for YAs with CKD, and all interviewees emphasised their significance. YAs stressed the need for confidence and empowerment in communicating with healthcare professionals (HCPs). They acknowledged that effective communication skills can lead to self-advocacy, ultimately easing the burden on the renal team, and it will empower YAs to effectively communicate their opinions, needs, and worries, and assertively seek support when necessary. Lack of CKD awareness and understanding (qualitative theme) further highlights the importance of YAs effectively communicating needs, preferences, and concerns with those who lack understanding of CKD and its consequences, mainly teachers and employers.

Additionally, social judgment, stigma, discrimination, and peer pressure barriers recognised further that YAs need effective communication and self-advocacy skills to deal with social perception and influence. Interviewees talked about CKD as an "invisible and misjudged disability". YAs discussed being judged by friends and family who do not fully understand their condition, leading to negative assumptions and even bullying. They also expressed concerns about feeling pressured by their peers to conform to social norms and not being understood when it comes to, for example, monitoring their alcohol intake when socialising.

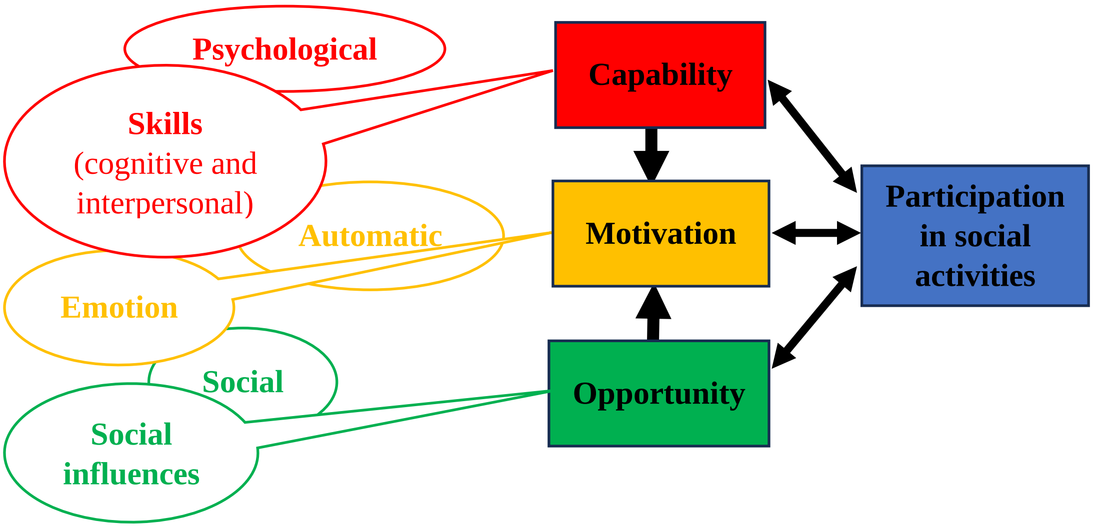
Finally, negative emotions (particularly anxiety and worries) were identified as barriers leading to a sense of insecurity and lack of confidence regarding the future, whereas family and peer support were considered enablers of target behaviour. Interviewees agreed that receiving support from family and peers is crucial. YAs spoke about the physical and emotional support they received from their family during their illnesses. Peer support programs, including focus groups, sports activities, open days, and access to champion patients, were highly valued by YAs. Thus, it was recognised that seeking emotional support from family and peers is important for YAs to manage their emotional well-being.

Consequently, addressing these selected barriers and leveraging the enablers through targeted intervention can help YAs enhance their confidence in navigating their social environments, and overall well-being and QoL, providing them with optimal psychosocial support. By addressing and improving YAs' effective communication and self-advocacy skills in these three areas, the novel intervention has the potential to improve their participation in social activities by enhancing their confidence and facilitating more meaningful and supportive connections.

In essence, the further behavioural diagnosis identified 3 out of 14 TDF domains, namely skills (cognitive and interpersonal), emotion, and social influences domains. As per COM-B diagnosis, changing YAs' perceived psychological capabilities and opportunities in their social environment may influence their automatic motivation for participating in social activities. Motivating YAs to increase participation in social activities may increase their capability (see Figure 8.1).

Figure 8.1

COM-B Logic Model



Adapted from Michie et al., (2014a).

The COM-B model and HAPA as a theoretical framework were considered in the next step when selecting BCTs. By combining both insights, we can address the multifaceted aspects of behaviour change by addressing capability, opportunity, and motivation, while considering the role of stage-specific self-efficacy, outcome expectancies, risk perception, goal-setting, action and coping planning, self-monitoring, and social support, and consequently encourage effective and long-lasting behaviour change in YAs with CKD.

Step 3 (formation of the possible solution to the problem):

Once the TDF domains were identified, they were then mapped to the relevant COM-B components and sub/components to inform the selection of intervention content (BCTs). Following this, six intervention functions were selected from nine broad types of intervention from the Behaviour Change Wheel (BCW) according to COM-B targets (Michie et al., 2014a). Subsequently, 28 potential BCTs were identified, guided by the online TATT (Johnston et al., 2021) and consideration of stages of behaviour change (HAPA), and were carefully examined and reviewed until an agreement on selection was reached. The results from this behavioural diagnosis organised into the matrix of links among the COM-B model, TDF domains, intervention functions, and BCTs for the intervention targeting YAs' participation in social activities can be accessed in

Appendix CCC, and the outline of these results is presented in Table 8.4 in next section. Finally, the delivery mode (how each selected technique will be delivered) was identified based on findings from the current survey study (phase 2, part 1) where YAs established their preferred modes of delivery.

Mode(s) of delivery:

Based on YAs' preferences, the novel intervention will be delivered face-to-face by professionals, particularly by nurses, in alignment with the existing literature review in Chapter 3 demonstrating the effectiveness of nurse-led SMIs. Additionally, building upon discussions throughout this thesis, particularly in Chapter 5, emphasising the importance of person-centred care (PCC), peer education, and robust evidence supporting successful self-management programs delivered by peers within the community setting (e.g., Lorig et al., 2001), it was decided to integrate an experienced CKD patient (termed champion patient in this thesis) as a co-facilitator in the novel intervention.

Although most YAs favoured individual sessions, it was decided to structure the intervention in the form of group workshops, acknowledging the focus of the intervention enhancing social interactions. Group workshops were chosen as these provide a supportive environment where participants can share experiences and learn from each other, fostering a sense of community and mutual encouragement that is particularly beneficial for YAs with CKD. This social interaction can help alleviate feelings of isolation and promote a sense of belonging, which is crucial for this age group. Group settings also allow for interactive and dynamic learning practises, where YAs can engage in discussions, participate in hands-on activities, and receive immediate feedback from peers and facilitators. This active engagement improves learning and retention of self-management skills. Group settings can also foster accountability among participants, as they are more likely to adhere to self-management practices when they are part of a supportive group that encourages and monitors each other's progress. Additionally, workshops can be more cost-effective and resource-efficient compared to individual sessions, allowing for the delivery of interventions to a larger number of participants within the same timeframe. Finally, group workshops enable facilitators to address common concerns and questions collectively, ensuring that all participants receive consistent and comprehensive information. It is recommended to deliver workshops at hospital clinics, if locally available, as preferred by the majority of YAs.

Intervention resources:

The researcher developed two resources to facilitate the implementation of the novel intervention. Namely, given the recognised lack of PCC plans in existing care, the resource for YAs involves a daily diary. The diary takes the form of a tailored PCC plan and aims to help YAs confidently create personalised plans during and outside the workshops, and equip them with appropriate self-management skills, including those principal skills coined by Lorig and Holman (2003), discussed in previous Chapters. Namely, the strategies considered in the diary aim to enable YAs to identify problems and create and implement possible solutions, make informed decisions and take action, form partnerships with HCPs, and utilise resources (see

Appendix DDD for details).

The second resource was developed for the facilitators as a comprehensive guide sheet to help lead the workshops and guide YAs to implement their PCC plans. This comprises detailed step-by-step instructions for facilitators, including pre-workshop preparations, “during” workshop activities, and post-workshop wrap-up, as well as several examples and guiding prompts, and estimated times for each activity including breaks (see Appendix EEE for details). Finally, to offer improved guidance for both YAs and professionals, resources include adapted elements of a Brief Action Planning (BAP) tool discussed in Chapter 5, the evidence-based approach that facilitates collaborative PCC goal-setting and action-planning and supports busy practitioners.

Step 4 (evaluation of the proposed intervention):

Given that participating in social activities behaviour was identified as important to target in intervention for YAs with CKD and was chosen following quantitative and qualitative syntheses, we were unable to determine the outcome measure for target behaviour change in advance. However, we suggest evaluating behaviour change, while considering the HAPA’s constructs, by using published guidelines (Schwarzer, 2007) and utilising the questionnaire developed by Schwarzer (2008) by adapting it for use with the target behaviour. The brief psychometric scales (with a 4-point or 7-point response option) included in this questionnaire compromise the assessment of risk awareness, positive outcome expectancies, action, maintenance, and recovery self-efficacy, behavioural intentions, action, and coping planning, and these can be adapted accordingly to participation in social activities. Likewise, in the current intervention development, the researcher produced questions to evaluate the YAs’ stage by adapting from Lipke, Nigg, and Maddock's (2012) study (refer to Table 8.3).

8.4 Phase 3 - Intervention Proposal

The novel intervention designed for YAs with CKD comprises four face-to-face, group (between 6-12 participants) workshops, spaced over approximately two months. The workshops aim to address the three selected behavioural determinants, with the fourth workshop focusing on evaluating behaviour change, with the overall goal of improving YAs' participation in social activities within the context of CKD (see Table 8.2 below).

Table 8.2

Workshops Structure

Effective communication and self-advocacy skills to:		
Workshop/ Week	Aim	Estimated time for each Workshop[b] (hrs)
1	*Communicate needs, preferences, and worries associated with CKD*	6-7
2	*Deal with social perception and influence*	5-7
3	*Seek emotional support*	5-7
4[a]	Review of behaviour change	4-5

[a] 1-month post-workshop 3; [b] contingent on participants' engagement (includes breaks); *CKD* Chronic Kidney Disease.

The workshops were structured by combining motivational and volitional strategies and selecting BCTs that align with the HAPA. The motivational stage aimed to increase YAs' motivation and readiness to improve communication and self-advocacy skills to communicate needs, preferences, and concerns, deal with social perception and influence, and seek support. Selected intervention strategies aimed to boost YAs' belief in their ability to change and engage in desired behaviours. Whereas, the volitional stage aimed to translate YAs' motivation into action. Strategies in this stage aimed to help YAs prepare for specific social situations and overcome barriers and challenges. Thus, combining both stages of the HAPA approach aimed to facilitate positive behaviour change, leading to enhanced participation in social activities in YAs with CKD.

The initial step in the workshops involves the needs assessment of YAs, particularly a stage assessment to determine whether YAs are currently located in the motivational stage (pre-intenders) or volitional stage (intenders or actors). However, it is important to acknowledge that although the proposed intervention assesses YAs' stages of readiness and considers stage-specific strategies, it is not stage-matched since it involves a group setting. However, the workshops were structured to accommodate and recognise the different stages of readiness for behaviour change among YAs. This flexible and adaptive approach enables facilitators to emphasise stage-specific effective strategies tailored to individual readiness to change, and it offers a possibility for future studies to apply stage-matched interventions in individual settings.

Specifically, in the current intervention involving a group setting, YAs' stages of readiness are indication points on a continuum, where they progress through these stages as they improve, assuming that they start as pre-intenders. Depending on which stage YA is at, different social-cognitive variables may be more or less significant. Previous studies (e.g., Lippke et al., 2005) established that the architecture of HAPA's social-cognitive variables, such as intention and planning, is stage-dependent. Knowing what stage YA is at will guide facilitators to identify which effective intervention strategies to emphasise based on their stage of readiness for behaviour change. Their stage can be evaluated by utilising the questions developed by the researcher (see example in Table 8.3 below). Whereas, when applied in the future as a stage-matched intervention, this stage assessment will allow for a greater personalisation to YAs' mindset by categorising them into different stages of readiness, utilising stage assessment as an outcome measure, tailoring tool, or both.

Table 8.3

Stage Assessment in Workshop 1

"Think back to the month before this workshop. Did you talk to someone about your needs, preferences, and worries associated with CKD? Please choose the statement that best describes you.				
1."No, and I do not intend to start"	2."No, but I am considering it"	3."No, but I seriously intend to start"	4."Yes, but only for a brief period"	5."Yes, and for a long period"
☐	☐	☐	☐	☐

Adapted from Lippke et al. (2012). *Note:* The above question is adapted to each Workshop, and YAs indicating 1 and 2 are categorised as pre-intenders, those indicating 3 as intenders, and 4 and 5 as actors.

The intervention utilises the resources for YAs to encourage the development of the PCC plan and for facilitators to guide YAs through this process. Detailed intervention content of each workshop is presented in

Appendix FFF, and a brief outline of all four workshops' content, structured based on the selected BCTs aligning with HAPA's stage-specific variables, is visually presented in Table 8.4 and each workshop is briefly described below. To attain a more comprehensive representation of the workshop's structure and content, accompany the description of the workshops below together with relevant Appendices DDD, EEE, and FFF.

Table 8.4

Brief Outline of the Intervention Workshops

HAPA stage (*Groups of YAs*)		
Motivational stage (*Pre-intenders*)	Volitional stage 1 (*Intenders*)	Volitional stage 2 (*Actors*)
Potential stage-specific variables/ mediators addressed[a]		
Self-efficacy (motivational) Risk perception Outcome expectancies Goal setting	Action planning Coping planning Social support Self-efficacy (maintenance)	Action planning Coping planning Social support Self-efficacy (recovery) Action control
Workshop 1: Intervention functions: *Education, Training, and Enablement*		
BCTs included in Workshops 1, 2, and 3		
5.1 Information about health consequences; 5.3 Information about social and environmental consequences; 1.1 and 1.3 Goal-setting (behaviour and outcome)	1.2 Problem-solving; 1.4 Action Planning; 1.8 Behavioural contract; 1.9 Commitment; 4.1 Instruction on how to perform the behaviour; 6.1 Demonstration of the behaviour; 8.1 Behavioural practice/ rehearsal	8.6 Generalisation of target behaviour; 8.7 Graded tasks; 10.9 Self-reward; 2.3 and 2.4 Self-monitoring of behaviour and outcome(s) of behaviour
Workshop 2 and 3: Intervention functions: *Environmental Restructuring, Persuasion, Modelling, and Enablement*		
Additional BCTs applied in Workshops 2 and 3		
2.2 and 2.7 Feedback on behaviour and the outcome(s) of behaviour; 1.5 and 1.7 Review behaviour goal(s) and outcome goal(s); 5.6 Information about emotional consequences[c]	6.2 Social comparison[b]; 3.1 and 3.3 Social support (unspecified)[b] and (emotional)[c]; 11.2 Reduce negative emotion[c]	12.2 Restructuring the social environment[b]; 6.3 Information about others' approval[b]
Workshop 4: Intervention focus: *Maintenance and Recovery phases*		
BCTs applied in Workshop 4		
2.2 and 2.7 remained	1.2; 4.1; and 3.1 remained	8.6; 8.7; 10.9; 2.3; and 2.4 remained, and the final homework included: 1.4; 1.8; 1.9; and 8.1

[a] Adapted from Schwarzer et al. (2011); [b] Workshop 2 only; [c] Workshop 3 only; *BCTs* Behaviour Change Techniques; *HAPA* Health Action Process Approach; *YAs* Young Adults. *Note:* intervention will be delivered by a credible source (BCT 9.1).

Workshop 1:

Workshop 1 was designed to improve YAs' communication and self-advocacy skills to confidently communicate their individual needs, preferences, and worries associated with CKD. First, the facilitators are instructed to prepare for workshops by defining objectives, planning agendas, gathering materials, checking the venue, and selecting icebreaker activities, with examples provided in the facilitators' resource. The latter is to be utilised in step 1, during the initial workshop, where facilitators begin by welcoming participants, introducing themselves, briefing YAs with the workshops' overview, getting to know them and building rapport. Then facilitators together with participants set ground rules to ensure a productive, respectful, and inclusive environment during group sessions, and note them down on the flipchart to ensure visibility and allow review when required. At the end of this introductory step, participants are reminded that their participation is voluntary, and facilitators are to be mindful of group dynamics and be prepared to adapt to needs, use simple-to-understand language, and encourage participants to use open-ended questions to expand on their responses. In step 2, facilitators assess YAs' stage of readiness by prompting them to answer the question developed by the researcher.

Following stage assessment, YA is considered as either pre-intender, intender, or actor, thus stage-specific intervention strategies may be emphasised. In the motivational stage, pre-intenders benefit from confrontation with outcome expectancies and risk perceptions by learning that communicating individual needs, preferences, and worries associated with CKD has positive outcomes (e.g., increased confidence and social interactions) as opposed to lacking these skills. Followed by group discussion, prompting a broader conversation of "What is the problem." Next, they form intentions by setting goals related to behaviour and the outcome of the desired behaviour and review them with facilitators to ensure that they follow SMART (Specific, Measurable, Achievable, Realistic, and Timely) goals adapted from the BAP tool. In situations where participants struggle to set personalised goals, facilitators are prompted to share 2-3 ideas drawn from their own experience (e.g., utilising champion patient's experience) or relevant concepts discussed in previous group sessions, if applicable (behavioural menu in BAP).

Whereas, intenders in the volitional stage 1, do not benefit as much from health messages because following setting goals, they have already moved beyond this stage. Instead, they may benefit more from planning to successfully follow through with their goals and translate their intentions into action. Planning is a key strategy for intenders who are motivated to change but do not act because they lack the appropriate skills to translate their mindset from intending into acting. Thus, the emphasis in this stage is on encouraging YAs to engage in both, action planning (determining when, where, and how to act) and coping planning (or problem-solving; anticipating potential barriers and planning personalised strategies to overcome them), to achieve their goals despite any obstacles they may encounter. Once discussed in the group and decided on an action plan, YAs' confidence to follow their plans is assessed on a scale of 0-10 scale, and facilitators check whether there is anything that can increase their confidence (if indicated >7 on the scale), potentially referring to the behavioural menu from BAP to suggest ideas. If YAs indicate that their confidence could be improved, they are directed to restate their plan and rating, otherwise, they are asked to commit to practising the skills by signing the behavioural contract together with facilitators.

Finally, the volitional stage 2 prepares acting YAs, who already translated their intentions into actions, by equipping them with relapse prevention strategies for specific high-risk situations where they may be more likely to experience setbacks and may need to take additional steps to avoid lapses. In this stage, to bridge the gap between theory and practice, YAs are provided with homework to continue practising skills learned at the workshop in real-life scenarios, starting with an easy-to-perform task and gradually increasing task difficulty once confident with performing the first task. Participants are also encouraged to self-reflect and self-monitor their behaviour and its outcomes and note them down daily in their PCC plans, as well as self-praise when progress has been made.

Furthermore, since self-efficacy is necessary throughout the entire process of behaviour adaptation and maintenance, and it changes as individuals pass through different stages of change, the current intervention targets different self-efficacy strategies in different phases of YA's mindset. For instance, as presented in Table 8.4 above, motivational self-efficacy is targeted by the goal-setting phase, whereas volitional self-efficacy (subdivided into maintenance and recovery self-efficacy) is addressed by the goal-pursuit phase. Additionally, to promote engagement and collaboration, tailor workshops to different learning styles, and enhance learning, all workshops were carefully structured by breaking up content delivery with interactive activities, including brainstorming, role-playing exercises, and group discussions. To further encourage learning, for each activity participants are stimulated to brainstorm ideas before facilitators provide them with relevant information. Involving participants in role-plays within groups of three and engaging them not only to act as YA participants (patient, employee, or student), but also as professionals, employers, and teachers, significantly increases their understanding and provides them with a holistic perspective on different viewpoints. Involving participants in the role of observers, tasked to provide constructive feedback, allows for an inclusive learning cycle that fosters reflection and empathy, improves effective communication skills, and further promotes a greater understanding of different viewpoints and dynamics. Overall, this multidimensional approach provides YAs with a comprehensive toolkit for interpersonal interactions, effective communication, and self-advocacy, which they can utilise in a range of real-life situations.

At the end of the workshop, facilitators together with YAs schedule the next workshop, summarise the workshop’s key points, encourage participants to ask questions and share their final thoughts to address any doubts or concerns they may have, and request verbal feedback from YAs on the session to indicate any areas of improvement for future workshops. Participants are reminded to take home the provided resource to enable homework and daily recording and are encouraged to use this networking opportunity and exchange contact information with workshop peers to foster ongoing learning, collaboration, communication, and discussions beyond the workshops.

Examples of main activities in Workshop 1:

1) Introduction (icebreaker activity and setting ground rules) 2) stage assessment 3) recognition of positive and negative health outcomes, followed by group discussion and broader discussion and identification of the problem 4) individual goal-setting and group discussion 5) identification of barriers and personal strategies to

overcoming these barriers, followed by group discussion 6) individual action-planning and written commitment 7) brainstorming exercises and group discussion 8) role-playing exercises followed by group discussion 9) discussion on homework (role-playing real-life scenarios) and self-reflection.

For a more detailed description, and breakdown of activities included in Workshops 2, 3, and 4, refer to

Appendix FFF.

Workshops 2 and 3:

Workshops 2 and 3 were structured similarly to workshop 1 and were designed to further improve YAs' communication and self-advocacy skills, particularly to confidently 1) deal with social perception and influence, including social judgment, stigma, discrimination, and peer pressure, and 2) seek emotional support from peers and family. Each subsequent workshop requires facilitators' pre-preparation by revising steps from Workshop 1, with the addition of Workshop 2 reviewing and adapting to YAs' feedback on the previous session. Facilitators remind YAs about previously set ground rules, re-establish rapport, and ask them how they have been doing since the last workshop, how their homework went, and whether they have any concerns they would like to discuss. Followed by brief constructive feedback on their learned skills, while addressing any areas of improvement and reinforcing successful performance, with examples of positive affirmations provided in the guide. Next, the participants undergo the stage assessment again, specific to behavioural determinants addressed in Workshops 2 and 3.

Correspondingly to the former Workshop, in Workshops 2 and 3, YAs go through the self-regulatory process of goal-setting (motivation) and goal-pursuit (volition), where pre-intenders are motivated by restating their outcome expectancies and risk perception relevant to behavioural determinants 2 and 3, and their intentions are formed by reviewing previous and setting new SMART goals related to relevant behaviours and outcomes of these desired behaviours. Then, the intenders' mindset is addressed by prompting YAs to detail action-planning and problem-solving specific to targeted behaviours, and their confidence to follow the new action plans is reassessed, and a new behavioural contract is signed. Thus, as in the first workshop, appropriate BCTs were selected to bridge the intention-behaviour gap, particularly both action and coping planning, as well as action control, namely self-monitoring. By keeping a daily record in the form of a diary, motivated YAs may become more aware of benefits and deficits, leading them to take further action.

Additionally, both workshops adapted (from Workshop 1) stage-specific self-efficacy strategies and workshop structures and strategies that promote engagement and learning. Group discussions, brainstorming and role-play exercises were adapted to further improve communication and self-advocacy skills in two different social aspects. Homework was also modified to prepare and encourage acting YAs to practice new skills, self-reflect, and self-monitor. However, some additional intervention strategies were utilised in both workshops. As per the newer version of HAPA (Schwarzer et al., 2011), the current intervention recognises the importance of barriers and resources. Predominantly, social support (unspecified and emotional) was employed to aid in facilitating the change process. YAs are stimulated to think about whom they could contact for encouragement for desired behaviours (Workshop 2) and emotional support when required (Workshop 3). Facilitators suggest a workshop buddy if participants made connections in the previous workshop, and provide YAs with relevant resources, such as peer groups, if locally available, or online forums. Moreover, both workshops begin with discussions about any issues that participants may have faced when performing activities at home, to recognise and address any barriers to enable resuming behaviour if interrupted, followed by facilitators' feedback on YAs' achievement. This addition of the provision of constructive feedback and discussion on any potential obstacles as YAs adopt new behaviours aims to motivate them to continue and maintain behaviours.

Workshop 2 addressing communication to deal with social perception and influence, includes three further BCTs. It involves social comparison in brainstorming exercise 2, where at the end of the practical exercise facilitators provide YAs with examples demonstrating the ideal responses to each scenario and encourage them to self-reflect and compare with their performance. Further, the homework adapted for Workshop 2 involves restructuring the social environment and information about others' approval, where participants are encouraged to identify strategies to rearrange their social environment to enable the positive performance of desired behaviour and seek others' approval and opinion on their performance.

Whereas, Workshop 3 involved two additional BCTs to target YAs' communication skills to seek emotional support. During this workshop, participants are also encouraged to think about outcome expectancies and risk perceptions, but with the addition of consideration of the impact on their emotional well-being. Additionally, they are stimulated to brainstorm potential situations that may require them to seek emotional support, and then in the subsequent task (role-playing exercises), they are encouraged to think of strategies to help them reduce negative emotions caused by specific situations, followed by facilitators adding other stress management strategies not listed by participants. Thus, they learn not only how to seek emotional support but also relevant strategies to reduce negative emotions. Finally, to conclude each workshop, facilitators summarise key points, encourage clarifying questions, and agree on the next session.

Workshop 4:

The final workshop aims to review YAs' behaviour change and focuses primarily on the maintenance and recovery phases to continue to progress towards behaviour change, prevent and overcome setbacks, and regain commitment. The workshop begins like the previous two workshops, and the participants undergo the last stage assessment, adapted to review their stage progress from the first workshop, this time for all three behavioural determinants, and together with facilitators review their stage improvement accompanied by facilitators verbal feedback. For this last workshop, it is expected that pre-intending participants have already progressed to intending or acting on their goals YAs. Therefore, reviewing and setting new goals was not included in this stage. However, if the assessment categorises the participant as a pre-intender, the guide advises a review and new SMART goals, otherwise, facilitators initiate discussion on relapse and prevention strategies by explaining the concept of relapse and its role in behaviour change. The participants are made aware that setbacks are a normal part of the process and relapse prevention is an ongoing process, and are stimulated to consider participation in social activities and individual triggers that may lead to relapse, resulting in the first activity.

Subsequently, facilitators encourage YAs to share their ideas with everyone and visibly note down potential triggers on the flipchart to refer to when discussing relapse prevention strategies. To enable this discussion, participants are tasked to brainstorm in small groups all possible preventive strategies they can think of for each identified trigger. This takes the form of coping planning to further prepare participants for anticipating potential barriers and future problem-solving when faced with obstacles. At the completion, the potential triggers that may cause a relapse and various prevention strategies are debated in the group discussion, where facilitators suggest additional strategies that were not mentioned.

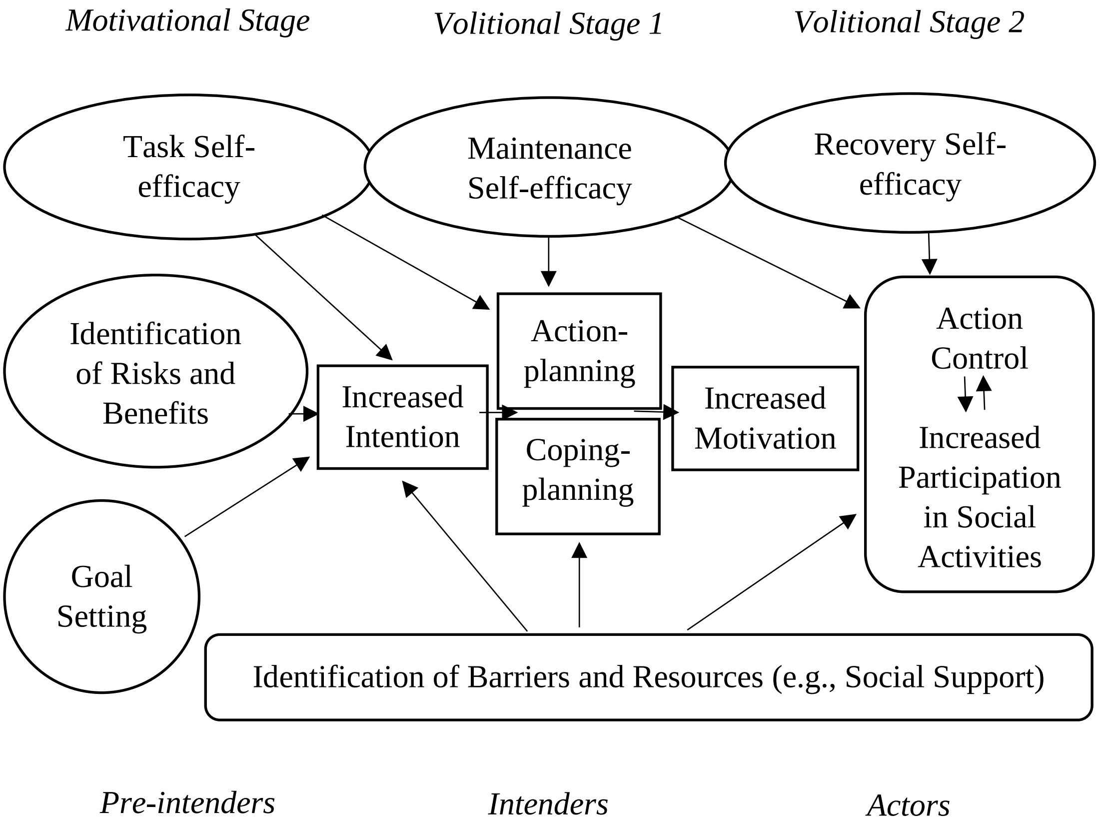
Following the refreshing break, the workshop shifts its focus from preventing setbacks to further equipping YAs with strategies to help them overcome barriers and get back on track if they experience a relapse. Coping planning and action control are continued to be encouraged in group discussion and the final homework, by adapting the topic and exercises to the recovery phase. Self-monitoring is further promoted by the continuous development of PCC plans, adapted to participation in social activities, beyond workshops. YAs are reminded that different strategies work for different people, which led to structuring the final homework to ensure the identification and implementation of individualised prevention and coping strategies that resonate with them. Additionally, social support remains included in this final workshop, where participants are tasked to identify whom they could contact for support when they experience setbacks, and facilitators re-emphasise the importance of ongoing support and suggest establishing a means for participants to stay connected to continue sharing progress, challenges, and success beyond workshops.

Finally, facilitators conclude by summarising the workshop’s key takeaways, addressing any final concerns that participants may have about any skills learned throughout all workshops, and thanking YAs for their active participation and engagement. At the end of their PCC plan, YAs are left with a motivational message emphasising the beginning, as opposed to the end, of a journey towards progress beyond workshops. They are advised not to face this journey alone and not to be discouraged by setbacks since these are normal and part of the ongoing relapse prevention process. Lastly, participants are encouraged to stay in touch, look out for opportunities to connect with fellow participants and expand their overall social network.

In Figure 8.2 below, the logic model is presented, illustrating how the proposed intervention, influenced by the HAPA’s stage-specific variables, may operate.

Figure 8.2

HAPA-Based Logic Model



Adapted from Schwarzer (2016).

8.5 Phase 3 - Discussion

The novel intervention targeting YAs’ participation in social activities behaviour is well-grounded in the understanding and recognition of the challenges this specific population faces, the importance of social factors in their lives, the need to sustain social and occupational roles, and the impact of socialising and peer pressure. By empowering YAs to navigate social challenges and pressures, and seek support, the novel intervention has the potential to support their transition into adulthood with CKD. Essentially, the current intervention development in phase 3 resulted in highly tailored to YAs with CKD, theory-based, structured workshops offering optimal psychosocial support by improving YAs’ communication and self-advocacy skills in three diverse social aspects (refer to Table 8.2).

Selecting and addressing these three behavioural determinants in the current intervention targeting participation in social activities is supported by previous studies. For instance, a recent focus group study (Cardol et al., 2022) on psychosocial barriers and enablers for adherence to a healthy lifestyle among individuals with CKD concluded from their findings from patients and HCPs that social environment is often perceived as a barrier, whereas social support as a facilitator, implying the need for BCTs that promote social support. To address this, the interviewees suggested teaching individuals with CKD interpersonal skills to voice their needs and ask for the support they require and prefer (Cardol et al., 2022).

Another study examining the role of social support in self-management within education and employment settings for YAs with end-stage kidney disease (ESKD) identified barriers (e.g., social judgment) and enablers (e.g., effective communication) to social support formation (Rupp et al., 2021). Particularly, effective communication was recognised as crucial to seeking social support. The interviewed YAs with ESKD listed some communication styles to successfully communicate and form relationships with employers and teachers (e.g., sustaining direct contact). They reported that by discussing their condition and forming support networks, they were able to access accommodations that allowed them to manage their CKD in the social environment (Rupp, et al., 2021). The proposed innovative intervention addresses these recognised needs specific to the young population with CKD, and gives YAs a voice to effectively communicate and self-advocate their requirements and concerns, assertively deal with social perception and influence, and seek support when required.

This novel intervention is considered personalised to YAs with CKD as it was developed based on comprehensive feedback from both YAs and their health and social care professionals who participated in both quantitative and qualitative studies. This collaborative approach ensured that the intervention addressed the specific needs, preferences, and challenges faced by YAs with CKD and those who look after them. The intervention is also structured around the HAPA, incorporating motivational and volitional strategies that align with each YA's stage of readiness for behaviour change. This design allows facilitators to identify and emphasise stage-specific strategies, making the intervention highly relevant for each participant. The workshops aim to boost YAs' belief in their ability to endorse desired behaviours and prepare them for social challenges, thus aiding in facilitating positive behaviour change. Furthermore, the initial needs assessment determines whether YAs are in the motivational or volitional stage, enabling a more focused and personalised approach within the group setting. Although not strictly stage-matched, the intervention is adaptable and recognises the different stages of readiness, providing tailored support to each YA. This flexibility ensures that the intervention remains responsive to individual progress and barriers, enhancing its personalisation. This flexible approach allows for individualised focus within the group context, laying the foundation for future studies to implement stage-matched interventions for even greater personalisation. Thus, the intervention's design is personalised by focusing on the specific social-cognitive variables that are significant at each stage of behaviour change, guided by initial assessments and continuous adaptation throughout the process.

Additionally, there are many strengths of the current intervention development. One of the most significant strengths is that the researcher takes a holistic approach to address the complex and multifaceted needs of YAs. Highly tailored workshops’ content that incorporates several components targeting cognitive, emotional, and behavioural aspects, ensures that participants receive appropriate and meaningful content which resonates with their unique circumstances. The researcher’s teaching qualification and extensive training experience in regularly delivering group sessions, including group discussions and role-plays, aided in structuring the workshops to prioritise inclusivity, foster motivation, promote engagement and active participation, and decide on the optimal number of participants in group workshops. The intervention involves collecting and providing regular feedback, adapting the content to different learning styles and participants’ preferences, and incorporating a range of diverse activities. The inclusion of interactive activities that emphasise transferable skills, fostering the integration of learned skills into various social situations, safeguards that the intervention aligns with the real-world situations and needs of the targeted audience.

Further, the activities chosen for all four workshops were considerately developed to address the broader issues identified in the current qualitative study.

For example, all interviewees expressed concern over the lack of CKD awareness and understanding, YAs felt that explaining their condition was a burden, and many reported being pressured by their peers. To address this, the brainstorming exercises in Workshop 2 involve challenging stigma and stereotypes, whereas role-playing exercises address assertive responses to peer pressure. Some scenarios reflected YAs' real-life examples. For instance, during interviews, YAs stated that CKD is often misjudged as an old person's disease. This example is included in one of the scenarios where YAs are encouraged to practice dismissing myths and stereotypes and addressing situations assertively. Creating activities that reflect specific issues faced by YAs, further caters to their needs in the current intervention.

In addition, the novel intervention is constructed upon extensive evidence-based strategies and techniques, drawing from established behaviour change and psychological theories and research findings, which is another significant strength of this study. The selected theories informed the pathways of behaviour change and guided intervention development. Including the HAPA as a theoretical framework allowed for consideration of diverse YAs' mindsets, targeting different self-efficacy strategies in diverse phases of readiness, while ensuring bridging the gap between intention and action. Moreover, given the increased focus on maintenance and recovery phases, especially in the final workshop, and equipping YAs with practical evidence-based skills and strategies to continue implementing positive changes beyond workshops, the intervention has the potential to enhance the likelihood of achieving positive and long-lasting change.

The principles of the HAPA have proven to be effective in the general population, however, little is known about the key variances between individuals with several chronic conditions and their unique needs (Schwarzer et al., 2011). Previous studies that included HAPA's principles and people with various chronic illnesses (e.g., Ziegelmann et al., 2006) show successful results for planning interventions and action control programs, focusing mainly on intenders and actors. However, pre-intenders and maintainers also need effective intervention, and according to Reuter and colleagues (2008), interventions focusing on intenders or maintainers are promising, but need further development and testing. The novel intervention considers all stages of YAs' change, thus opening the possibility of evaluating behaviour change in all stages in future research.

It is also important to note that employing BCTs in the intervention development for YAs with CKD was strongly supported by all professionals in the current interview study, who acknowledged the importance and benefits of using BCTs, but noted that these are not utilised in current care. Similarly, the inclusion of PCC plan development addresses the lack of important individualised plans recognised in the current quantitative study. While this novel intervention may not be considered a typical SMI, it is believed that incorporating evidence-based strategies into YAs' personalised care coordination, in the form of PCC plan development, can empower YAs by equipping them with skills to establish goals, engage in proactive action and coping planning, and consequently enhance their CKD self-management within social settings. Frequently utilising this resource going forward may potentially address the issue of consistency in care, identified in phase 2, and it facilitates co-production and ownership. Whereas, the comprehensive facilitators' guide sheet may be employed to ensure the consistent and appropriate use of stage-specific tools and strategies, while confidently guiding YAs in their behaviour change journey.

Additionally, given that the current qualitative synthesis revealed that YAs struggle financially, it is recommended to include a Kidney Wales Patient Support Pack 2023, recently published by the study stakeholders, to be distributed to participants at the end of the intervention (accessible from https://kidneywales.cymru/patient-resources/). This brief resource offers volunteering opportunities, educational events, access to information on CKD and financial advice. Further, it is anticipated that including peer education will support both YAs and HCPs, lessen YAs' fear about CKD and its consequences, improve their confidence in communicating their needs and desires, and positively impact their daily self-management, as indicated by previous studies on YAs with CKD (e.g., Sattoe et al., 2013). The inclusion of a champion patient will also increase the credibility of facilitators, ensuring that the entire intervention will be provided by a "credible source". However, it is suggested that both facilitators, nurse and champion patient, undertake competence training in teaching and BCTs.

Furthermore, the researcher employed rigorous and systematic methods to develop the intervention, guided by a four-step approach (French et al., 2012) and APEASE criteria. Employing the latter, allowed for resolving disagreements and reaching team consensus on several decisions throughout the entire process. Whereas, combining BCTs and TATT, while considering MoAs, allowed for a systematic and consistent approach to identifying the active elements within the intervention strategies and understanding how they facilitate the behaviour change, and including the HAPA in the process offered a clear and comprehensive theoretical foundation for this integration. To date, intervention developers tend to use theories, empirical literature, and common sense when identifying the most appropriate BCTs to employ. However, in the current intervention development, the researcher additionally consults their decisions utilising the TATT tool for modifying MoAs considered relevant for changing target behaviour and ensures that selected BCTs align with the HAPA (e.g., those promoting self-efficacy, and motivational and volitional constructs of the model).

Additionally, systematic reporting of the current intervention described using defined terminology (e.g., BCTs) and its theoretical underpinnings facilitates intervention replication and implementation, and recognition of MoAs allows for future assessment of the theoretical mechanisms influencing behaviour and may serve as an important reference for future research. There is also a potential of utilising the proposed intervention’s content and structure in the recently planned mobile app development for YAs with CKD, discussed by professionals during the interviews who emphasised the use of technology with this specific cohort. Particularly, one professional who expressed their intention to develop an interactive mobile app for YAs with CKD, hoped that the findings of the present research would aid in the development, and particularly tailoring the app to YAs’ needs and their readiness for behaviour change, which is currently lacking in current care. Incorporating the novel intervention into an app will facilitate stage-matched intervention. The potential for future research to adapt the proposed intervention to an individual context and explore and refine this technology-driven approach is a promising avenue for improving the impact and scalability of this novel intervention. Moreover, when implementing the proposed intervention as stage-matched, patient activation levels, discussed in Chapter 5, could be adapted in place of the current stages of change given their corresponding levels. Lastly, while the researcher had no previous experience in the use of BCTs, their competence in its application to specify the intervention content was safeguarded by the completion of comprehensive BCTTv1 online training. Nevertheless, there are some limitations to the study.

First of all, while the proposed intervention holds promise, it has not yet been evaluated in robust assessment methodologies, and thus we are unable to definitively conclude its effectiveness, reliability, validity, impact, and sustainability for the intended audience. Accordingly, this study is limited by drawing inferences based on theoretical frameworks included in the study, offering a conceptual basis for understanding how the proposed intervention may operate. However, these assumptions need to be evaluated through empirical investigation, thus we recommend robust assessment in the future, preferably longitudinal controlled trials, to resolve uncertainties about the intervention's outcomes, and its feasibility in real-world settings, and to capture changes over time.

Another shortcoming of this novel work involves some challenges experienced by the researcher when assessing the problem. Typically studies structure interviews around TDF questions, but in the current study, codes were generated inductively from interview synthesis, and these fitted the TDF well. However, deductively identifying TDF domains relevant to these barriers/enablers caused difficulty operationalising the TDF, hypothetically leading to some domains being underrepresented or not explored. Additional analysis was required to further select appropriate behavioural determinants to ensure that these are modifiable at the YAs' level. Given that the TDF was initially developed for HCPs' behaviour (Michie et al., 2005), it was challenging to translate some domains to YAs' behaviour. These difficulties were resolved by team discussions and consensus.

Although employing the group settings and personalisation of the intervention has its benefits, it is important to acknowledge some limits to this approach. The group setting offers a supportive environment where YAs can share experiences and learn from peers, fostering a sense of community and reducing feelings of isolation. However, this format can also pose challenges in delivering truly personalised care, as it requires balancing group dynamics with individual needs. While the intervention is designed to be flexible and adaptive, recognising different stages of readiness among participants, there remains a potential for some individuals to feel that their unique circumstances are not fully addressed. Future development of this novel intervention might benefit from integrating more individualised components, such as one-on-one sessions or personalised digital tools, to complement the group workshops. This hybrid approach could enhance the personalisation and effectiveness of the intervention, ensuring that each YA receives tailored support that aligns closely with their specific stage of readiness and personal context.

Finally, it should be noted that the initial behavioural diagnosis resulted in barriers and enablers across almost all domains of the COM-B and TDF matrix, suggesting that most intervention functions from the BCW framework were potentially relevant and modifiable at YAs, professional, and service levels. However, the assessment of the problem intends to narrow down intervention options focusing on one or two TDF domains (Michie et al., 2014a). The current intervention focuses on barriers/enablers modifiable at the YAs' level and the assessment of these at professional and service level was not within the scope of this study. Future research may benefit from exploring wider factors influencing YAs' participation in social activities by assessing and addressing barriers/enablers adaptable at professionals (e.g., enhanced patient education) or service levels (e.g., improved accessibility to facilities). Lastly, as acknowledged by critics of highly structured group-based programmes based on Lorig and Holman's (2003) self-management skills in Chapter 5, group settings decrease isolation and thus foster self-efficacy, but these settings do not suit everyone and make it difficult to address individual needs. While the novel intervention maintains a robust structure, it promotes flexibility to accommodate individual requirements. However, to further enhance its tailoring, we recommend the adaptation of this novel intervention for individual settings (e.g., a mobile app discussed above).

8.6 Phase 3 - Conclusion

As far as this research indicates, this is the first behavioural SMI targeting YAs' participation in social activities in the context of CKD. This novel intervention is characterised by a high level of tailoring to YAs' needs and preferences, drawing on both evidence and theory, aimed to facilitate enablers and break down barriers commonly encountered by YAs with CKD, by focusing on improving their communication and self-advocacy skills to navigate their social environment effectively and confidently. Thus, the intervention's benefits lie in its individualised approach and established evidence, maximising its possible effectiveness, relevance, and potential to produce positive and long-lasting change.

8.7 Chapter Summary

This Chapter proposed innovative YA-centred, theory-based behavioural SMI aimed at empowering YAs by providing them with the necessary support and strategies to improve their confidence in navigating their social environments, ultimately improving their CKD management and overall well-being, and suggested recommendations for future research and intervention evaluation. In the following final Chapter 9, each phase of this research project is briefly discussed and concluded, considering the overall research and its implications.

Chapter 9: Final Discussion and Conclusion

9.1 Introduction

In each phase of the current study, research rationales were provided and a comprehensive discussion of the findings was conducted, along with an examination of the studies' strengths and limitations. The implications of findings for practice, policy, and future research were also thoroughly explored, particularly in relation to each phase and the importance of each finding in the intervention development. This Chapter includes the final discussion (section 9.1.1) and conclusion (section 9.1.2), considering the overall research and its implications.

9.1.1 Overall Discussion

Phases 1 and 2 of the current research, which served as a needs assessment for phase 3, provided preliminary insights that helped recognise the intervention objectives specific to young adults (YAs) with chronic kidney disease (CKD) and establish measurable and realistic goals to guide the intervention development. The literature review (phase 1) revealed high-quality evidence that self-management interventions (SMIs) improve self-efficacy compared to usual care. Further, it was established that interventions that utilise, for instance, self-regulation theory, behaviour change techniques (BCTs), and Social-Cognitive Theory (SCT) with the principles of problem-solving, while employing multiple intervention topics (most commonly CKD knowledge, diet, medication, and symptom management) presented in various formats and provided by nurses or multiple providers were associated with improved outcomes. A noticeable paucity in the literature concerning the lack of personalised, theory-based interventions was also identified.

The findings from surveys and interviews in phase 2 yielded insights and suggested the optimal support for YAs (aged 18-35 years old) with CKD by shedding light on their existing self-management behaviours and identifying specific factors the interventions should target to improve their CKD self-management practices and overall well-being. The similarities in the findings between the quantitative and qualitative analyses indicated a strong agreement concerning the unmet needs, the importance of social factors, the occurrence of psychological disorders, and inconsistent care faced by YAs with CKD. Whereas, the discrepancies between the findings from the two analyses suggested the complexity of disease self-management and emphasised the necessity of obtaining a comprehensive understanding of the various factors that influence it. Considering both quantitative and qualitative perspectives from YAs and their professionals allowed for a more holistic approach to the intervention development aimed at addressing challenges and improving the overall care for YAs with CKD.

In phase 3, further analysis of the qualitative data identified modifiable barriers and enablers specific to the recognised target behaviour. This allowed for a nuanced understanding of the unique needs and preferences of YAs facing CKD challenges. It was recognised that YAs are currently proficient in managing their self-care tasks daily, but psychosocial issues, including anxiety, and lack of social connections and support, present specific challenges for them that affect their daily lives and CKD management. Consequently, by building on the insights gained from previous phases, it was decided that to best support this unique cohort, while considering their specific needs and challenges, YAs would benefit from intervention targeting their participation in social activities. To improve their social engagement, the intervention aimed to enhance YAs’ communication and self-advocacy skills in three areas, particularly to 1) communicate individual needs, preferences, and worries associated with CKD, 2) deal with social perception and influence, and 3) seek emotional support. Finally, to address the evidence gap recognised in Phase 1, the novel behavioural SMI intervention was personalised to YAs and based on relevant behaviour change theories. This highly tailored, theory-based intervention holds promise by addressing this demographic's specific requirements and preferences, ultimately offering a targeted approach to fostering their participation in social activities in the context of CKD.

A recent systematic review by Moreels et al. (2024) and the patient voice study by Trunk (2024) highlighted the importance of SMIs in enhancing life participation for individuals with kidney failure. Moreels and colleagues' (2024) systematic review of existing SMIs, emphasised the critical role of life participation, which includes medical, emotional, and everyday life management, in improving quality of life (QoL) and reducing mortality. They found that while most interventions focus on medical management, there is a significant need for strategies addressing everyday life aspects, such as daily activities, work, leisure, mobility, relationships, and social participation. Trunk's study (2024) echoes these findings, with patient feedback highlighting the relevance of these life-participation areas and calling for more targeted interventions. Both studies align with the current research aimed at developing SMIs for YAs with CKD, suggesting that enhanced psychosocial support could benefit YAs, but also a broader age range.

Further, other recent studies, particularly the randomised controlled trial (RCT) by Mueller-Weinitschke, Bengel, Baumeister, and Kramer (2023) and the systematic review and meta-analysis by Yang, Qi, and Pei (2024) both highlight the effectiveness of psychosocial interventions in reducing depressive symptoms. Mueller-Weinitschke et al. (2023) demonstrated that a web-based Behavioral Activation intervention grounded in the Health Action Process Approach (HAPA) significantly improved clinician-rated depressive symptoms in individuals with depression, also improving motivational and volitional outcomes. Yang et al. (2024) extended this understanding by systematically reviewing and analysing several studies, concluding that psychosocial interventions are effective in decreasing depression levels in adults with CKD. These findings support the notion that integrating psychosocial support within self-management interventions can enhance the QoL for CKD patients, thus strengthening the importance of addressing both mental health and motivational components in therapeutic strategies.

Research’s strengths and limitations:

One of the strengths of the current study was the conduct of a thorough literature review which revealed important information for future studies and the current intervention development phase. However, in phase 1, the effect of SMI on CKD self-management, knowledge, and estimated glomerular filtration rate (eGFR) outcomes was limited by inconsistency and imprecision in the results. We were unable to conclude on the treatment effect, and to statistically determine which key elements of SMIs were more effective as it could not be quantitatively estimated for all these outcomes due to noticeable heterogeneity and lacking data.

While the systematic literature review provided preliminary insights into CKD SMIs, its primary focus on broader age groups or older adults limits direct applicability to YAs aged 18-35 with CKD. The identified strategies offer foundational principles that can be adapted for YAs. However, variations in lifestyle, psychosocial factors, and health priorities necessitate tailored interventions. Phase 2 of this study addressed these concerns to some extent by directly engaging YAs, and those who look after them, to understand their preferences for support delivery and intervention content. Moving forward, future research should prioritise developing and testing SMIs specifically designed for YAs to improve engagement, adherence, and health outcomes in this demographic.

The overall research design, which involved the addition of qualitative findings (rich data) to complement the results of the quantitative study (thick data), is another strength of the study. By combining the findings from different data sources, the current study enhances the validity and depth of the results. Both quantitative surveys and qualitative interviews revealed diverse and comparable findings. Additionally, the inclusion of health and social care professionals’ views and opinions, alongside YAs in both studies, was another advantage of the current research. By incorporating the perspectives of professionals, the study gained valuable insights into the complexities of providing care for YAs with CKD. These insights may contribute to enhancing the support and interventions offered to YAs, and recognising areas for improvement within the healthcare system. Including professionals broadens the scope of the research and ensures that findings are grounded in the experiences, views, and expertise of those directly involved in YAs’ care, adding depth and richness to the findings, and enhancing the overall understanding of the factors that influence the care and support provided to this specific population.

However, while their perspectives are valuable for understanding the professional viewpoint and identifying practical implementation strategies, their views may introduce biases that do not fully align with the lived experiences of YAs with CKD, potentially impacting the development of a user-centred intervention. The potential for conflicting perspectives between YAs and professionals may complicate the development process and require careful synthesis of the data to ensure the final intervention is both YA-centred and feasible within the healthcare system. Balancing these professional insights with the direct experiences of YAs in the current interview study aided in developing SMI that addresses both practical and emotional needs. Moreover, although it was not the aim of the current research, findings from phase 2 may not be transferable or generalisable to other age groups or populations. The specific challenges and preferences of YAs with CKD may differ from those of older patients or individuals with different chronic conditions.

Furthermore, this research has a few notable limitations that need to be addressed. Firstly, the current research is limited by the small sample size and the use of a cross-sectional design, relying on a single-time-point analysis. This limited scope may hinder the reliability of the results and limit the researcher’s ability to draw robust conclusions. In the quantitative analysis, only one out of four main analyses achieved sufficient statistical power, further raising concerns about the reliability of the results. Additionally, while the qualitative study reached saturation, there was an imbalance in the number of males and females limited by CKD stages 3 and 5 and YAs’ ages, further affecting the generalisability of the findings to this specific demographic. These limitations should be considered when interpreting the study’s conclusions.

While the cross-sectional design allowed for capturing a snapshot of the current self-management behaviours, psychological characteristics, and clinical factors among YAs with CKD at a single point in time, due to the study's cross-sectional nature, it was impossible to determine whether certain predictors directly influenced outcomes or if observed relationships were due to other unmeasured factors. Additionally, while the study utilised validated scales and ensured that assumptions for regression analyses were met, the small sample size raises concerns about the generalisability and robustness of the findings. The limited number of participants may not fully capture the variability and complexity of the broader YA population with CKD. Further, while the group setting of the intervention fosters peer support and community, it may limit the extent of personalisation achievable. Balancing group dynamics with individualised care remains a methodological challenge that future research should address, potentially through a hybrid model combining group and individualised components. Despite these limitations, the methodology provided valuable insights and laid a foundation for future longitudinal research to explore causative links and further validate the findings with larger, more diverse samples.

It is noteworthy that the process of recalculating the sample size for the revised study design and conducting additional post-hoc analyses demonstrates the researcher’s commitment to ensuring the study has sufficient statistical power and adapting to unforeseen challenges. While this approach is commendable for addressing the limitations of sample size and maximising the available data, it is important to acknowledge that the decision to limit the number of variables included in the statistical analyses may have resulted in the omission of important information. Particularly, by selecting a subset of variables for analysis, there is a possibility of overlooking potential relationships or associations that could have been captured by examining a broader set of variables. Thus, it is crucial to interpret the quantitative results within the context of the variables included in the current study and recognise the potential limitations of the analyses in capturing the entire complexity of the research question. In addition, the inclusion of several questionnaires in the original study design may have resulted in erroneous participant responses. Completing multiple questionnaires may have introduced survey fatigue or cognitive overload, potentially leading to hasty or careless responses.

Further, the novel intervention is limited by drawing inferences based on theoretical frameworks included in the study, offering a conceptual basis for understanding how the proposed intervention may operate. However, to ascertain its impact and potential for broader application in the management of CKD among YAs, its effectiveness needs to be rigorously evaluated in future research. Finally, it is worth noting Biglan’s (1987) criticism of the SCT (refer to section 4.4.2 in Chapter 4) highlighting a perceived limitation in neglecting the significant influence of the environment on behaviour. While self-efficacy theory from the SCT and

HAPA acknowledges the importance of personal determinants in behaviour change, interventions solely grounded in these theories might overlook the broader impact of environmental factors on individuals' actions. Although, the current intervention development based on the HAPA principles addresses the environmental or contextual barriers that could hinder YAs' behaviour change (e.g., social support), greater consideration and integration of additional environmental factors (e.g., social norms, policies and guidelines, and physical surroundings) would further benefit the novel intervention for behaviour change.

Implications for practice, policy, and future research:

Given the noticeable heterogeneity, lacking data, as well as inconsistency and imprecision in the results concerning the effect of SMI on CKD self-management, knowledge, and eGFR outcomes in phase 1, more evidence from high-quality studies, with a longer follow-up, and larger sample size, targeting YA demographic of 18 to 35 years is needed to support future CKD SMIs and to fully capture the diversity of experiences and needs within this cohort. Further, given that dialysis patients may have different self-management needs and goals compared to non-dialysis individuals as suggested in the current narrative synthesis, the difference in the interventions for these two groups should be investigated. Future research would benefit from a systematic literature review to thoroughly investigate the effectiveness of SMIs, while expanding on the set of databases (including grey literature), employing a more rigorous quality assessment for all included outcomes, incorporating various study designs beyond RCTs, and contacting the study authors for clarification to minimise potential bias in the review process.

Another recommendation for future research is to employ a larger sample size and optimise the overall study design to achieve sufficient statistical power. By increasing the number of participants, researchers can improve the robustness of findings and obtain more reliable insights into the relationships and differences between the variables under study. A larger sample size would also contribute to increased representativeness of the study population, improving the reliability and applicability of the findings to the wider target population. Additionally, future studies could explore the broader set of variables (e.g., those omitted in the current quantitative analysis and/or the assessment of sub-scales), in the alternative research design and/or analyses, to capture a more comprehensive understanding of the research question. By doing so, researchers can enhance the depth and breadth of the findings, obtain a more holistic view of the phenomenon under investigation, and potentially uncover new insights or patterns that may have been overlooked when only a limited set of variables was considered. However, in the future, researchers should carefully consider the number and complexity of questionnaires included in the study to mitigate the risk of potential participant fatigue and ensure the reliability of the collected data.

To further improve the qualitative study, future studies should also incorporate focus groups alongside individual interviews and include parents/guardians as originally intended in the research protocol (refer to Chapter 2). This would allow for the collection of multiple perspectives and enable the exploration of the interview topics from the viewpoint of parents/guardians as well. During the interviews, YAs expressed the importance of support from their parents. By interviewing parents, future research may gain a greater, more in-depth insight into enhancing YAs' self-management behaviours and supporting the transition of responsibilities from parents to YAs. Future interview studies should also include a broader age range to effectively guide the development of SMIs for YAs (aged 18-35) with CKD.

In the future, it may be beneficial to integrate both quantitative and qualitative studies in a mixed-methods approach to gain a more nuanced understanding of the experiences and needs of YAs with CKD at different stages of their disease trajectory. The combination of the strengths from both approaches will allow researchers to address the limitations and discrepancies identified in the current study, and it may provide a better understanding of the experiences and needs of YAs with CKD by capturing both statistical trends and individual experiences.

Additionally, given the recognised similarities in the findings between the quantitative and qualitative analyses, as well as the discrepancies between the findings from the two analyses highlighting the complexity of CKD self-management, future research and practice should prioritise obtaining a comprehensive understanding of the various factors that influence CKD self-management in this population. This could involve investigating additional factors (e.g., social support system, access to healthcare services, cultural influences, or socioeconomic factors) that may contribute to YAs' unmet needs, the presence of psychological disorders, and inconsistent care. Further, healthcare providers should consider the complex and multifaced nature of CKD self-management among YAs by taking into account not only their physical aspects of the disease but also their psychological and emotional well-being.

Furthermore, the iterative nature of the current intervention development in phase 3, together with the insights gained from each previous phase, positions this novel behavioural SMI as a potential, promising strategy for improving YAs' communication and self-advocacy skills to navigate their social environment effectively and confidently, and ultimately improving their CKD management and overall well-being. As we move forward, the evaluation of this novel intervention will be critical in determining its effectiveness, relevance, and impact on the lives of YAs with CKD. Researchers should consider broader guidance to evaluate the intervention in the future. For instance, the previously discussed, recent United Kingdom Medical Research Council guidance (UK MRC, 2021) for developing and evaluating complex interventions may be instrumental in shaping the next steps of this novel intervention. This would involve going beyond asking whether the intervention works in regard to achieving intended outcomes, and the guide provides examples of a broader set of questions to address [see Skivington et al. (2021) for more details].

Considering this specific intervention, particular recommendations for its implications and evaluation can be suggested, tailored to its unique characteristics. For instance, in line with MRC (2021), the novel intervention should be evaluated to assess its feasibility and acceptability by gathering feedback, from both YA participants and intervention facilitators to gain an understanding of how well the intervention aligns with real-world situations. To ensure that the intervention remains relevant and responsive to the needs and preferences of the targeted audience, stakeholders, including YAs with CKD, their healthcare professionals (HCPs), and relevant community groups should be involved, not only in the development of the intervention but also in its evaluation process. The novel intervention may also benefit from the evaluation of integration with existing healthcare systems and clinical practices by assessing how well it aligns with the broader healthcare context and whether it complements the care provided by HCPs.

Additionally, as discussed in the previous Chapter, the mechanisms of change are crucial for refining and optimising the intervention components, thus the mechanisms through which the novel SMI influences participation in social activities in YAs with CKD should be investigated. The implications and evaluation process of the novel SMI should also consider its long-term impact on social activity participation among YAs, for example, by adapting the questionnaire developed by Schwarzer (2008), recommended in step 4 of the intervention development in the previous Chapter, and implementing the follow-up assessments at intervals to measure sustained behaviour change. Additional assessment may involve the cost-effectiveness evaluation to assess the economic implications of the novel SMI (e.g., assessing the costs associated with its implementation against the benefits gained).

Finally, we recommend the implementation and evaluation of the proposed SMI in a stage-matched intervention to assess how the novel intervention aligns with YAs' diverse stages of change. Particularly, implementing the novel intervention into a mobile app seems promising for this particular population. Similarly, it is also recommended to adapt the current intervention to patient activation levels (as per its corresponding levels with current stages of change, identified in Chapter 5, Table 5.3). This will allow for a more comprehensive evaluation of stages of readiness by utilising the patient activation measure (PAM), recently validated in the CKD population (Lightfoot et al., 2021), which could serve as an outcome measure (e.g., to evaluate interventions or change over time), tailoring tool (e.g., to tailor the intervention to YAs' level of activation), or both. By following these recommendations, this novel SMI can be comprehensively evaluated, aligning with the MRC guide for complex interventions.

9.1.2 Overall Conclusion

To my knowledge, this is the first behavioural SMI targeting YAs' participation in social activities in the context of CKD, empowering them to navigate their social environment, improve confidence, and enhance CKD management. This novel intervention integrates key components of person-centred care, focusing on the YAs’ unique needs, preferences, and experiences, while drawing from established theories to enable them to navigate social interactions effectively. Thus, the approach is individualised and evidence- and theory-based, increasing its effectiveness and potential to produce positive and long-lasting change. By emphasising the enhancement of communication and self-advocacy skills tailored to the YAs’ specific challenges, this new intervention not only fills a critical gap in existing support systems but also lays the foundation for a more supportive and inclusive environment. By fostering these pivotal skills, the intervention has the potential to increase YAs’ social participation, enhancing their sense of belonging and empowerment within their communities. The innovative nature of this behavioural SMI paves the way for improved social engagement and QoL for this specific demographic navigating life with CKD, highlighting its potential to significantly impact their well-being.

Although the intervention resulted in highly structured workshops, it offers flexibility to be implemented as a stage-matched intervention in individual settings (e.g., incorporated into a mobile app), allowing for greater personalisation to YAs’ mindset. Moreover, this novel intervention offers a conceptual basis for understanding how it may operate, however, these assumptions must be evaluated through empirical investigation in future studies. Given that this novel approach aims to support YAs who face the challenges of living with CKD, comprehensive assessment and ongoing evaluation are crucial. Future examination of the intervention's effectiveness, scalability, and long-term impact will not only validate the intervention’s efficacy but also facilitate potential refinements, ensuring its continued relevance and applicability.

In conclusion, this novel intervention for YAs with CKD, characterised by its group workshop format and personalised approach, offers a promising strategy aiming to facilitate positive behaviour change. The group workshops, grounded in the HAPA, offer a structured yet flexible framework that accommodates varying stages of readiness for behaviour change. By incorporating feedback from both YAs and their professionals through quantitative cross-sectional studies and qualitative thematic analysis, the intervention is tailored to the specific needs and preferences of its target audience. However, it is important to critically reflect on the methodology and the current stage of the intervention's development for future empirical studies.

Appendices:

Appendix A

STROBE Checklist

STROBE Statement - Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	**Recommendation**	**Page No**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	ii
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	ii
Introduction			
Background /rationale	2	Explain the scientific background and rationale for the investigation being reported	25; 49-51
Objectives	3	State-specific objectives, including any prespecified hypotheses	52
Methods			
Study design	4	Present key elements of study design early in the paper	29-31
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	31
Participants	6	(*a*) Give the eligibility criteria and the sources and methods of selection of participants	31-35
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	35-45; 49-52
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	35-45; 49-52
Bias	9	Describe any efforts to address potential sources of bias	62 (and Appendix - summary of ethical consi

			derations)
Study size	10	Explain how the study size was arrived at	31-33
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	52-54
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	52-54
		(*b*) Describe any methods used to examine subgroups and interactions	52-54
		(*c*) Explain how missing data were addressed	52-54
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	31-33
		(*e*) Describe any sensitivity analyses	N/a
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	207
		(b) Give reasons for non-participation at each stage	N/a
		(c) Consider the use of a flow diagram	Figure 6.1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	207-209
		(b) Indicate the number of participants with missing data for each variable of interest	N/a
Outcome data	15*	Report numbers of outcome events or summary measures	209-213
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	214-219
		(*b*) Report category boundaries when continuous variables were categorised	N/a
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/a
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	219
Discussion			
Key results	18	Summarise key results with reference to study objectives	Section 6.3
Limitations	19	Discuss the limitations of the study, taking into account sources of potential bias or imprecision.	Section 6.3

		Discuss both the direction and magnitude of any potential bias	
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Section 6.3
Generalisability	21	Discuss the generalisability (external validity) of the study results	Section 6.3
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Study protocol

*Give information separately for exposed and unexposed groups.

Note: *An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.*

Appendix B

COREQ Checklist

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal Characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	26
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	i (title page)
Occupation	3	What was their occupation at the time of the study?	N/a
Gender	4	Was the researcher male or female?	N/a
Experience and training	5	What experience or training did the researcher have?	264
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	Appendix "Ethical Considerations"
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Appendices: "Participants information sheet"; "Interview topic guide", and consent forms

Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	56-57
Domain 2: Study design			
Theoretical framework			
Methodological Orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	54-58
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	33
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	45-46; 48-49
Sample size	12	How many participants were in the study?	33
Non-participation	13	How many people refused to participate or dropped out? Reasons?	228-229
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	48-49
Presence of nonparticipants	15	Was anyone else present besides the participants and researchers?	No. 48-49
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	31-35
Data collection			
Interview guide	17	Were questions, prompts, and guides provided by the authors? Was it pilot-tested?	54 and Appendix "Topic Guide"
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	N/a
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	55-56

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Field notes	20	Were field notes made during and/or after the interview or focus group?	58
Duration	21	What was the duration of the interviews or focus groups?	229-230
Data saturation	22	Was data saturation discussed?	33
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	N/a
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	58-61
Description of the coding tree	25	Did authors provide a description of the coding tree?	N/a
Derivation of themes	26	Were themes identified in advance or derived from the data?	57-61
Software	27	What software, if applicable, was used to manage the data?	35-36
Participant checking	28	Did participants provide feedback on the findings?	N/a
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	58-61
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Section 7.2
Clarity of major themes	31	Were major themes clearly presented in the findings?	e.g, Figure 7.1
Clarity of minor themes	32	Is there a description of diverse cases or a discussion of minor themes?	Section 7.2

Developed from: Tong, A., Sainsbury, P., & Craig., J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. *Volume 19, Number 6: pp.* 349-357.

Appendix C

Research Approval

Research approval from the Health Research Authority (HRA) and Health and Care Research Wales (HCRW)

Professor Jaynie Rance
Swansea University   Email: hra.approval@nhs.net
Singleton Park   HCRW.approvals@wales.nhs.uk
UK
SA2 8PP

18 December 2019

Dear Professor Rance

HRA and Health and Care	
Study title:	**A person-centred, theory-based self-management intervention specific to young adults (YAs) living with Chronic Kidney Disease (CKD) stages 1 to 5 in Wales. A systematic review and mixed-methods study**
IRAS project ID:	**266183**
Protocol number:	**RIO 026-19**
REC reference:	**19/EM/0339**
Sponsor	**Swansea University**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above-referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study-wide governance report (including this letter) have been sent to the coordinating centre of each participating nation.

The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **266183**. Please quote this on all correspondence.

Yours sincerely,

Kevin Ahmed

Approvals Manager

Email: hra.approval@nhs.net

Copy to: *Dr Sherrill Snelgrove* **List of Documents**

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Advertising email]	0.7	05 October 2019
Copies of advertisement materials for research participants [Advertising poster]	0.7	05 October 2019
Covering letter on headed paper [Response to Po]		21 November 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of insurance]	1	01 August 2019
Interview schedules or topic guides for participants [Topic guide for interviews]	0.2	24 October 2019
IRAS Application Form [IRAS_Form_22102019]		22 October 2019
Letter from sponsor [Letter in Principle]	1	09 October 2019
Non-validated questionnaire [Questionnaire -6]	0.2	24 October 2019
Non-validated questionnaire [Questionnaire -11]	0.2	24 October 2019
Non-validated questionnaire [Questionnaire -12]	0.2	24 October 2019
Non-validated questionnaire [Questionnaire -13.1]	0.2	24 October 2019
Non-validated questionnaire [Questionnaire -13.2]	0.2	24 October 2019
Non-validated questionnaire [Questionnaire -13.3]	0.2	24 October 2019
Other [Debrief form]	0.6	10 August 2019
Other [Email from the recruitment team]	0.1	16 July 2019
Other [GCP certificate]	0.1	11 October 2019
Participant consent form [Consent form for YAs]	0.7	17 November 2019

Participant consent form [Consent form for guardians, caregivers, and HCPs]	0.7	17 November 2019
Participant information sheet (PIS) [PIS for YAs]	0.8	17 November 2019
Participant information sheet (PIS) [PIS for guardians, caregivers, & HCPs]	0.8	17 November 2019
Research protocol or project proposal [Research protocol]	10	17 November 2019
Summary CV for Chief Investigator (CI) [CV of the CI]	1	14 July 2019
Summary CV for student [CV of the researcher]	1	03 October 2019
Summary CV for supervisor (student research) [CV of the external supervisor]	1	17 October 2019
Summary CV for supervisor (student research) [CV of the academic supervisor]	1	17 October 2019
Validated questionnaire [CKD Self-management Questionnaire]	1	14 July 2019
Validated questionnaire [Self-efficacy Questionnaire]	1	14 July 2019
Validated questionnaire [Health-related behaviors Questionnaire]	1	06 September 2019
Validated questionnaire [Psychological distress Questionnaire]	1	14 July 2019
Validated questionnaire [HRQoL Questionnaire]	1	14 July 2019
Validated questionnaire [CKD knowledge Questionnaire]	1	14 July 2019
Validated questionnaire [Patient Activation Questionnaire]	1	14 July 2019

Appendix D

Consent Form Part 1 - YAs

Swansea University
Prifysgol Abertawe

CONSENT FORM

Study Number:

Study group: 1

Participant Number:

A person-centred, theory-based self-management intervention specific to young adults (YAs) living with Chronic Kidney Disease (CKD) stages 1 to 5. A systematic literature review and a mixture of quantitative and qualitative studies.

Name of Researcher: Paula Krawiec

If you agree,
please initial box

1. I confirm that I have read the information sheet dated 30/01/2021 (Version 11) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that I am free to ask any questions at any time before and during the study. ☐

4. I agree with the use of anonymised quotations in research reports and publications. ☐

5. I am happy for the information I provide to be used anonymously in academic papers, such as reports and the researcher’s PhD thesis. ☐

6. I understand that the information collected about me may be used to support other research in the future, and may be shared anonymously with other researchers. ☐

7. I agree to take part in the above study. ☐

OPTIONAL:

	YES	**NO**
8. I agree to be contacted with a view of participating in a focus group or individual Interview.	☐	☐

If yes, please provide your preferred contact details below:

Email address:...

And/or telephone number:...

Thank you for your participation in this study. Your help is very much appreciated.

____________________ ____________________ ____________________

Name of Participant Date Signature___________

_______ ____________________ ____________________

Name of Person taking consent Date Signature

Appendix E

Consent Form Part 2 - YAs

CONSENT FORM

Study Number:

Study group: 1

Participant Number:

A person-centred, theory-based self-management intervention specific to young adults (YAs) living with Chronic Kidney Disease (CKD) stages 1 to 5. A systematic literature review and a mixture of quantitative and qualitative studies.

Name of Researcher: Paula Krawiec

The next phase of this project will involve developing and implementing an appropriate person-centred, theory-based self-management intervention for YAs living with CKD. If you agree to be contacted about this next phase of the research, please give your consent below.

I agree to be contacted about the next phase of this project for which I may be suitable. I understand that agreeing to be contacted does not oblige me to participate
in any further studies.

YES ☐ **NO** ☐

If yes, please provide your preferred contact details below:

Email address:..

And/or telephone number:..

Thank you for your participation in this study. Your help is very much appreciated.

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix F

Consent Form Part 3 - YAs

Swansea University
Prifysgol Abertawe

CONSENT FORM

Study Number:

Study group: 1

Participant Number:

A person-centred, theory-based self-management intervention specific to young adults (YAs) living with Chronic Kidney Disease (CKD) stages 1 to 5. A systematic literature review and a mixture of quantitative and qualitative studies.

Name of Researcher: Paula Krawiec

If you agree,
please initial box

1. I confirm that I have read the information sheet dated 30/01/2021 (version 11) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that I am free to ask any questions at any time before and during the study. ☐

4. I agree with the use of anonymised quotations in research reports and publications. ☐

5. I am happy for the information I provide to be used anonymously in academic papers, such as reports and the researcher's PhD thesis. ☐

6. I understand that the information collected about me may be used to support other research in the future, and may be shared anonymously with other researchers. ☐

7. I consent to the interviews being audio recorded. ☐

8. I agree to take part in a focus group or individual interview. ☐

Thank you for your participation in this study. Your help is very much appreciated.

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of Person taking consent	Date	Signature

Appendix G

Consent Form Part 1 - Health and Social Care Professionals

CONSENT FORM

Study Number:

Study group: 2

Participant Number:

A person-centred, theory-based self-management intervention specific to young adults (YAs) living with Chronic Kidney Disease (CKD) stages 1 to 5. A systematic literature review and a mixture of quantitative and qualitative studies.

Name of Researcher: Paula Krawiec

If you agree,
please initial box

9. I confirm that I have read the information sheet dated 26/03/2021 (Version 12) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

10. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

11. I understand that I am free to ask any questions at any time before and during the study. ☐

12. I agree with the use of anonymised quotations in research reports and publications. ☐

13. I am happy for the information I provide to be used anonymously in academic papers, such as reports and the researcher's PhD thesis. ☐

14. I understand that the information collected about me may be used to support other research in the future, and may be shared anonymously with other researchers. ☐

15. I agree to take part in the above study. ☐

OPTIONAL:

	YES	**NO**
16. I agree to be contacted with a view of participating in a focus group or individual Interview.	☐	☐

If yes, please provide your preferred contact details below:

Email address:...

And/or telephone number:...

Thank you for your participation in this study. Your help is very much appreciated.

______________________	______________________	______________________
Name of Participant	Date	Signature
______________________	______________________	______________________
Name of Person taking consent	Date	Signature

Appendix H

Consent Form Part 2 - Health and Social Care Professionals

CONSENT FORM

Study Number:
Study group: 2
Participant Number:

A person-centred, theory-based self-management intervention specific to young adults (YAs) living with Chronic Kidney Disease (CKD) stages 1 to 5. A systematic literature review and a mixture of quantitative and qualitative studies.

Name of Researcher: Paula Krawiec

If you agree,
please initial box

1. I confirm that I have read the information sheet dated 26/03/2021 (version 12) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that I am free to ask any questions at any time before and during the study. ☐

4. I agree with the use of anonymised quotations in research reports and publications. ☐

5. I am happy for the information I provide to be used anonymously in academic papers, such as reports and the researcher's PhD thesis. ☐

6. I understand that the information collected about me may be used to support other research in the future, and may be shared anonymously with other researchers. ☐

7. I agree to take part in a focus group or individual interview. ☐

8. I consent to the interviews being audio recorded. ☐

Thank you for your participation in this study. Your help is very much appreciated.

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of Person taking consent	Date	Signature

Appendix I

Participant Information Sheet - YAs

Swansea University
Prifysgol Abertawe

PARTICIPANT INFORMATION SHEET

Study Number:

Study group: 1

Participant Number:

A person-centred, theory-based self-management intervention specific to young adults (YAs) living with Chronic Kidney Disease (CKD) stages 1 to 5. A systematic literature review and a mixture of quantitative and qualitative studies.

We would like to invite you to take part in our research study, which is funded by Kidney Wales. Joining the study is entirely up to you, before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. We'd suggest this should take about 15 minutes. Please feel free to talk to others about the study if you wish. The first part of the Participant Information Sheet tells you the purpose of the study and what will happen to you if you take part. Then we give you more detailed information about the conduct of the study.
Do ask if anything is unclear.

What is the purpose of the research?

Researcher Paula Krawiec conducting research, which is part of a PhD project, to understand how young adults aged 18-35 manage their kidney disease, to look at aspects that work well and to identify areas that might need a different approach. The aim of the study is to produce tools to help young adults to manage their health condition.

You have been invited for this study as you are a young adult (male or female between 18 to 35 years old) diagnosed with CKD stages 1 to 5, and are able to understand written and spoken English.

What happens if I agree to take part?

If you agree to take part in this study, you will be asked to complete a set of questionnaires related to CKD self-management, along with some background information. Completing the questionnaires will take approximately 30 - 40 minutes. Prior to the study, you will be able to choose to complete the questionnaires either online or via pen and paper. If you choose to complete the questionnaires online, you will be provided with the link to the online survey. Whereas, if you choose to complete the questionnaires by pen and paper, you will be sent a hard copy of the questionnaires via post together with a return envelope and stamp. Depending on COVID restrictions, you could also complete the questionnaires either at the Kidney Wales office in Cardiff or the Swansea University Singleton campus.

After completing all questionnaires, you may be invited to take part in a focus group or individual interview, depending on your preference. You may not be required to take part in the interviews if sufficient numbers have already been recruited. In the consent form, you will be asked if you agree to be contacted with a view of participating in the interviews. If you agree to take part, we may contact you to invite you to participate in the focus groups or individual interviews by telephone or via video conference (such as Zoom) or dependent on COVID restrictions, it could also take place either at the Kidney Wales office in Cardiff or the Swansea University Singleton campus. However, if you do not wish to take part in the interviews, you can still complete the above-mentioned questionnaires. The focus groups or individual interviews will take approximately 30 to 60 minutes.

Are there any risks associated with taking part?

The research has been approved by the NHS Research Ethics Committee. There are no anticipated risks associated with participation.

Research Ethics Committee name: HRA and Health and Care Research Wales (HCRW)

Reference number: 19/EM/0339

Data Protection and Confidentiality.

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. No names will be recorded on any of the measures. Your data will only be viewed by the research team. Your personal information, such as name, will be anonymised by providing a code, which will be your participant number. The use of quotations in research reports and publications will also be anonymised by using pseudo names. The researcher will be responsible for coding the audio recordings and the research supervisors will be validating a sample of the transcripts.

All electronic data will be stored on a password-protected computer file on the researcher's private laptop computer. The data file will also be encrypted, a password will also be needed to open the files. All paper records will be stored in a locked filing cabinet in the researcher's office or the lead supervisor's office. Your consent information, which will include some identifiable data such as your name and your signature, will be kept separately from your responses to minimise risk in the event of a data breach.

Please note that the data we will collect for this study will be made anonymous, thus it will not be possible to identify and remove your data at a later date. Therefore, if at the end of this research, you decide to have your data withdrawn, please let us know before you either leave the office, submit your data online or return the hardcopy via post.

What will happen to the information I provide?

Research project data may be accessed by authorised individuals from the Sponsor or host NHS site for monitoring and audit purposes.

An analysis of the information will form part of the report at the end of the study and may be presented to interested parties and published in scientific journals and related media. *Note that all information presented in any reports or publications will be anonymous and unidentifiable. Additionally, your data will be archived for up to 5 years and destroyed after this period.*

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research**.**

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

Is participation voluntary and what if I wish to later withdraw?

Your participation is entirely voluntary - you do not have to participate if you do not want to. If you decide to participate, but later wish to withdraw from the study (before the data is anonymised), then you are free to withdraw without giving a reason and without your medical care or legal rights being affected. Your data will be then destroyed. However, if you wish to withdraw from the research after the data has already been collected and anonymised then the data cannot be withdrawn and further data collection will not take place.

Who is the sponsor for this study?

Swansea University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Swansea University will keep identifiable information about you for 5 years.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate.

If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.
You can find out more about how we use your information researchgoverance@swansea.ac.uk.

Data Protection Privacy Notice.

The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data and can be contacted at the Vice Chancellors' Office: VCO@swanseauniversity.com. Swansea University's Data Protection Officer is Bev Buckley and she may be contacted at b.y.buckley@swansea.ac.uk.
Your personal data will be processed for the purposes outlined in this information sheet. Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you. However, the legal basis on which this task is being performed is public interest, approved by the NHS Research Ethics Committee.
If you are concerned about how your personal data is being processed, please contact Swansea University's Data Protection Officer at b.y.buckley@swansea.ac.uk.
Details of your individual rights are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

Who is carrying out the research?

The data are being collected by Paula Krawiec under the supervision of Professor Jaynie Rance, Dr Chris Hamilton, and Professor Paul Bennett in the College of Human and Health Sciences at Swansea University. The research has been approved by the NHS Research Ethics Committee. This research is funded by Kidney Wales.

What if I have other questions?

If you have further questions about this study, please do not hesitate to contact us:

Paula Krawiec College of Human and Health Sciences	Professor Jaynie Rance College of Human and Health Sciences

Swansea University [redacted]	Swansea University [redacted]

Independent contact:
Dr Sherrill Snelgrove
Academic Lead for Research Integrity
Swansea University
researchgovernance@swansea.ac.uk
Health issues:
Cardiff & Vale of Glamorgan Comunity Health Council (CHC)
02920 377407 chief.officer@cavogchc.org.uk
Management issues:
Ceri Phillips [redacted]

Appendix J

Participant Information Sheet - Health and Social Care Professionals

Swansea University
Prifysgol Abertawe

PARTICIPANT INFORMATION SHEET

Study Number:

Study group:

Participant Number:

A person-centred, theory-based self-management intervention specific to young adults (YAs) living with Chronic Kidney Disease (CKD) stages 1 to 5. A systematic literature review and a mixture of quantitative and qualitative studies.

We would like to invite you to take part in our research study, which is funded by Kidney Wales. Joining the study is entirely up to you, before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. We'd suggest this should take about 15 minutes. Please feel free to talk to others about the study if you wish. The first part of the Participant Information Sheet tells you the purpose of the study and what will happen to you if you take part. Then we give you more detailed information about the conduct of the study.
Do ask if anything is unclear.

What is the purpose of the research?

Researcher Paula Krawiec conducting research, which is part of a PhD project, to understand how young adults aged 18-35 manage their kidney disease, to look at aspects that work well and to identify areas that might need a different approach. The aim of the study is to produce tools to help young adults to manage their health condition.

You have been invited for this study as you are a guardian, caregiver, or health and social care professional (male or female over 18 years old) of a young adult (between 18 to 35 years old) with CKD stages 1 to 5, and being able to understand written and spoken English.

What happens if I agree to take part?

If you agree to take part in this study, whether you are a parent, guardian, caregiver, or health-care professional of a young adult (YA), you will be asked to complete a set of questionnaires related to YA's person-centred care plans and CKD self-management. Completing all the above questionnaires will take approximately 5 - 10 minutes. Prior to the study, you will be able to choose to complete the questionnaires either online or via pen and paper. If you choose to complete the questionnaires online, you will be provided with the link to the online survey. Whereas, if you choose to complete the questionnaires by pen and paper, you will be sent a hard copy of the questionnaires via post together with a return envelope and stamp. Depending on COVID restrictions, you could also complete the questionnaires either at the Kidney Wales office in Cardiff or the Swansea University Singleton campus.
After completing all questionnaires, you may be invited to take part in a focus group or individual interview, depending on your preference. You may not be required to take part in the interviews if sufficient numbers have already been recruited. In the consent form, you will be asked if you agree to be contacted with a view of participating in the interviews. If you agree to take part, we may contact you to invite you to participate in the focus groups or individual interviews by telephone or via video conference (such as Zoom) or dependent on COVID restrictions, it could also take place either at the Kidney Wales office in Cardiff or the Swansea University Singleton campus. However, if you do not wish to take part in the interviews, you can still complete the above-mentioned questionnaires. The focus groups or individual interviews will take approximately 30 to 60 minutes.

Are there any risks associated with taking part?

The research has been approved by the NHS Research Ethics Committee. There are no anticipated risks associated with participation.

Research Ethics Committee name: HRA and Health and Care Research Wales (HCRW)
Reference number: 19/EM/0339

Data Protection and Confidentiality.

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. No names will be recorded on any of the measures. Your data will only be viewed by the research team. Your personal information, such as name, will be anonymised by providing a code, which will be your participant number. The use of quotations in research reports and publications will also be anonymised by using pseudo names. The researcher will be responsible for coding the audio recordings and the research supervisors will be validating a sample of the transcripts.

All electronic data will be stored on a password-protected computer file on the researcher’s private laptop computer. The data file will also be encrypted, a password will also be needed to open the files. All paper records will be stored in a locked filing cabinet in the researcher’s office or the lead supervisor’s office. Your consent information, which will include some identifiable data such as your name and your signature, will be kept separately from your responses to minimise risk in the event of a data breach.

Please note that the data we will collect for this study will be made anonymous, thus it will not be possible to identify and remove your data at a later date. Therefore, if at the end of this research, you decide to have your data withdrawn, please let us know before you either leave the office, submit your data online or return the hardcopy via post.

What will happen to the information I provide?

Research project data may be accessed by authorised individuals from the Sponsor or host NHS site for monitoring and audit purposes.

An analysis of the information will form part of the report at the end of the study and may be presented to interested parties and published in scientific journals and related media. *Note that all information presented in any reports or publications will be* *anonymous and unidentifiable. This information will not identify you and will not be combined with other information in a way that could identify you. Additionally, your data will be archived for up to 5 years and destroyed after this period.*

Is participation voluntary and what if I wish to later withdraw?

Your participation is entirely voluntary - you do not have to participate if you do not want to. If you decide to participate, but later wish to withdraw from the study (before the data is anonymised), then you are free to withdraw without giving a reason and without your legal rights being affected. Your data will be then destroyed. However, if you wish to withdraw from the research after the data has already been collected and anonymised then the data cannot be withdrawn and further data collection will not take place.

Who is the sponsor for this study?

Swansea University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Swansea University will keep identifiable information about you for 5 years.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate.

If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information researchgoverance@swansea.ac.uk.

Data Protection Privacy Notice.

The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data and can be contacted at the Vice Chancellors' Office:

VCO@swanseauniversity.com. Swansea University's Data Protection Officer is Bev Buckley and she may be contacted at b.y.buckley@swansea.ac.uk.

Your personal data will be processed for the purposes outlined in this information sheet. Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you. However, the legal basis on which this task is being performed is public interest, approved by the NHS Research Ethics Committee.

If you are concerned about how your personal data is being processed, please contact Swansea University's Data Protection Officer at b.y.buckley@swansea.ac.uk.

Details of your individual rights are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

Who is carrying out the research?

The data are being collected by Paula Krawiec under the supervision of Professor Jaynie Rance, Dr Chris Hamilton, and Professor Paul Bennett in the College of Human and Health Sciences at Swansea University. The research has been approved by the NHS Research Ethics Committee. This research is funded by Kidney Wales.

What if I have other questions?

If you have further questions about this study, please do not hesitate to contact us:

Paula Krawiec College of Human and Health Sciences Swansea University [redacted]	Professor Jaynie Rance College of Human and Health Sciences Swansea University [redacted]

Independent contact:
Dr Sherrill Snelgrove
Academic Lead for Research Integrity
Swansea University researchgovernance@swansea.ac.uk
Health issues:
Cardiff & Vale of Glamorgan Comunity Health Council (CHC)
02920 377407 chief.officer@cavogchc.org.uk
Management issues: Ceri Phillips [redacted]

Appendix K

Debrief Form for All Participants

Swansea University
Prifysgol Abertawe

DEBRIEF FORM

A person-centred, theory-based self-management intervention specific to young adults (YAs) living with Chronic Kidney Disease (CKD) stages 1 to 5. A systematic literature review and a mixture of quantitative and qualitative studies.

Thank you for taking part in our research! Now that we've finished, let us explain the rationale behind this work.

We are interested in improving the support that is currently available for young adults (YAs) living with Chronic Kidney Disease (CKD). The purpose of the study is to identify existing self-management behaviours among YAs living with CKD stages 1 to 5. This research aims to understand what aspects of the existing CKD self-management interventions work and what aspects might need improvement. The findings from this study will provide information that will help us to develop better support for young adults living with CKD.

If you are a young adult with CKD who participated in this study and who agreed on the consent form to be contacted about the next phase of the research, we may contact you about this shortly.

Previous research has shown that person-centred, theory-based intervention can be effective in CKD self-management.

This research aimed to address the following question: *Among YAs living with CKD, what aspects of the existing CKD self-management interventions need improvement and what additional aspects may they benefit from?* In order to identify the existing self-management behaviours among young adults living with CKD, YAs have been asked to complete a set of questionnaires (either online or via pen and paper) related to CKD self-management, self-efficacy, health-related behaviours, psychological distress, patient activation, person-centred care plans, along with some background information. Whereas, health and social care professionals have been asked to complete questionnaires related to YAs' CKD self-management and person-centred care plans. Following the questionnaire-based study, some of you were invited to take part in either a focus group or individual interview depending on individual preferences.

If you would like to discuss any concerns about the research itself, then please contact the study Supervisor:
Professor Jaynie Rance [redacted]
For health concerns, you may wish to contact your GP.

If you have any other questions about the research, please do not hesitate to contact us at:

Paula Krawiec
College of Human and Health Sciences
Swansea University
[redacted]

Professor Jaynie Rance
College of Human and Health Sciences
Swansea University
[redacted]

Appendix L

Participant Background Information - YAs

Participant background information

1. Please state where you live:
   ....
2. Please state your age:
   ....
3. What is your gender? **(Circle one)**
   a) Male
   b) Female
4. What is the highest level of education that you have completed? **(Circle one)**
   a) No formal education
   b) Primary school
   c) Secondary school
   d) High school
   e) Diploma
   f) Bachelor's degree
   g) Doctorate degree
   h) Other: please specify...
5. Are you currently employed/self-employed? **(Circle one)**
   a) Yes, if yes please state your occupation
   ……………………………………………………………….......................
   b) No
6. Please state the estimated monthly household income.……………………………
7. How many people live in your household?..
8. Please state the time since diagnoses……………………………………………

9. What is the current stage of your Chronic Kidney Disease (CKD)? **(Circle one)**
   a) Stage 1: with normal or high GFR (GFR > 90 mL/min
   b) Stage 2: Mild CKD (GFR = 60-89 mL/min)
   c) Stage 3: A) Moderate CKD (GFR = 45-59 mL/min)
   d) Stage 3: B) Moderate CKD (GFR = 30-44 mL/min)
   e) Stage 4: Severe CKD (GFR = 15-29 mL/min)
   f) Stage 5: End-stage kidney disease (GFR <15 mL/min)
10. Do you suffer from other comorbid (related to your CKD) conditions? **(Circle one)**
   a) Yes, if yes please specify……………………………………………………………….
   b) No

<u>Please check you have answered all the questions.</u>

Office use only
Participant No. ………………………………………………………………………...
Study group
………………………………………………………………………....

Appendix M

Partners In Health (PIH) - YAs

Partners In Health (PIH)

Office use only
Participant No. ...
Study group **1**

Score the following from 0-8 (0=very little, never, not very well; 8=a lot, always, very well):

1. Overall, what I know about my health condition(s) is:

0 1 2 3 4 5 6 7 8

2. Overall, what I know about the treatment, including medication, of my health condition(s) is:

0 1 2 3 4 5 6 7 8

3. I take medications or carry out the treatments asked by my doctors or health worker:

0 1 2 3 4 5 6 7 8

4. I share decisions made about my health condition(s) with my doctor or health worker:

0 1 2 3 4 5 6 7 8

5. I am able to deal with health professionals to get the services I need that fit with my culture, values and beliefs:

0 1 2 3 4 5 6 7 8

6. I attend appointments as asked by my doctor or health worker:

0 1 2 3 4 5 6 7 8

7. I keep track of my symptoms and early warning signs (blood sugar levels, peak flow, weight, shortness of breath, pain, sleep problems, mood):

0 1 2 3 4 5 6 7 8

8. I take action when my early warning signs and symptoms get worse:

0 1 2 3 4 5 6 7 8

9. I manage the effect of my health condition(s) on my physical activity (walking, household tasks):

0 1 2 3 4 5 6 7 8

10. I manage the effect of my health condition(s) on how I feel (that is, my emotions and spiritual well-being):

0 1 2 3 4 5 6 7 8

11. I manage the effect of my health condition(s) on my social life (how I mix with other people):

0 1 2 3 4 5 6 7 8

12. Overall, I manage to live a healthy life – no smoking, moderate alcohol, healthy food, regular physical activity, manage stress:

0 1 2 3 4 5 6 7 8

Please check you have answered all the questions.

Appendix N

Self-Efficacy for Managing Chronic Disease (SEMCD-6) -YAs

Self-Efficacy for Managing Chronic Disease (SEMCD)

Office use only
Participant No. …..
Study group **1**

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident do you feel that you can keep the fatigue caused by your disease from interfering with the things you want to do?

not at all 1 2 3 4 5 6 7 8 9 10 **totally confident**

2. How confident do you feel that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

not at all 1 2 3 4 5 6 7 8 9 10 **totally confident**

3. How confident do you feel that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

not at all 1 2 3 4 5 6 7 8 9 10 **totally confident**

4. How confident do you feel that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

not at all 1 2 3 4 5 6 7 8 9 10
totally
confident

5. How confident do you feel that you can the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?
not at all 1 2 3 4 5 6 7 8 9 10
totally
confident

6. How confident do you feel that you can do things other than just taking medication to reduce how much your illness affects your everyday life?
not at all 1 2 3 4 5 6 7 8 9 10
totally
confident

Please check you have answered all the questions.

Appendix O

Health-related Behaviours Questionnaire - YAs

Health-related behaviours

Office use only
Participant No. …..
Study group **1**

<u>Smoking:</u>

1. Do you smoke? **(Circle one)**
    a) Yes, if yes please state how many cigarettes per day
    ……………………………………………..
    b) No

<u>Alcohol consumption:</u>

1. How often do you have a drink containing alcohol? **(Circle one)**
    a) Never
    b) Monthly or less
    c) 2-4 times a month
    d) 2-3 times a week
    e) 4 or more times a week
2. How many drinks containing alcohol do you have on a typical day when you are drinking? **(Circle one)**
    a) 1 or 2
    b) 3 or 4
    c) 5 or 6
    d) 7 to 9
    e) 10 or more
3. How often do you have six or more drinks containing alcohol on one occasion? **(Circle one)**
    a) Never
    b) Less than monthly
    c) Monthly
    d) Weekly

e) Daily or almost daily

Diet - Self-Regulation of Eating Behaviour Questionnaire (SREBQ):

1. Do you find any of these foods tempting (that is, do you want to eat more of them than you think you should)? (Tick all those that you find tempting)

Chocolate ☐
Crisps ☐
Cakes ☐
Ice cream ☐
Bread/toast ☐
Fizzy drinks ☐
Biscuits ☐
Sweets ☐
Popcorn ☐
Pastries ☐
Pizza ☐
Fried foods ☐
Chips ☐
Other foods ☐
I don't find any food tempting ☐

If you have ticked 'Other foods', please specify: ☐

2. Do you intend NOT to eat too much of the foods you find tempting in the previous question?

Yes ☐
No ☐

3. Do you intend to have a healthy diet?

Yes ☐
No ☐

4. Please read the following statements and tick the boxes most appropriate to you. For the next few questions, please, understand that:

- 'Tempting foods' are any food you want to eat more of than you think you should.
- 'Eating intentions' refer to the way you are aiming to eat, for example, you may intend to avoid tempting foods or eat healthy foods.

	Never	Rarely	Sometimes	Often	Always
A. I give up too easily on my eating intentions	☐	☐	☐	☐	☐
B. I'm good at resisting tempting food	☐	☐	☐	☐	☐
C. I easily get distracted from the way I intend to eat	☐	☐	☐	☐	☐
D. If I am not eating in the way I intend to, I make changes	☐	☐	☐	☐	☐
E. I find it hard to remember what I have eaten throughout the day	☐	☐	☐	☐	☐

Physical activity – International Physical Activity Questionnaire (IPA) Short Form:
We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the **last 7 days**. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.
Think about all the **vigorous** activities that you did in the **last 7 days**. **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.

1. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling?

_____ days per week

☐ No vigorous physical activities → **Skip to question 3**

2. How much time did you usually spend doing **vigorous** physical activities on one of those days?

_____ hours per day

_____ minutes per day

☐ Don’t know/Not sure

Think about all the **moderate** activities that you did in the last **7 days. Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.

3. During the **last 7 days**, on how many days did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

_____ days per week

☐ No moderate physical activities → **Skip to question 5**

4. How much time did you usually spend doing moderate physical activities on one of those days?

_____ hours per day

_____ minutes per day

☐ Don’t know/Not sure

Think about the time you spent **walking** in the **last 7 days**. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.

5. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?

_____ days per week

☐ No walking → **Skip to question 7**

6. How much time did you usually spend **walking** on one of those days?

_____ hours per day

_____ minutes per day

☐ Don’t know/Not sure

The last question is about the time you spent **sitting** on weekdays during the **last 7 days**. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

7. During the **last 7 days**, how much time did you spend **sitting** on a **weekday**?

_____ hours per day

_____ minutes per day

☐ Don’t know/Not sure

Please check you have answered all the questions.

Appendix P

Hospital Anxiety and Depression Scale (HADS) - YAs

Hospital Anxiety and Depression Scale (HADS)

Office use only
Participant No. …..
Study group **1**

Tick the box beside the reply that is closest to how you have been feeling in the past week.

Don’t take too long over you replies: your immediate is best.

		I feel tense or 'wound up':			**I feel as if I am slowed down:**
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			**I get a sort of frightened feeling like 'butterflies' in the stomach:**
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			**I have lost interest in my appearance:**
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			**I feel restless as I have to be on the move:**

0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			**I look forward with enjoyment to things:**
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			**I get sudden feelings of panic:**
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			**I can enjoy a good book or radio or TV program:**
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

Please check you have answered all the questions.

Appendix Q

Short Form Health Survey-12-Item (SF-12) - YAs

Short Form Health Survey-12-Item (SF-12)

Office use only
Participant No. …..
Study group **1**

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Answer each question by choosing just one answer. If you are unsure how to answer a question, please give the best answer you can.

1. In general, would you say your health is:
☐1 Excellent ☐2 Very good ☐3 Good ☐4 Fair
☐5 Poor

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
☐1 - yes, limited a lot; ☐2 - yes, limited a little; ☐3 - no, no limited at all

2. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.
☐1 ☐2 ☐3

3. Climbing several flights of stairs.
☐1 ☐2 ☐3

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?
☐1 YES ☐2 NO

4. Accomplished less than you would like. ☐1 ☐2

5. Were limited in the kind of work or other activities. ☐1 ☐2

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?
☐1 YES ☐2 NO

6. Accomplished less than you would like. ☐1 ☐2

7. Did work or activities less carefully than usual. ☐1 ☐2

8. During the past 4 weeks, how much did pain interfere with your normal work (including work outside the home and housework)?
☐1 Not at all ☐2 A little bit ☐3 Moderately ☐4 Quite a bit

☐5 Extremely

These questions are about how you have been feeling during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks…
1- all of the time; 2- most of the time; 3- a good bit of the time; 4- some of the time; 5- a little of the time; 6- none of the time

9. Have you felt calm and peaceful?
☐1 ☐2 ☐3 ☐4 ☐5 ☐6

10. Did you have a lot of energy?
☐1 ☐2 ☐3 ☐4 ☐5 ☐6

11. Have you felt down-hearted and blue?

☐1 ☐2 ☐3 ☐4 ☐5 ☐6

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?
☐1 All of the time ☐2 Most of the time ☐3 Some of the time ☐4 A little of the time
☐5 None of the time

☐1 ☐2 ☐3 ☐4 ☐5

Please check you have answered all the questions.

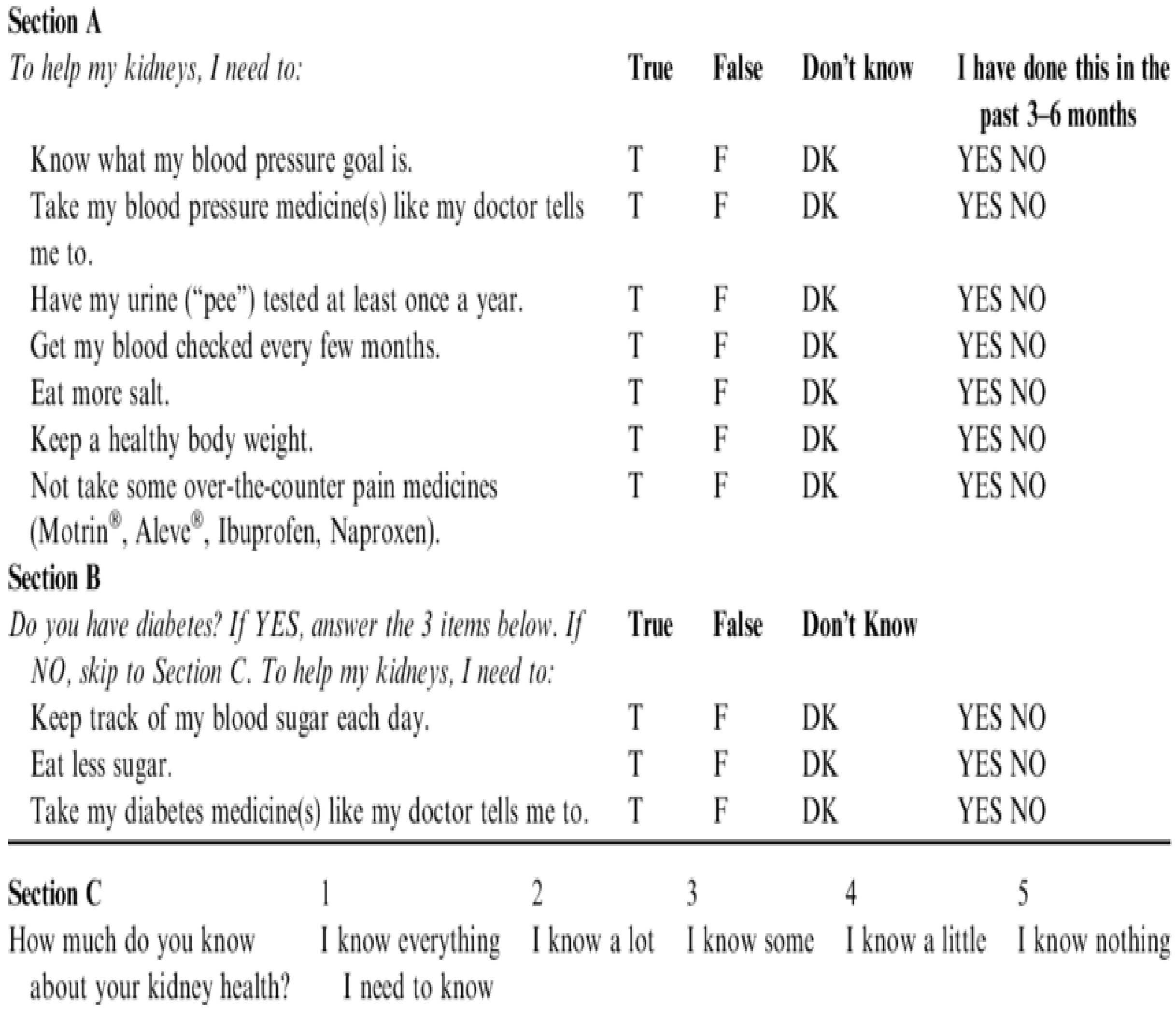
Appendix R

CKD Self-Management Knowledge Tool (CKD-SMKT) - YAs

CKD - Self-Management Knowledge Tool (CKD-SMKT)

Office use only
Participant No. …..
Study group **1**

Please answer the following questions:



Section A

To help my kidneys, I need to:	**True**	**False**	**Don't know**	**I have done this in the past 3–6 months**
Know what my blood pressure goal is.	T	F	DK	YES NO
Take my blood pressure medicine(s) like my doctor tells me to.	T	F	DK	YES NO
Have my urine ("pee") tested at least once a year.	T	F	DK	YES NO
Get my blood checked every few months.	T	F	DK	YES NO
Eat more salt.	T	F	DK	YES NO
Keep a healthy body weight.	T	F	DK	YES NO
Not take some over-the-counter pain medicines (Motrin®, Aleve®, Ibuprofen, Naproxen).	T	F	DK	YES NO

Section B

Do you have diabetes? If YES, answer the 3 items below. If NO, skip to Section C. To help my kidneys, I need to:	**True**	**False**	**Don't Know**	
Keep track of my blood sugar each day.	T	F	DK	YES NO
Eat less sugar.	T	F	DK	YES NO
Take my diabetes medicine(s) like my doctor tells me to.	T	F	DK	YES NO

Section C	1	2	3	4	5
How much do you know about your kidney health?	I know everything I need to know	I know a lot	I know some	I know a little	I know nothing

Please check you have answered all the questions.

Appendix S

The Short Version of the Patient Activation Measure (PAM) - YAs

The short version of the Patient Activation Measure (PAM)

Office use only
Participant No. …..
Study group **1**

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and not just what you think the doctor wants you to say. If the statement does not apply to you, circle N/A.

1. When all is said and done, I am the person who is responsible for taking care of my health.

Disagree Strongly Disagree Agree Strongly Agree N/A

2. Taking an active role in my own health care is the most important thing that affects my health.

Disagree Strongly Disagree Agree Strongly Agree N/A

3. I am confident I can help prevent or reduce problems associated with my health.

Disagree Strongly Disagree Agree Strongly Agree N/A

4. I know what each of my prescribed medications do.

Disagree Strongly Disagree Agree Strongly Agree N/A

5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.

Disagree Strongly Disagree Agree Strongly Agree N/A

6. I am confident that I can tell a doctor concerns I have even when he or she does not ask.

Disagree Strongly Disagree Agree Strongly Agree N/A

7. I am confident that I can follow through on medical treatments I may need to do at home.

Disagree Strongly Disagree Agree Strongly Agree N/A

8. I understand my health problems and what causes them.

Disagree Strongly Disagree Agree Strongly Agree N/A

9. I know what treatments are available for my health problems.

Disagree Strongly Disagree Agree Strongly Agree N/A

10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising.

Disagree Strongly Disagree Agree Strongly Agree N/A

11. I know how to prevent problems with my health.

Disagree Strongly Disagree Agree Strongly Agree N/A

12. I am confident I can figure out solutions when new problems arise with my health.

Disagree Strongly Disagree Agree Strongly Agree N/A

13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress.

Disagree Strongly Disagree Agree Strongly Agree N/A

Please check you have answered all the questions.

Appendix T

Person-Centred Care Plans and Self-Management Questions -YAs

Person-centred care plans and self-management

Office use only
Participant No. …..
Study group **1**

The below questionnaire includes 2 sections: Section 1 - questions related to Chronic Kidney Disease (CKD)' person-centred care plans and Section 2 - self-management for CKD. Please complete both sections.

<u>Section 1: Questions related to Chronic Kidney Disease (CKD)' person-centred care plans:</u>

1. Do you have a CKD care plan? **(Circle one)**
    a) Yes, if yes go to question 2
    b) No, if no go to section 2
2. Have you seen your care plan? **(Circle one)**
    a) Yes, if yes go to question 3
    b) No, if no go to next section
3. Have you worked together with healthcare professionals to develop your care plan? **(Circle one)**
    a) Yes
    b) No
4. Does it include your agreed goals and actions? **(Circle one)**
    a) Yes
    b) No
5. Does it include your needs and wants? **(Circle one)**
    a) Yes
    b) No
6. Was your care plan used and updated during the transition from paediatric to adult services? **(Circle one)**

a) Yes
b) No
c) I do not know

Section 2: Questions related to self-management for CKD:

To what extent would you like to learn more about (rate from 0 = "not at all" to 10 = "very much"): (Circle one)

1. **Disease-specific knowledge** (information about what kidneys do, how they work, what happens in CKD, treatment options, ways to delay dialysis)

0 1 2 3 4 5 6 7 8 9 10

2. Managing medications (understanding why medications are prescribed, possible side effects, what might happen if not taken, how to take them as prescribed)

0 1 2 3 4 5 6 7 8 9 10

3. Engaging and sustaining social support (engaging with friends and family to get CKD support, becoming involved with community groups including support groups)

0 1 2 3 4 5 6 7 8 9 10

4. Maintaining social and occupational roles (continuing to work, sustaining hobbies, maintaining relationships and home roles)

0 1 2 3 4 5 6 7 8 9 10

5. Modifying lifestyle (adhering to fluid and dietary guidelines, engaging in appropriate physical activity)

0 1 2 3 4 5 6 7 8 9 10

6. Developing and sustaining a positive attitude and caring for mental and physical wellbeing (avoiding anxiety and depression, staying positive, staying generally physically healthy)

0 1 2 3 4 5 6 7 8 9 10

7. Building and sustaining effective relationships with healthcare providers (developing effective working relationships with doctors, nurses, clinic staff, allied health professionals, and any other members of an individual's healthcare team)

0 1 2 3 4 5 6 7 8 9 10

8. Establishing a routine and planning ahead (getting into good self-management habits, putting effective strategies such as reminder systems in place)

0 1 2 3 4 5 6 7 8 9 10

9. Actively participating in healthcare (learning to change self-management behaviour based upon results, working collaboratively with HCPs regarding CKD and its treatment)

0 1 2 3 4 5 6 7 8 9 10

10. Recognising and effectively responding to symptoms (noticing signs and symptoms of CKD and knowing what to do when they occur, learning to avoid worsening CKD symptoms)

0 1 2 3 4 5 6 7 8 9 10

11. Any other not mentioned above?

a) Yes, if yes please state…………………………………………………………………......
b) No

Please also answer the questions below:

1. **How would you like to receive self-management support?** (for example, via the telephone or face-to-face)

   ………………………………………………………………………………………
2. **When in the week could you attend sessions?**

   ………………………………………………………………………………………
3. **Where could you attend sessions?**

   ………………………………………………………………………………………
4. **Would you prefer group/face-to-face/phone call sessions?**

   ………………………………………………………………………………………
5. **Would you like to bring a friend/family member?**

   ………………………………………………………………………………………

6. **Who would you like to receive support from?** (for example, GP, nurse, nephrologist, or self-management expert external to your healthcare)

   ……………………………………………………………………………………

Please check you have answered all the questions.

Appendix U

The Summary of Survey Questions for YAs

Table U1

Summary of Survey Questions for YAs

Outcomes:	Measures:	Reliability/Validity	Items and Scoring
Background Information	Background and clinical details	N/A	10 items assessing background and clinical characteristics
	CCI (Charlson et al., 1994)	Valid in predicting death risk from comorbid conditions (Charlson et al., 1994)	CCI was assessed by combining age and number of pre-determined serious comorbidities into a single index. The researcher used the online tool to calculate the CCI score (Ortho ToolKit, 2021a)
CKD Self-Management	PIH (Battersby et al., 2003)	Valid and reliable (α=0.88; Petkov et al., 2010) comprehensive measure of health-related outcomes for people involved in various chronic condition management and self-management programmes	12 items scored on a zero to eight scale, with zero=very little or never or not very well, and eight=a lot or always or very well. Overall scale score = mean of items zero to eight, with a higher score indicating better self-management
Self-Efficacy	(SEMCD (Lorig et al., 2001)	A reliable and valid instrument for assessing self-efficacy for managing chronic conditions (α=0.88; Ritter & Lorig, 2014)	Six items scored on a one to 10 scale. Overall scale score = mean of items one to 10. Note that: if two consecutive numbers were selected, the researcher would code the lower number (less self-efficacy). However, if the numbers were not consecutive, the item was not scored. If more than two items were missing, the researcher would not score the scale. A higher number indicated higher self-efficacy
Health-Related Behaviours **Smoking**	Question about smoking behaviour	Directly assess smoking behaviour	One question developed by the researcher assessing smoking behaviour followed by a question (for those who smoke) asking to state how many cigarettes per day

Outcomes:		**Measures:**	**Reliability/Validity**	**Items and Scoring**
	Alcohol Consumption	AUDIT-C) (Bush et al., 1998)	High reliability and validity (α=0.98; Osaki et al., 2014) indicate that AUDIT-C is a useful measure for identifying alcohol use disorders or risky drinking	Three multiple-choice questions with the option of five responses scored zero to four. Based on the recommendations from previous validation studies (Bradley et al., 2003; 2007), in males, a score of four or higher was considered positive, whereas, in females, a score of three or higher was considered positive. Commonly, the greater the AUDIT-C score, the more likely it is that a person's drinking is affecting their health and safety
	Diet	SREBQ (Kliemann et al., 2016)	Consistent, valid and reliable for the measure of eating self-regulatory capacity (Cronbach's α=0.75; Kliemann et al., 2016)	Questions one to three in SREBQ were used to exclude participants who do not have healthy eating intentions. Whereas, question 4 was used to score "eligible" participants by calculating the mean score of 5 items scored on a one to five scale (never, rarely, sometimes, often, and always). Items one, three, and five of the SREBQ question 4 were coded reversed and then the mean score was calculated. The responses were divided into the official categories: "low" (<2.8), "middle" (2.8 – 3.6), and "high" (>3.6), with a higher score indicating better self-regulatory skills in eating behaviour.
	Physical Activity	(IPAQ Short Form (Craig et al., 2003)	High reliability (Cronbach α<0.80; IPAQ, 2016) measure assessing physical activity.	The researcher used the IPAQ scoring tool (Cheng, 2016) to score the questionnaire. The responses were recorded as a categorical variable, which included three levels of physical activity: low, moderate and high.
Psychological Distress		HADS Zigmond & Snaith, 1983)	Valid and reliable in assessing Anxiety (HADS-A; Cronbach's alpha between 0.68 to 0.93) and Depression (HADS-D; Cronbach's alpha between 0.67 to 0.90) (Bjelland et al. (2002)	Total scores for HADS-A and HADS-D were calculated. Scores zero to seven=normal; eight to 10= borderline abnormal (borderline case); and 11 to 12=abnormal (case)

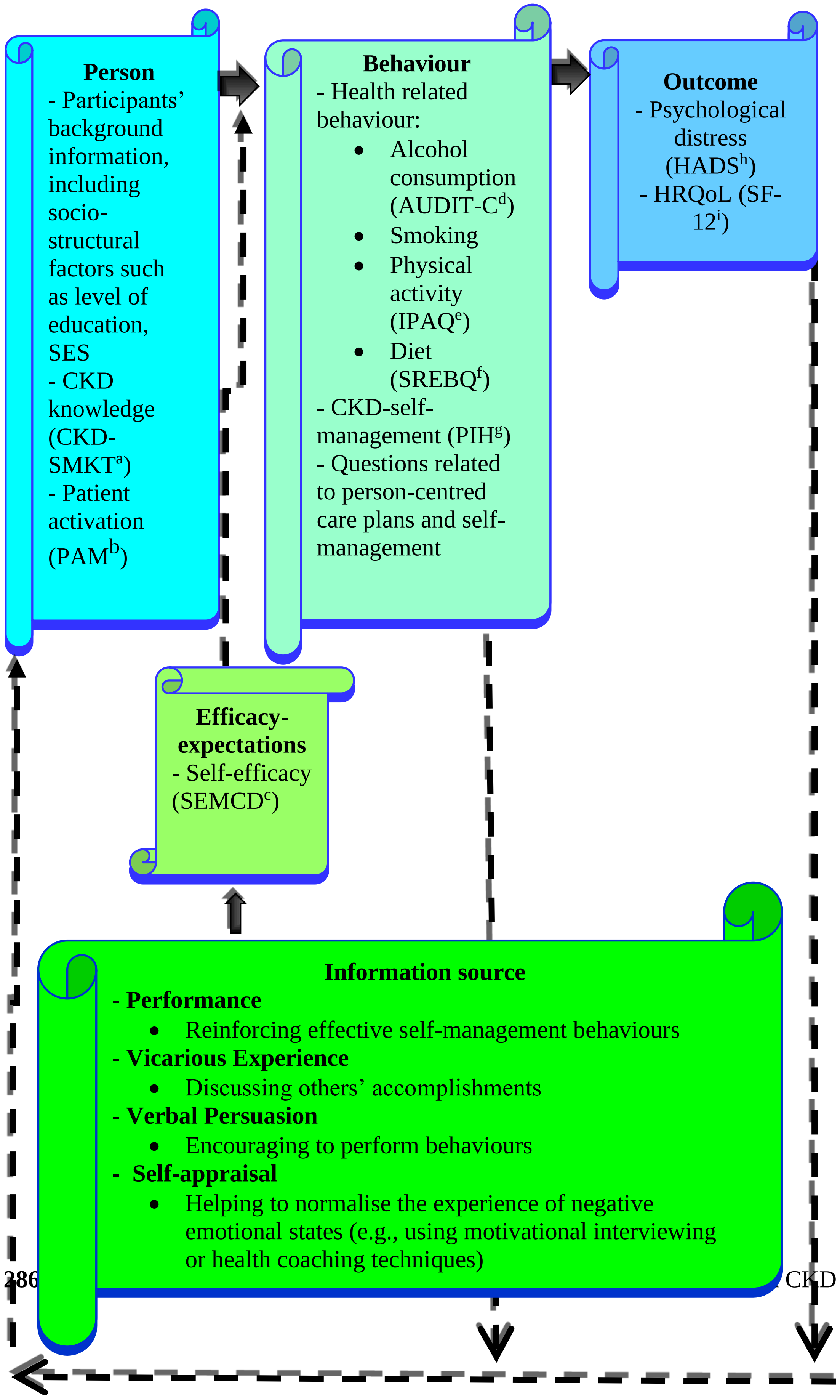
Outcomes:	**Measures:**	**Reliability/Validity**	**Items and Scoring**
HRQoL	SF-12 (Ware, Kosinski & Keller, 1996)	Both, PCS and MCS scores have demonstrated high reliability (PCS: α=0.87; and MCS: α=0.86) and good and moderate validity (ICC; PCS=0.79; MCS=0.59) in assessing HRQoL (Shah & Brown, 2020)	The researcher used the online tool (Ortho ToolKit, 2021b) to score the questionnaire. Both MCS and PCS were reported, with higher scores indicating better health.
CKD Knowledge	CKD-SMKT (Devraj & Wallace, 2013)	A content-valid instrument, designed to measure a person's kidney disease knowledge of several key self-management behaviours (content validity ratio of 11 items >0.49, *p>.05*, and an overall Lexile score of the final CKD-SMKT of 470, correspondent to a ≈3rd-grade reading level; Devraj & Wallace, 2013)	The percentage of correct responses for the 10-item scale was recorded.
Patient Activation	PAM Short Form (Hibbard et al., 2004)	Satisfactory internal consistency overall (α=0.81; Prey et al., 2016) in determining health engagement and thus self-reported behaviours, skills, confidence, and knowledge for chronic disease self-management	13-item scale with four possible response options ranging from (1) strongly disagree to (4) strongly agree, and an additional "not applicable" option. To calculate the total PAM score, the raw score was divided by the number of items answered (except non-applicable items) and multiplied by 13. The resulting score placed the participant at one of four levels of activation. The researcher obtained the research licence for the PAM 13 from Insignia Health and employed their Excel tool to collect and score the questionnaire.
Questions related to person-centred care plans (section 1)	Questions about the existence and use of person-centred care plans	Directly assessing the use of care plans	6 multiple-choice questions developed by the researcher with the option of two to three responses

Outcomes:	**Measures:**	**Reliability/Validity**	**Items and Scoring**
Questions related to self-management (section 2)	Questions about self-management and the preferences for support delivery	Directly assessing the existing self-management behaviours and the preferences for support delivery	10 questions related to areas of CKD self-management previously identified as requiring additional support (Havas et al., 2016) scored on zero (“not at all”) to 10 (“very much”) scale, with an 11th optional question, and 6 items taken from Havas et al. (2017a) related to the preferences of support delivery

AUDIT-C Alcohol Use Disorders Identification Test Consumption; *CCI* Charlson Comorbidity Index; *CKD* Chronic Kidney Disease; *CKD-SMKT* Self-Management Knowledge Tool; *HADS* Hospital Anxiety and Depression Scale; *HRQoL* Health-Related Quality of Life; *IPAQ* International Physical Activity Questionnaire; *PAM* Patient Activation Measure; *PIH* Partners In Health; *SEMCD* Self-Efficacy for Managing Chronic Disease; *SF-12* Short Form Health Survey-12-Items; *SREBQ* Self-Regulation of Eating Behaviour Questionnaire.

Figure U1

Self-Efficacy Model and Outcomes in the Current Study



Note. [a]CKD self-management knowledge tool (Devraj & Wallace, 2013); [b]Short version of the Patient Activation Measure (Hibbard et al., 2004); [c]Self-Efficacy for Managing Chronic Disease (Lorig et al., 2001); [d]Alcohol Use Disorders Test Consumption Questions Scale (Bush et al., 1998); [e]Short version of International Physical Activity Questionnaire (Craig et al., 2003); [f]Self-Regulation of Eating Behaviour Questionnaire (Kliemann et al., 2016); [g]Partners In Health (Battersby et al., 2003); [h]Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983); [i] Short Form Health Survey-12-Items (Ware, Kosinski & Keller, 1996). (Adopted from Lenz & Shortridge-Baggett, 2002).

The self-efficacy model above illustrates how the outcome measures were applied in this study (particularly, phase 2, part 1 - quantitative study) to explain and predict behaviour in YAs with CKD. It also demonstrates the interaction of behavioural (CKD self-management behaviours), personal (demographics, CKD knowledge and patient activation), and environmental factors (the novel intervention for YAs with CKD) from the SCT triadic reciprocal causation (refer to figure 4.3 in thesis Chapter 4).

Appendix V

Person-Centred Care Plans and Self-Management Questions - Health and Social Care Professionals

Questions related to Chronic Kidney Disease (CKD)' person-centred care plans (section 1) and self-management for CKD (section 2)

Office use only
Participant No. …..
Study group **2**

The below questionnaire includes 2 sections: Section 1 - questions related to Chronic Kidney Disease (CKD)' person-centred care plans and Section 2 - self-management for CKD. Please complete both sections.

<u>Section 1: Questions related to Chronic Kidney Disease (CKD)' person-centred care plans:</u>

1. Are there care plans in place? **(Circle one)**
    a) Yes, if yes go to question 2
    b) No, if no go to section 2
2. Are they used on a regular basis? **(Circle one)**
    a) Yes
    b) No
3. Are they updated regularly? **(Circle one)**
    a) Yes, if yes please state how often……………….................................
    b) No
4. Are they developed and updated together with the patient? **(Circle one)**
    a) Yes
    b) No
5. Do they include the patient's agreed goals and actions? **(Circle one)**
    a) Yes
    b) No
6. Do they include the patient's needs and wants? **(Circle one)**

   a) Yes
   b) No

7. Are they available to patients and guardians and shared across the multidisciplinary team? **(Circle one)**
   a) Yes
   b) No
8. Are they used and updated during the transition from paediatric to adult services? **(Circle one)**
   a) Yes
   b) No

<u>Section 2: Questions related to self-management for CKD:</u>

To what extent patients need support with (rate from 0 = "not at all" to 10 = "very much"): (Circle one)

1. Disease-specific knowledge (information about what kidneys do, how they work, what happens in CKD, treatment options, ways to delay dialysis)

0 1 2 3 4 5 6 7 8 9 10

2. Managing medications (understanding why medications are prescribed, possible side effects, what might happen if not taken, how to take them as prescribed)

0 1 2 3 4 5 6 7 8 9 10

3. Engaging and sustaining social support (engaging with friends and family to get CKD support, becoming involved with community groups including support groups)

0 1 2 3 4 5 6 7 8 9 10

4. Maintaining social and occupational roles (continuing to work, sustaining hobbies, maintaining relationships and home roles)

0 1 2 3 4 5 6 7 8 9 10

5. Modifying lifestyle (adhering to fluid and dietary guidelines, engaging in appropriate physical activity)

0 1 2 3 4 5 6 7 8 9 10

6. Developing and sustaining a positive attitude and caring for mental and physical wellbeing (avoiding anxiety and depression, staying positive, staying generally physically healthy)

0 1 2 3 4 5 6 7 8 9 10

7. Building and sustaining effective relationships with healthcare providers (developing effective working relationships with doctors, nurses, clinic staff, allied health professionals, and any other members of an individual's healthcare team)

0 1 2 3 4 5 6 7 8 9 10

8. Establishing a routine and planning ahead (getting into good self-management habits, putting effective strategies such as reminder systems in place)

0 1 2 3 4 5 6 7 8 9 10

9. Actively participating in healthcare (learning to change self-management behaviour based upon results, working collaboratively with HCPs regarding CKD and its treatment)

0 1 2 3 4 5 6 7 8 9 10

10. Recognising and effectively responding to symptoms (noticing signs and symptoms of CKD and knowing what to do when they occur, learning to avoid worsening CKD symptoms)

0 1 2 3 4 5 6 7 8 9 10

11. Any other not mentioned above?

a) Yes, if yes please state…………………………………………………………………......

b) No

Please check you have answered all the questions.

Appendix W

Advertising Poster and Flyer

Can you help us?

Research study into young adults with **Chronic Kidney Disease** (CKD) - *We need you!*

Please help us to help other young adults

PhD student **Paula Krawiec**, from Swansea University, is conducting research to understand how young adults, age 18-35, manage their kidney disease.

Funded by **Kidney Wales**, the study aims to produce tools to help young adults to manage their health condition.

Who do we want to speak to?

- Young adults (males or females between 18 to 35 years old) with CKD stage 1 to 5
- Parents and guardians (males or females over 18 years old) of young adults with CKD stage 1 to 5
- Caregivers (males or females over 18 years old) who care for young adults with CKD stage 1 to 5; and
- Healthcare professionals (males or females over 18 years old) who care for young adults with CKD stage 1 to 5

What do I need to do?

✓ Complete a questionnaire (online or hard copy)

✓ Have a one-to-one interview or be part of a focus group (telephone or video conference) - optional

Who to contact:

If you would like to take part or want further information, please contact the researcher **Paula Krawiec** on email address:

[redacted]

or email one of the study gatekeepers:

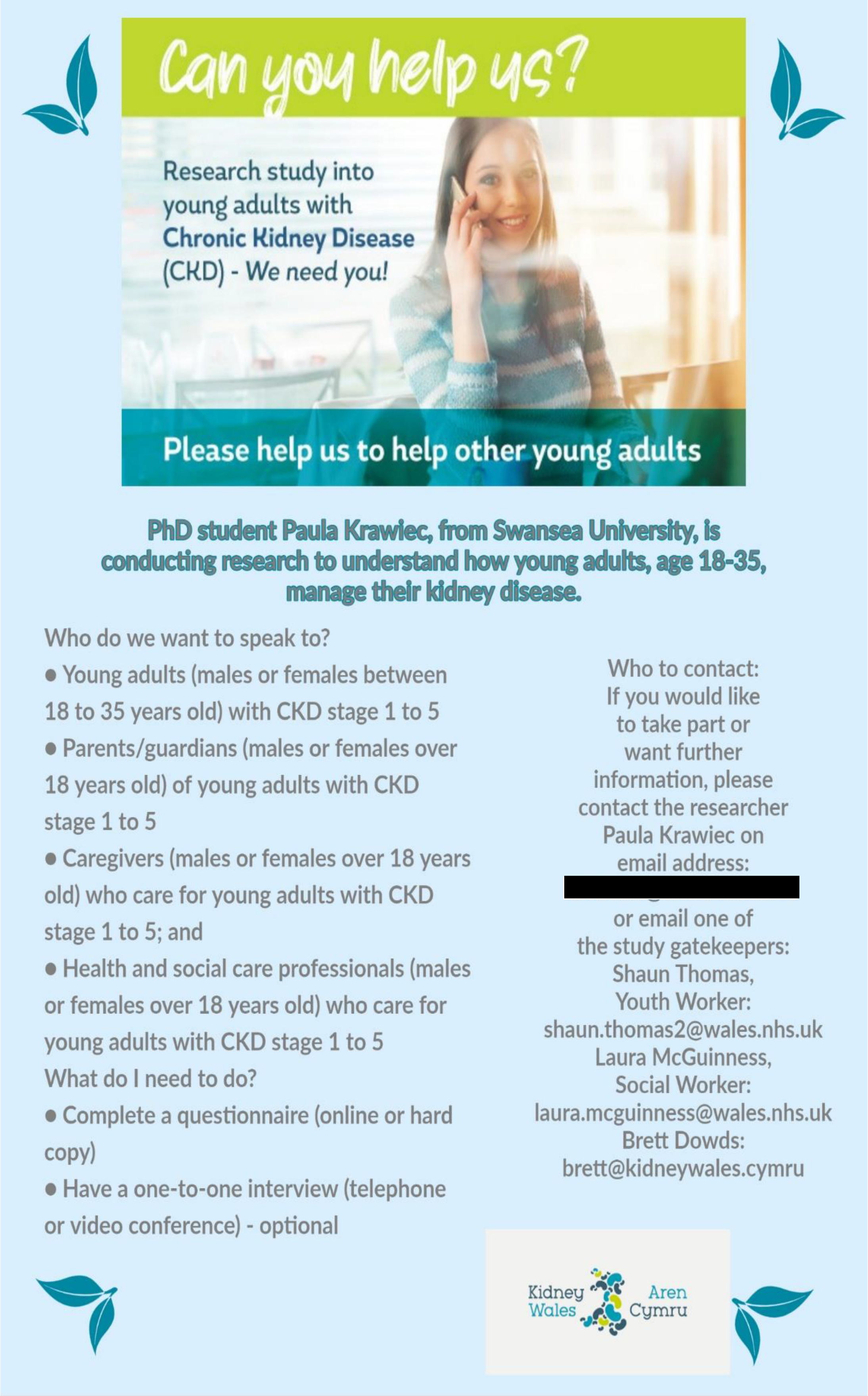
Shaun Thomas, Youth Worker:
shaun.thomas2@wales.nhs.uk

Laura McGuinness, Social Worker:
laura.mcguinness@wales.nhs.uk

Brett Dowds:
brett@kidneywales.cymru

Thank You!

Kidney Wales
Aren Cymru



Can you help us?

Research study into young adults with **Chronic Kidney Disease** (CKD) - *We need you!*

Please help us to help other young adults

PhD student Paula Krawiec, from Swansea University, is conducting research to understand how young adults, age 18-35, manage their kidney disease.

Who do we want to speak to?

- Young adults (males or females between 18 to 35 years old) with CKD stage 1 to 5
- Parents/guardians (males or females over 18 years old) of young adults with CKD stage 1 to 5
- Caregivers (males or females over 18 years old) who care for young adults with CKD stage 1 to 5; and
- Health and social care professionals (males or females over 18 years old) who care for young adults with CKD stage 1 to 5

What do I need to do?

- Complete a questionnaire (online or hard copy)
- Have a one-to-one interview (telephone or video conference) - optional

Who to contact:
If you would like
to take part or
want further
information, please
contact the researcher
Paula Krawiec on
email address:
[redacted]
or email one of
the study gatekeepers:
Shaun Thomas,
Youth Worker:
shaun.thomas2@wales.nhs.uk
Laura McGuinness,
Social Worker:
laura.mcguinness@wales.nhs.uk
Brett Dowds:
brett@kidneywales.cymru

Kidney Wales Aren Cymru

Appendix X

Advertising Email

Advertising email for YAs (study group 1):

Hello,

Researcher Paula Krawiec is conducting research into how young adults aged 18-35 manage their Chronic Kidney Disease (CKD). Funded by Kidney Wales, the study aims to find out which aspects work well and to identify areas that might need a different approach. The aim of the study is to produce tools to help young adults to manage their health condition.

To take part in this study, you must be aged 18-35 (male or female), with CKD stage 1-5, and you must be able to understand written and spoken English.

If you agree to take part in the study, you will be asked to complete a set of questionnaires to gather information about you and how you manage your kidney disease. It is quite a detailed survey that takes 30-40 minutes to complete; you can complete it online or a paper copy. If you choose to complete the questionnaires online, you will be provided with the link to the online survey. Whereas, if you choose to complete the questionnaires by pen and paper, you will be sent a hard copy of the questionnaires via post together with a return envelope and stamp. Depending on COVID restrictions, you could also complete the questionnaires either at the Kidney Wales office in Cardiff or the Swansea University Singleton campus.

After completing the questionnaires, you may be invited to take part in a focus group or individual interview, depending on your preference. You may not be required to take part in the interviews if sufficient numbers have already been recruited. You will be sent a consent form, in which you will be asked if you agree to be contacted with a view of participating in the interviews. If you agree to take part, we may contact you to invite you to participate in the focus groups or individual interviews by telephone or via video conference (such as Zoom) or dependent on COVID restrictions, it could also take place either at the Kidney Wales office in Cardiff or the Swansea University Singleton campus. However, if you do not wish to take part in the interviews, you can still complete the above-mentioned questionnaires. The focus groups or individual interviews will take approximately 30 to 60 minutes.

If you would like to be involved in this research, please reply to this e-mail and return the attached "consent to contact" form. The lead researcher, Paula Krawiec, will then contact you directly to let you know about the questionnaires. Please get in touch with Paula directly if you have any questions: [redacted] or email one of the study gatekeepers:

Brett Dowds: brett@kidneywales.cymru
Shaun Thomas: shaun.thomas2@wales.nhs.uk
Laura McGuinness: laura.mcguinness@wales.nhs.uk

Advertising email for health and social care professionals (study group 2):

Hello,

Researcher Paula Krawiec is conducting research into how young adults aged 18-35 manage their chronic kidney disease (CKD). The study aims to find out which aspects work well and to identify areas that might need a different approach. Funded by Kidney Wales, the aim of the study is to produce tools to help young adults to manage their health condition.

To take part in this study, you must be a health and social care professional (male or female over 18 years old) of a young adult aged 18 to 35 years old with CKD stages 1 to 5, and be able to understand written and spoken English.

If you agree to take part in the study, you will be asked to complete a set of questionnaires related to young adults' person-centred care plans and CKD self-management. Completing all the above questionnaires will take approximately 5-10 minutes. You can complete it online or a paper copy. If you choose to complete the questionnaires online, you will be provided with the link to the online survey.

Whereas, if you choose to complete the questionnaires by pen and paper, you will be sent a hard copy of the questionnaires via post together with a return envelope and stamp. Depending on COVID restrictions, you could also complete the questionnaires either at the Kidney Wales office in Cardiff or the Swansea University Singleton campus.

After completing all questionnaires, you may be invited to take part in a focus group or individual interview, depending on your preference. You may not be required to take part in the interviews if sufficient numbers have already been recruited. In the consent form, you will be asked if you agree to be contacted with a view of participating in the interviews. If you agree to take part, we may contact you to invite you to participate in the focus groups or individual interviews by telephone or via video conference (such as Zoom) or dependent on COVID restrictions, it could also take place either at the Kidney Wales office in Cardiff or the Swansea University Singleton campus. However, if you do not wish to take part in the interviews, you can still complete the above-mentioned questionnaires. The focus groups or individual interviews will take approximately 30 to 60 minutes.

If you would like to be involved in this research, please reply to this e-mail and return the attached 2consent to contact” form. The lead researcher, Paula Krawiec, will then contact you directly to let you know about the questionnaires. Please get in touch with Paula directly if you have any questions: [redacted]k or email one of the study gatekeepers:

Brett Dowds: brett@kidneywales.cymru

Shaun Thomas: shaun.thomas2@wales.nhs.uk

Laura McGuinness: laura.mcguinness@wales.nhs.uk

Appendix Y

Consent-to-Contact form

Invitation to Contact for Research Purposes

TITLE: ***A person-centred, theory-based self-management intervention specific to young adults (YAs) living with Chronic Kidney Disease (CKD) stages 1 to 5. A systematic literature review and a mixture of quantitative and qualitative studies.***

SPONSOR: Swansea University

INVESTIGATORS: Professor Jaynie Rance/Paula Krawiec

Student Project

You are being invited to give consent for Paula Krawiec (PhD student) to contact you at some time in the future to invite you to participate in a research study.

If you agree,
please initial box

1. I agree to be contacted by the researcher with information about the study. ☐

If yes, you will be contacted at a later date. Please include your contact information below.

☐ ***[Telephone]*:** ______________________________

☐ ***[E-mail]*:** ______________________________

You authorise to disclose your contact details to the research team for the purpose of being contacted to learn more about the research study named above.

Every effort will be made to safeguard your contact information.

You have been made aware of the reasons why the contact information is needed in the participant information sheet v. 11 Date 30/01/2021.

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix Z

Invitation Email for Interviews

Dear X,

You have recently taken part in research looking into how young adults, aged 18-35, manage their chronic kidney disease (CKD). Thank you again for completing the online survey, your views and experiences are extremely important to us!

In the survey, you have given your consent to be contacted about the second part of the study and we would now like to invite you to take part in a research interview. The interview will take place via the Zoom Videoconferencing platform, and it will take approximately 30 to 60 minutes. It will involve a friendly chat on relevant topics and you are more than welcome to bring a cup of tea/coffee with you!

If you are still interested, please sign the consent form (see the attached document) and return it by replying to this email, and choose your date and time preference (see the table below with the available dates and time slots). Once this is done, you will receive a link with an invitation to the online Zoom meeting. If you do not have Zoom or you have never used it, don't worry! It is a free and easy-to-use videoconferencing platform. You can sign up and use it for free by following the link below: https://zoom.us/signup

Please note that in the circumstances when you may only be available at specific times (e.g., early morning or late afternoon/evening) or specific dates (e.g., different dates or months), we will try to arrange the interview in the period that best suits you.

Example of available dates and time slots:

December 2021		**January 2022**	
Date:	**Time slots:**	**Date:**	**Time slots:**
1st (Wednesday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm	**1st** (Saturday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
2nd (Thursday)	10am – 11am 11:30am – 12:30pm	**2nd** (Sunday)	10am – 11am 11:30am – 12:30pm

	1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm		1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
3rd (Friday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm	**3rd** (Monday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
4th (Saturday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm	**4th** (Tuesday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
5th (Sunday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm	**5th** (Wednesday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
6th (Monday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm	**6th** (Thursday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
7th (Tuesday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm	**7th** (Friday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
10th (Friday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm	**8th** (Saturday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
11th (Saturday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm	**9th** (Sunday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
12th (Sunday)	10am – 11am 11:30am – 12:30pm	**10th** (Monday)	10am – 11am 11:30am – 12:30pm

	1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm		1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
15th (Wednesday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm	**11th** (Tuesday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
18th (Saturday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm	**14th** (Friday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
19th (Sunday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm	**15th** (Saturday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
20th (Monday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm	**16th** (Sunday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
21st (Tuesday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm	**17th** (Monday)	10am – 11am 11:30am – 12:30pm 1pm – 2pm 2:30pm – 3:30pm 4pm – 5pm
		And so on	

If you have any questions or require more information, do not hesitate to contact me.

I look forward to hearing from you!

Kind regards,

Paula

Appendix AA

Good Clinical Practice Certificate

NIHR | National Institute for Health Research

CERTIFICATE OF ACHIEVEMENT

Paula Krawiec

has completed the course

Introduction to Good Clinical Practice (GCP) eLearning

June 1, 2019

Modules Completed:

Introduction to Research in the NHS and other settings
Good Clinical Practice and Standards in Research
Study Set-up and Responsibilities
Informed Consent
Data Collection and Documentation
Safety Reporting
Summary

This course is worth 4 CPD points.

CPD®
The CPD Certification Service

NIHR | National Institute for Health Research

THANK YOU FOR BEING A PART
OF RESEARCH

As we all know, it is important to invest in continuing professional development (CPD).

The NIHR provides programmes, resources and communities to support your learning.

Further details can be found at nihr.ac.uk.
Follow us on Twitter @OfficialNIHR #nihrgcp

Appendix BB

Be Informed Certificate

EIDO Healthcare
be INFOrMED

About You - Paula Krawiec

You registered for *be* INFOrMED on 3rd March 2020 at Cardiff and Vale University Health Board

Your registered email address is [redacted]

You have told us that...

- you take consent for procedures which you also perform
- you do not work with patients under the age of 16
- you do not work with obstetrics cases
- you do not work in accident and emergency
- your work involves research and innovative treatment

Your learning

Core Modules	Main Content	Test Scenarios	Self-test Questions
CM1 - Consent and the Law	Last Viewed: 03/03/2020 (100% read)	Last Viewed: 03/03/2020	83%
CM2 - Consent in Practice	Last Viewed: 03/03/2020 (100% read)	Last Viewed: 03/03/2020	80%
CM3 - Capacity and Consent	Last Viewed: 03/03/2020 (100% read)	Last Viewed: 03/03/2020	71%
CM4 - End of Life Issues	Last Viewed: 03/03/2020 (100% read)	Last Viewed: 03/03/2020	70%
Specialist Modules	**Main Content**	**Test Scenarios**	**Self-test Questions**
SM1 - Obstetrics	Not required	Not required	Not required
SM2 - Paediatrics	Not required	Not required	Not required

SM3 - Accident and Emergency	Not required	Not required	Not required
SM4 - Research	Last Viewed: 03/03/2020 (100% read)	Last Viewed: 03/03/2020	73%

Final Assessment	Date	Status
84%	Completed 3 Mar 2020	(Passed)

Your Final Assessment score is valid until 03/03/2023. You can retake it earlier if you wish.

12 CPD hours

CME & CPD APPROVED
Association of Surgeons of Great Britain and Ireland

Appendix CC

Topic Guide and Schedule for Semi-Structured Interviews

Schedule for semi-structured interviews for both groups of participants:

1. Introductory:
    - Welcome the participant, introduce yourself, and thank for them agreeing to participate
    - Provide an overview of the topic, and check if they have any questions
    - Remind the participant that their participation is voluntary and that they can withdraw at any time without giving any reason
    - Confirm that they are happy for the interview to be recorded, remind them that their information will be used anonymously, and check if they are comfortable and willing to continue
    - Begin with asking demographic questions and move on to the main topics. Encourage participants to expand on their responses by using open-ended questions
2. Conclude - thank participants for taking part in the study, check if they have any questions, and inform them that they will shortly receive an email with a debrief form that includes information about the study and relevant contact details

Topic guide for semi-structured interviews - young adults (YAs) with Chronic Kidney Disease (CKD):

Before we move on to discuss the main topics, could you please tell me a little bit about yourself: what is your age and gender? what is the current stage of your CKD, and time since diagnosis?

Topic 1 – Challenges associated with managing CKD, specific to YAs:

I would like to find out about your experiences and perspectives of living with CKD, and the challenges associated with managing your condition.

- ✓ **I have no direct experience of CKD; how would you explain to someone like me what it is like to live with CKD?**

  Additional questions/prompts:

- What makes it harder to live with CKD? - what areas of your life are most impacted or limited by your condition, and how? What do you find the most challenging in managing your condition?

Topic 2 - CKD self-management:

I am interested in how you self-manage your CKD. By self-management, I mean engaging in specific behaviours that are necessary to manage your CKD on a day-to-day basis.

- ✓ **Have you been given support/strategies about how you can self-manage your condition? What are they?**

  Additional questions/prompts:

- What are your thoughts/ideas/worries on the current CKD self-management support?

*[**In case the participant is currently NOT receiving self-management support:** Have you been told about available support/strategies about how you can self-manage your condition? What are they? Have you considered any of these? What are your thoughts/ideas/worries about available CKD self-management support?]*

- ✓ **Tell me about things you currently do/strategies you use to self-manage your condition on a day-to-day basis?**

  Additional questions/prompts:

- Are these helpful for you? - If you were talking to a new patient, what would be your top tip for self-managing CKD?
- ✓ **What things are most important for you to self-manage your CKD?**
- ✓ **What could be done or improved to help you self-manage your condition more effectively?** Do you think that there is anything your health staff could do to help you that they are not already doing?
- ✓ **In your opinion, what influences whether you do what you are meant to do to self-manage your condition?**

PAM-specific questions (knowledge, skills and confidence - if not already discussed):

I am interested to find out what you know about your condition and its self-management.

- ✓ **In your opinion, what things do you have to do to self-manage your condition well?**

  Expand on CKD self-management knowledge - additional questions/prompts:

- In what areas of self-management, do you think your knowledge could be improved? - What strategies are currently in place to help you develop or improve the necessary knowledge to self-manage your condition? Are these helpful for you? Are these personalised to your needs? - What factors would improve your knowledge to self-manage your condition? How health staff could help you with these?

I am also interested to know how skilled and confident you feel about self-managing your condition.

- ✓ **Do you feel that you have the necessary skills to self-manage your condition?**

  Expand on CKD self-management skills - additional questions/prompts:

- In what areas of self-management your skills could be improved? - What strategies are currently in place to help you develop or improve the necessary skills to self-manage your condition? Are these helpful for you? Are these personalised to your needs? - What factors would improve your skills to self-manage your condition? How health staff could help you with these?

- ✓ **Do you feel confident to carry out specific behaviours to self-manage your condition?**

  Expand on confidence to self-manage CKD - additional questions/prompts:

- In what areas of self-management your confidence could be improved? - What strategies are currently in place to help you develop or improve the necessary confidence to self-manage your condition? Are these helpful for you? Are these personalised to your needs? - What factors would improve your confidence to self-manage your condition? How health staff could help you with these?

- ✓ **Final question:** Is there anything else that could help you look after yourself better? Have we missed anything? Would you like to add something? Are there any questions that you would like to ask me?

Topic guide for semi-structured interviews - health and social care professionals:

Before we move on to discuss the main topics, could you please tell me a little bit about yourself: what is your role in working with YAs (between 18 and 35 years old) with CKD, and how long have you worked in this role?

Topic 1 - Challenges associated with managing CKD, specific to YAs:

I would like to find out about your experiences and perspectives of working with YAs who suffer from CKD, and the challenges associated with managing CKD.

- ✓ **Tell me about the impact of CKD on YAs. In your opinion, what areas of life, specific to YAs who suffer from CKD, are most impacted or limited by their condition, and how?**

  Additional questions/prompts:

- What do you think is the most challenging for YAs with CKD in managing their condition?
- ✓ **What is the most challenging for YOU in helping YAs with CKD in managing their condition?**

Topic 2 - CKD self-management:

I am interested to find out how YAs self-manage their CKD, that is how they engage in specific behaviours that are necessary to manage their condition on a day-to-day basis.

- ✓ **In your opinion, what things do YAs with CKD have to do to self-manage their condition well?**

- ✓ **What support/strategies are given to YAs with CKD to help them self-manage their condition?**

  Explore more on what currently works well for YAs to self-manage their condition improvement - additional questions/prompts:

- What are your thoughts/ideas/worries on the current self-management support for YAs with CKD? - In your experience, what things do you think are most important for YAs (specifically) to self-manage their CKD? - What kind of helpful things/strategies are currently there that you think help YAs with CKD to self-manage their condition?
- ✓ **What kind of things/strategies do you think would help YAs with CKD to self-manage their condition more effectively?** What requires improvement? Do you think that there is anything that health staff could do to help YAs with CKD that they are not already doing?
- ✓ **In your opinion, what influences whether YAs with CKD do what they are meant to do regarding the treatment and self-management of their condition?**

PAM-specific questions (knowledge, skills and confidence):

I am interested in the use of the Patient Activation Measure (PAM) in clinics.

- ✓ **Have you come across PAM before?**

If yes:

- ✓ **Is PAM used in clinics during the initial consultation to identify where a person is in terms of activation in order to tailor support - provide the appropriate amount and type of support to the individual?**

  If yes, do you know what type of measures are used? What is your opinion of PAM as a tailoring tool? Is it helpful for YAs with CKD?

  If not, do you think it would be helpful to assess patient activation in order to tailor the treatment to YAs with CKD?

- ✓ **Is PAM regularly used in clinics to track progress over time, for instance, the effectiveness of an intervention, and to improve patient activation when required?**

If yes, do you know what type of measures are used? What is your opinion of PAM as an outcome measure? Is it helpful for YAs with CKD?

If not, do you think it would be helpful to assess patient activation in order to assess the effectiveness of the treatment and to improve patient activation?

[If not: explain what PAM measures and ask: - Do you think it would be helpful to assess patient activation in order to tailor the treatment to YAs with CKD? - Do you think it would be helpful to assess patient activation in order to assess the effectiveness of the treatment and to improve patient activation?]

✓ **What strategies are currently in place to help YAs with CKD develop or improve the necessary knowledge, skills, and confidence to self-manage their condition?** Are these helpful for YAs with CKD? Are these personalised to their needs?

Explore more, if required, on how to improve each: knowledge, skills, and confidence - additional questions/prompts:

- What factors do you think would improve YA's: knowledge; skills; and confidence to self-manage CKD? What strategies/support could be offered? How could health staff help with these?

Finally, research showed that health coaching (including skills such as motivational interviewing) has a positive impact on health activation.

✓ **Are staff trained in behaviour change techniques, such as motivational interviewing (or other behaviour change techniques)?**

✓ **Have you used these skills with YAs to tailor support according to individual needs and to increase their ability to self-manage their condition more effectively? Or do you know if other professionals use these skills?**

If yes, were these helpful for YAs with CKD? Which strategies in particular? What could be improved?

If not, do you think using these skills would be helpful to tailor support and to increase YA's ability to look after themselves more effectively?

- ✓ **Final question:** Is there anything else that you think could help YAs with CKD to look after themself better? Have we missed anything? Would you like to add something? Are there any questions that you would like to ask me?

Appendix DD

Assumptions Testing and Analysis 1

H_1: the YAs' levels of self-efficacy and patient activation will be significant predictors of their level of self-management skills while controlling for time since diagnosis

A Summary of the Assumption of Multiple Regression Analysis 1:

Assumptions		Results (SPSS statistics)	Reference
1	Sample size - common rule: 20 records for each predictor variable (if normally distributed, otherwise more than 20 records are required)	Based on the common rule as well as Gpower calculation, this assumption was not met	**Thesis Chapter 6, section 6.2.3**
2	Dependent variable measured on a continuous scale and two or more independent variables measured on either continuous or categorical scales	Dependent variable: PIH scale- continuous interval variable Independent variables: SEMCD and PAM- continuous interval variables Time since diagnosis covariate- continuous interval variable	
3	The independence of observations errors (or residuals)	There was no independence of residuals as assessed by the Durbin-Watson statistic of 2.159 (the Durbin-Watson statistic can range between 0 to 4 and a value of approximately 2 is ideal to indicate that there is no correlation between residuals)	**Analysis 1**
4	Linearity	There was a linear relationship between the dependent variable and each independent variable as assessed by visual inspection of the scatterplot matrix (and additionally, a single scatterplot with a Loess curve)	**Analysis 2**
5	Normality	There was a normal distribution of residuals (errors) as assessed by a histogram with a superimposed normal curve, and a Normal P-P Plot (and additionally, the Normal Q-Q Plot of the studentized residuals)	**Analysis 3**
6	Homoscedasticity	There was homogeneity of residual variances as assessed by visual inspection	**Analysis 4**

	Assumptions	Results (SPSS statistics)	Reference
		of a scatterplot of studentized residuals versus unstandardised predicting values	
7	Multicollinearity	There was no evidence of multicollinearity as assessed by tolerance values >0.1 and variance inflation factors (VIFs) <10 (and additionally, correlation of predictor variables)	**Analysis 5**
8	The absence of outliers in all variables, high leverage points, and highly influential points	Casewise diagnostic conducted - residuals are less than or equal to 3, thus there are no significant outliers. Cook's distance values in the residual statistics table, showed no highly influential points with all values below 1. Based on the formula assessing leverage points [(k+1)/n; k=nr of predictors, n=nr of participants; with the maximum leverage= (N-1)/N], leverage points equalled 0.22 which was less than the maximum leverage point of 0.94, indicating the absence of high leverage points.	**Analysis 6**

Assumptions of multiple regression - Analysis 1:

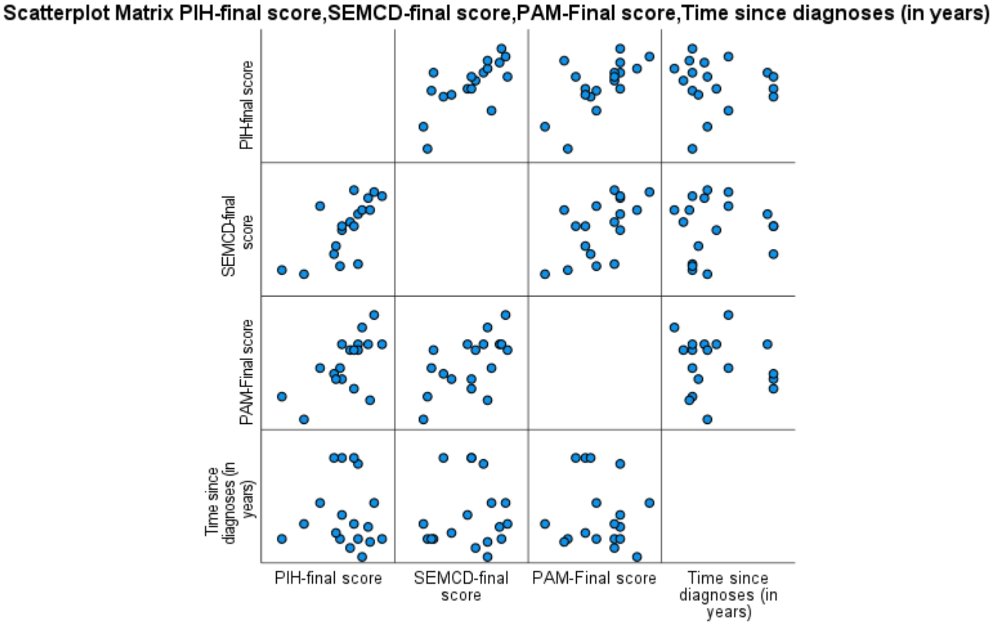
Model Summary[b]

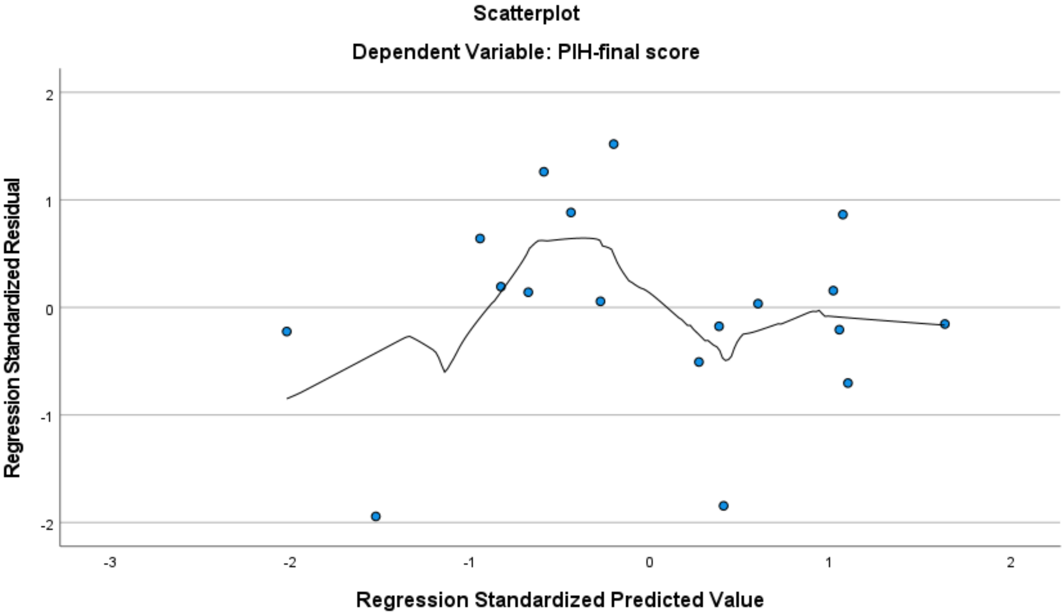
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.751[a]	.564	.470	.76074	**2.159**

a. Predictors: (Constant), PAM-Final score, Time since diagnoses (in years), SEMCD-final score

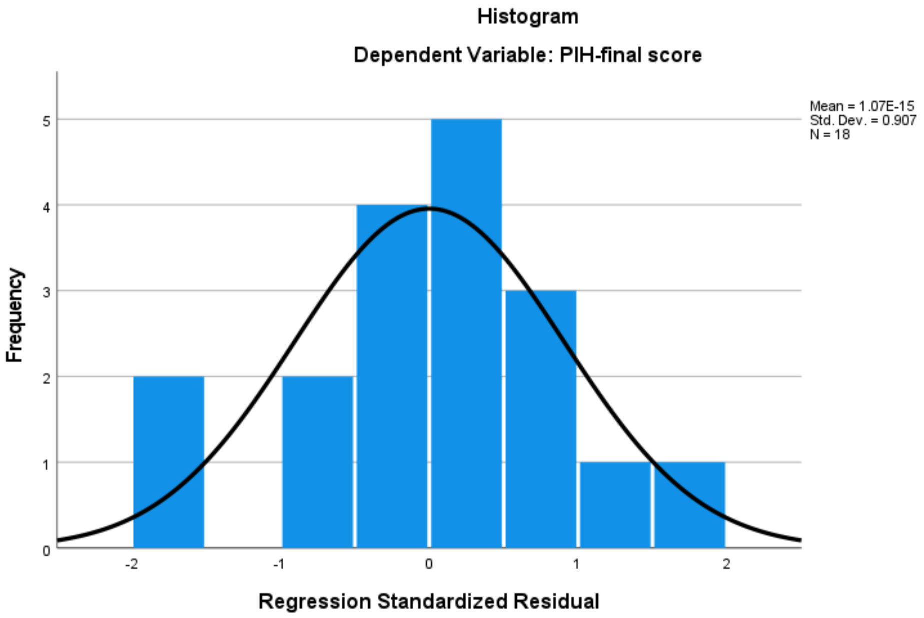
b. Dependent Variable: PIH-final score

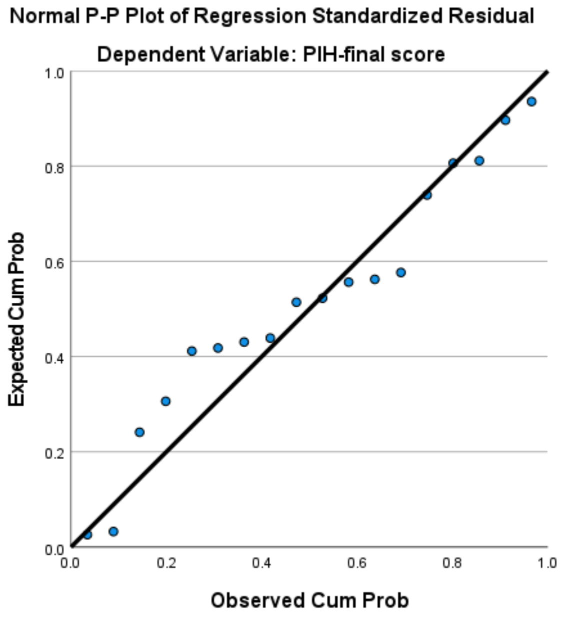
Assumptions of multiple regression - Analysis 2:

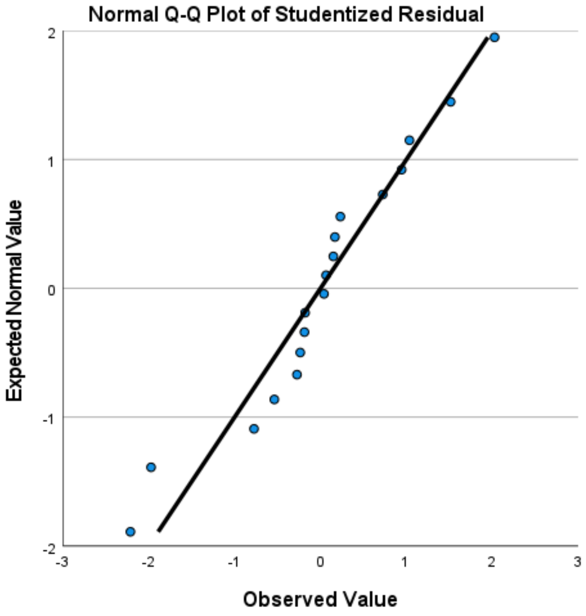




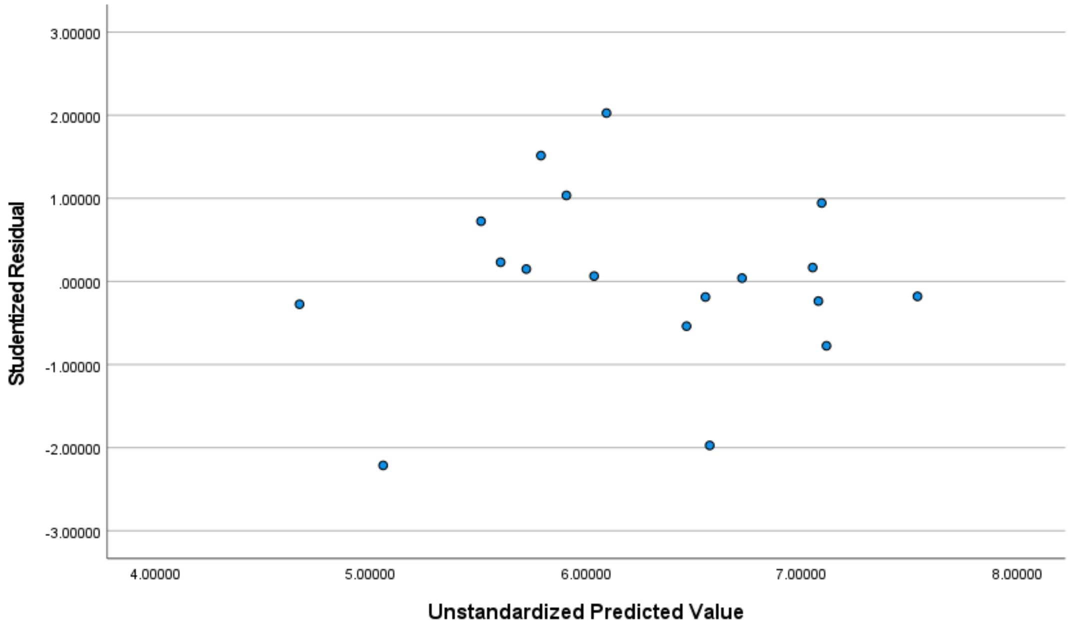
<u>Assumptions of multiple regression - Analysis 3:</u>


Histogram
Dependent Variable: PIH-final score
Mean = 1.07E-15
Std. Dev. = 0.907
N = 18
Frequency
0
1
2
3
4
5
-2
-1
0
1
2
Regression Standardized Residual


Normal P-P Plot of Regression Standardized Residual
Dependent Variable: PIH-final score
Expected Cum Prob
0.0
0.2
0.4
0.6
0.8
1.0
0.0
0.2
0.4
0.6
0.8
1.0
Observed Cum Prob



Assumptions of multiple regression - Analysis 4:



Assumptions of multiple regression - Analysis 5:

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	3.197	1.046		3.057	.009		

	Time since diagnoses (in years)	-.002	.017	-.019	-.107	.916	**.965**	1.036
	SEMCD-final score	.216	.098	.489	2.204	.045	**.633**	1.580
	PAM-Final score	.032	.021	.348	1.557	.142	**.625**	1.599

a. Dependent Variable: PIH-final score

Correlations of predictor variables:

Correlations

		Time since diagnoses (in years)	PAM-Final score	SEMCD-final score
Time since diagnoses (in years)	Pearson Correlation	1	-.117	.047
	Sig. (2-tailed)		.642	.854
	N	18	18	18
PAM-Final score	Pearson Correlation	-.117	1	.595**
	Sig. (2-tailed)	.642		.009
	N	18	18	18
SEMCD-final score	Pearson Correlation	.047	.595**	1
	Sig. (2-tailed)	.854	.009	
	N	18	18	18

**. Correlation is significant at the 0.01 level (2-tailed).

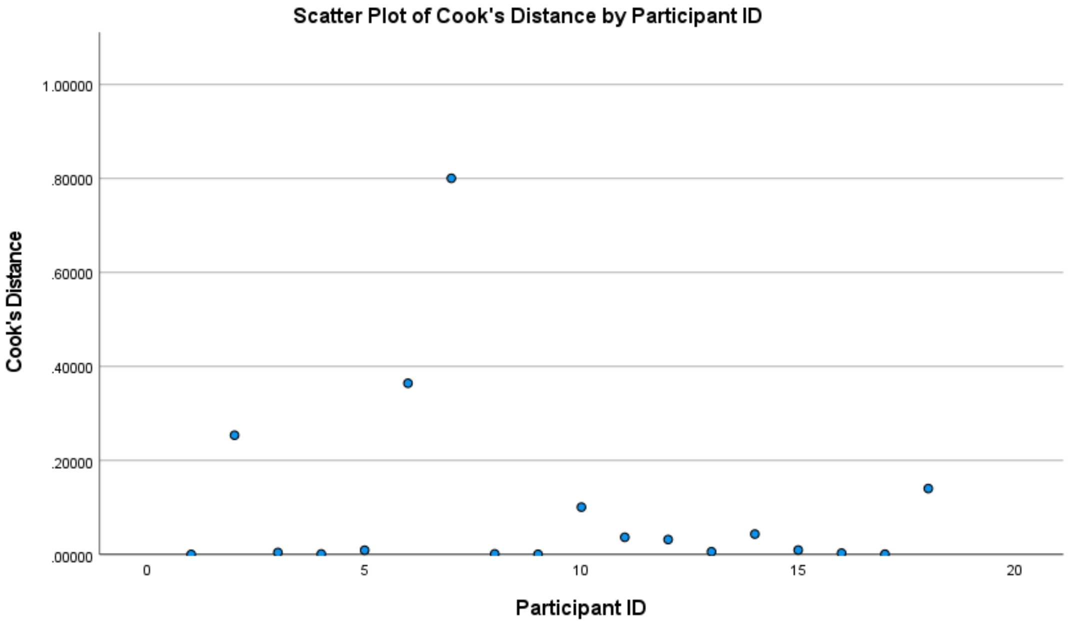
Assumptions of multiple regression - Analysis 6:

Residuals Statistics[a]

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	4.6699	7.5369	6.2544	.78451	18
Std. Predicted Value	-2.020	1.635	.000	1.000	18
Standard Error of Predicted Value	.243	.503	.352	.073	18
Adjusted Predicted Value	4.7548	7.5788	6.2011	.83659	18
Residual	-1.47797	1.15597	.00000	.69036	18
Std. Residual	-1.943	1.520	.000	.907	18
Stud. Residual	-2.213	2.027	.030	1.053	18
Deleted Residual	-1.91778	2.05688	.05339	.94107	18
Stud. Deleted Residual	-2.645	2.324	.013	1.177	18
Mahal. Distance	.792	6.502	2.833	1.534	18
Cook's Distance	**.000**	**.800**	**.100**	**.202**	**18**

Centered Leverage Value	.047	.382	.167	.090	18

a. Dependent Variable: PIH-final score



Multiple linear regression analysis (1):

Results:

Determining how well the model fits:

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.751[a]	.564	.470	.76074

a. Predictors: (Constant), PAM-Final score, Time since diagnoses (in years), SEMCD-final score

b. Dependent Variable: PIH-final score

Statistical significance:

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	10.463	**3**	3.488	**6.026**	**.007[b]**
	Residual	8.102	**14**	.579		
	Total	18.565	17			

a. Dependent Variable: PIH-final score

b. Predictors: (Constant), PAM-Final score, Time since diagnoses (in years), SEMCD-final score

Estimated model coefficient:

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B	
		B	Std. Error	Beta	**t**	**Sig.**	Lower Bound	Upper Bound
1	(Constant)	**3.197**	1.046		**3.057**	**.009**	.954	5.441
	Time since diagnoses (in years)	**-.002**	.017	-.019	**-.107**	**.916**	-.038	.034
	SEMCD-final score	**.216**	.098	.489	**2.204**	**.045**	.006	.427
	PAM-Final score	**.032**	.021	.348	**1.557**	**.142**	-.012	.076

a. Dependent Variable: PIH-final score

Appendix EE

Assumptions Testing and Analysis 2

H_2: There will be a significant impact of time since diagnosis on 10 SMS areas while controlling for self-efficacy

A Summary of the Assumption of Multiple Regression Analysis 2:

Assumptions		Results (SPSS statistics)	Reference
1	Sample size - common rule: 20 records for each predictor variable (if normally distributed, otherwise more than 20 records are required)	Based on the common rule as well as Gpower calculation, this assumption was not met	**Thesis Chapter 6, section 6.2.3**
2	Dependent variable measured on a continuous scale and two or more independent variables measured on either continuous or categorical scales	Dependent variable: 10 SMS areas - ordinal variable (but because the scale includes 10 values, it may be treated as a continuous variable) Independent variables: Time since diagnosis and self-efficacy as a covariate - both: continuous interval variable	
3	The independence of observations errors (or residuals)	There was no independence of residuals as assessed by the Durbin-Watson statistic of 1.889 (the Durbin-Watson statistic can range between 0 to 4 and a value of approximately 2 is ideal to indicate that there is no correlation between residuals)	**Analysis 1**
4	Linearity	There was a linear relationship between the dependent variable and each independent variable as assessed by visual inspection of the scatterplot matrix (and additionally, a single scatterplot with a Loess curve)	**Analysis 2**
5	Normality	There was a normal distribution of residuals (errors) as assessed by a histogram with a superimposed normal curve, and a Normal P-P Plot	**Analysis 3**
6	Homoscedasticity	There was homogeneity of residual variances as assessed by visual inspection of a scatterplot of studentized residuals versus unstandardised predicting values	**Analysis 4**

Assumptions		Results (SPSS statistics)	Reference
7	Multicollinearity	There was no evidence of multicollinearity as assessed by tolerance values >0.1 and variance inflation factors (VIFs) <10 (and additionally, correlation of predictor variables)	**Analysis 5**
8	The absence of outliers in all variables, high leverage points, and highly influential points	Casewise diagnostic conducted - residuals are less than or equal to 3, thus there are no significant outliers. Cook's distance values in the residual statistics table, showed no highly influential points with all values below 1. Based on the formula assessing leverage points [(k+1)/n; k=nr of predictors, n=nr of participants; with the maximum laverage= (N-1)/N], leverage points equalled 0.17 which was less than the maximum leverage point of 0.94, indicating the absence of high leverage points.	**Analysis 6**

Assumptions of multiple regression - Analysis 1:

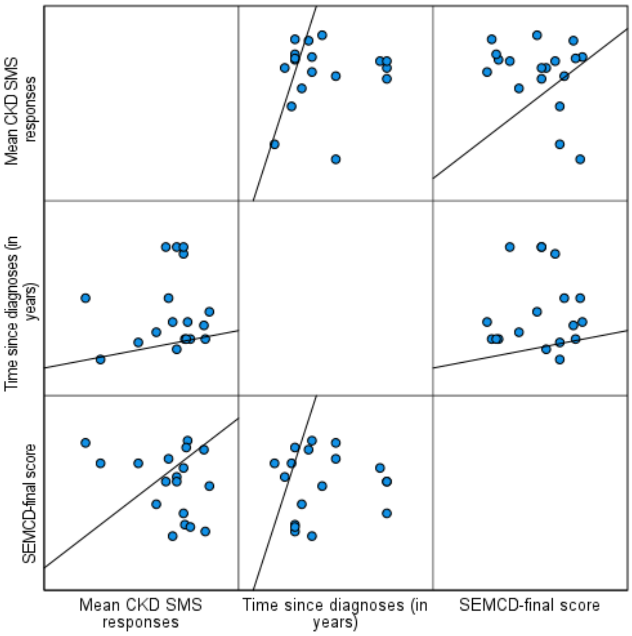
Model Summary[b]

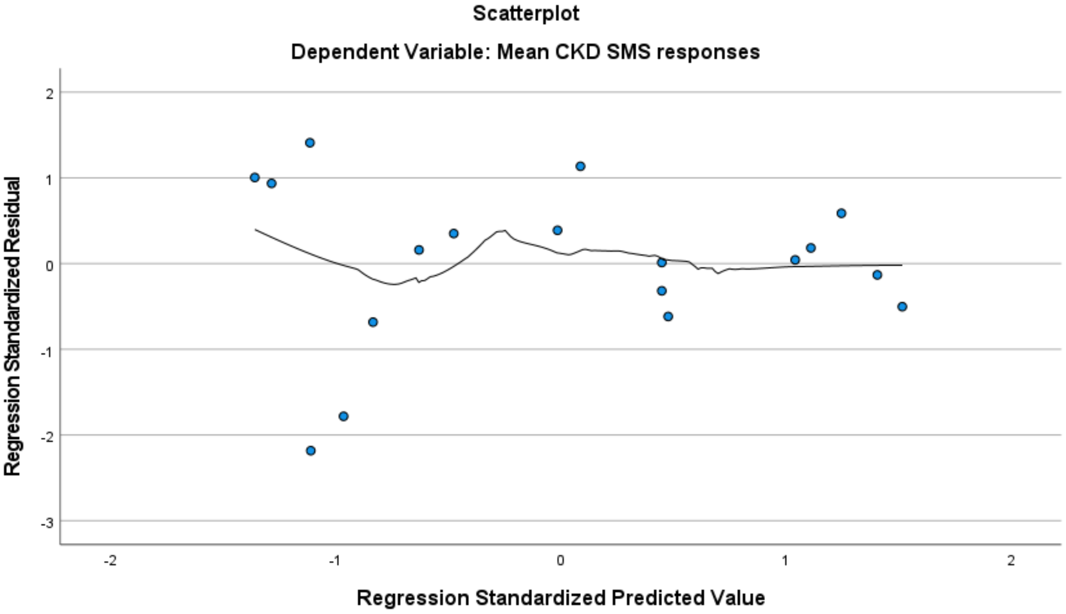
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.363[a]	.132	.016	2.42238	**1.889**

a. Predictors: (Constant), SEMCD-final score, Time since diagnoses (in years)

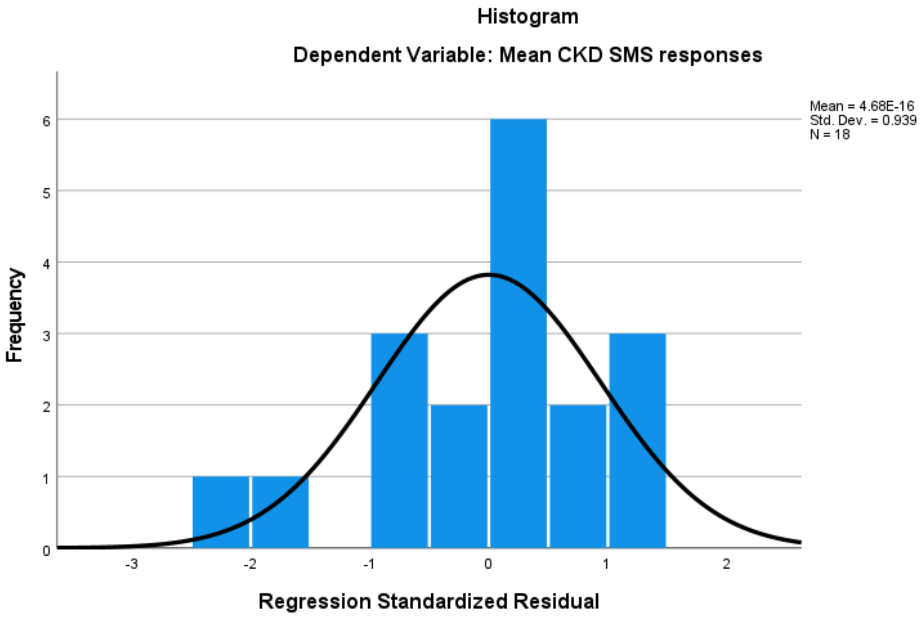
b. Dependent Variable: Mean CKD SMS responses

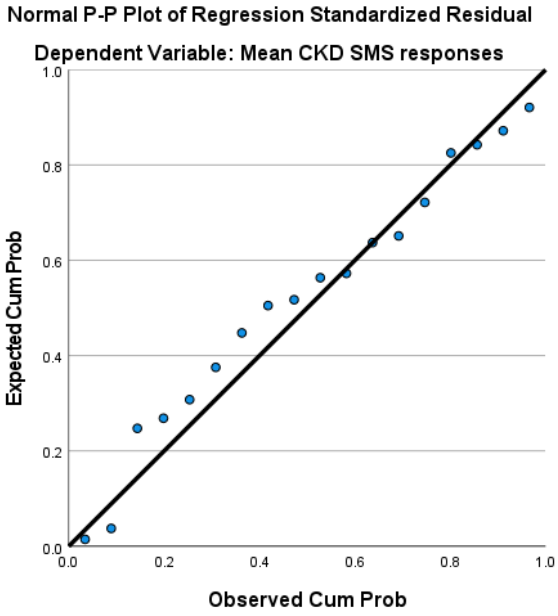
Assumptions of multiple regression - Analysis 2:



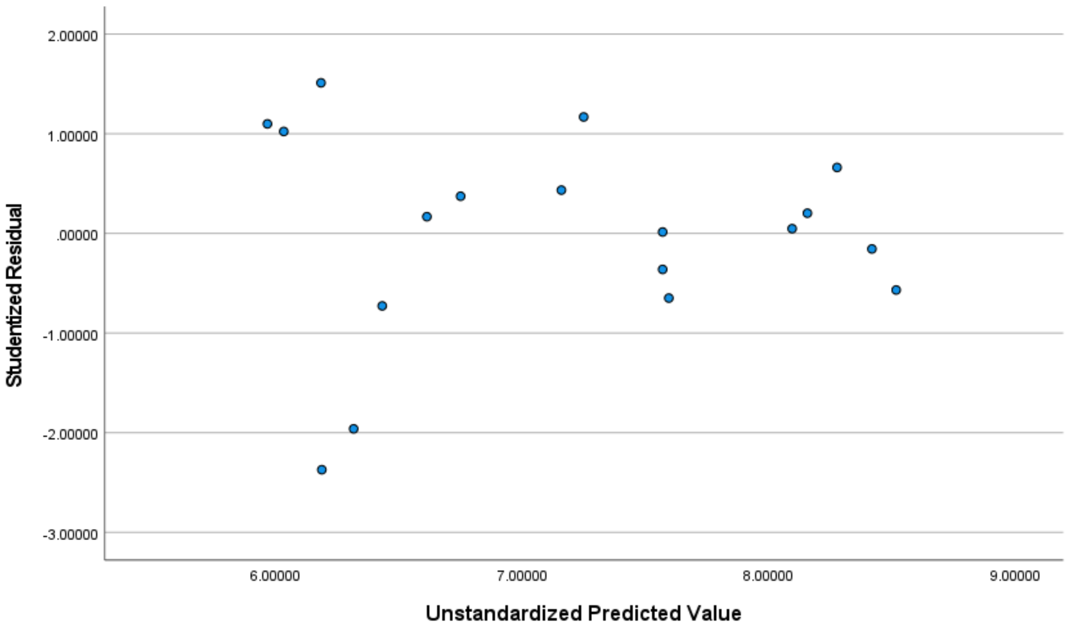


Assumptions of multiple regression - Analysis 3:





<u>Assumptions of multiple regression - Analysis 4:</u>



Assumptions of multiple regression - Analysis 5:

Coefficients^a

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% Confidence Interval for B		Correlations			Collinearity Statistics	
		B	Std. Error	Beta			Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	8.882	1.716		5.175	<.001	5.224	12.541					
	Time since diagnoses (in years)	.023	.053	.106	.441	.665	-.089	.135	.090	.113	.106	**.998**	**1.002**
	SEMCD-final score	-.364	.249	-.352	-1.463	.164	-.895	.166	-.347	-.353	-.352	**.998**	**1.002**

a. Dependent Variable: Mean CKD SMS responses

Assumptions of multiple regression - Analysis 6:

Residuals Statistics[a]

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	5.9655	8.5167	7.1710	.88726	18
Std. Predicted Value	-1.359	1.517	.000	1.000	18
Standard Error of Predicted Value	.573	1.296	.973	.179	18
Adjusted Predicted Value	5.4864	8.8535	7.1954	.97752	18
Residual	-5.28617	3.41715	.00000	2.27543	18
Std. Residual	-2.182	1.411	.000	.939	18
Stud. Residual	-2.371	1.511	-.005	1.019	18
Deleted Residual	-6.24129	3.92298	-.02446	2.67794	18
Stud. Deleted Residual	-2.897	1.586	-.041	1.126	18
Mahal. Distance	.008	3.920	1.889	.980	18
Cook's Distance	**.000**	**.339**	**.058**	**.096**	18
Centered Leverage Value	.000	.231	.111	.058	18

a. Dependent Variable: Mean CKD SMS responses

Multiple linear regression analysis (2):

Results:

Determining how well the model fits:

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.363[a]	.132	.016	2.42238

a. Predictors: (Constant), SEMCD-final score, Time since diagnoses (in years)

Statistical significance:

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	13.383	**2**	6.691	**1.140**	**.346**[b]
	Residual	88.019	**15**	5.868		
	Total	101.402	17			

a. Dependent Variable: Mean CKD SMS responses

b. Predictors: (Constant), SEMCD-final score, Time since diagnoses (in years)

Estimated model coefficient:

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B	
		B	Std. Error	Beta	**t**	**Sig.**	Lower Bound	Upper Bound
1	(Constant)	**8.882**	1.716		**5.175**	**<.001**	5.224	12.541
	Time since diagnoses (in years)	**.023**	.053	.106	**.441**	**.665**	-.089	.135
	SEMCD-final score	**-.364**	.249	-.352	**-1.463**	**.164**	-.895	.166

a. Dependent Variable: Mean CKD SMS responses

Appendix FF

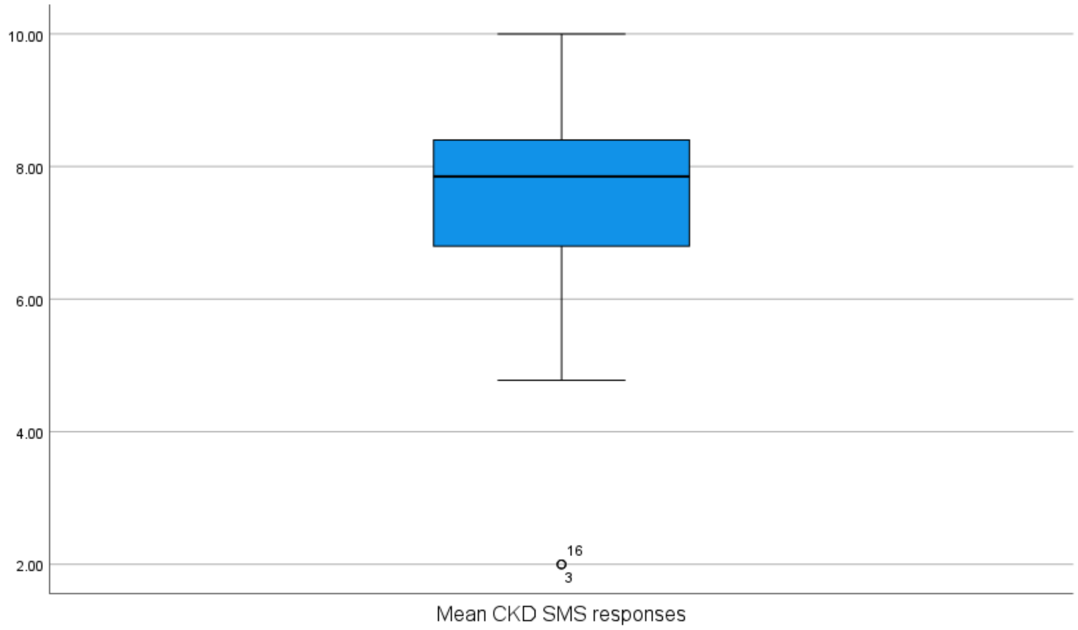
Assumptions Testing and Analysis 3

H_3: There will be a significant difference between the level of interest in receiving SMS based on the stage of CKD
H_O: the distribution of the two groups is equal
H_A: the mean ranks of the two groups are not equal

A Summary of the Assumption of Independent-Test Analysis 3:

	Assumptions	**Results (SPSS statistics)**	**Reference**
1	Sample size	Based on the Gpower calculation, this assumption was not met	**Thesis Chapter 6, section 6.2.3**
2	One dependent variable measured at the continuous (interval or ratio level), and the independent variable consists of two categorical, independent groups (e.g., dichotomous variable)	Dependent variable: CKD SMS (ordinal variable, but because the scale includes 10 values, it may be treated as a continuous variable) Independent variables: CKD stages (categorical variable with two independent groups: early-CKD stages vs late-CKD stages)	
3	The independence of observations	There was no relationship between the observations in each group of the independent variable or between the groups themselves which was determined by the study design (e.g., the researcher ensured that there are different participants in each group with no participants being in more than one group)	
4	The absence of outliers	No significant outliers were detected as assessed by visual inspection of the boxplot and Histogram	**Analysis 1 and 2**
5	Normality and homogeneity of variance	Data appears normally distributed following investigation of a simple boxplot and Histogram including responses from both groups. Levene's test for Equality of variance was not significant meaning that the null hypothesis can be accepted, meaning that the assumption of equal distribution between two groups is satisfied	**Analysis 2**

Assumptions testing - Analysis 1:



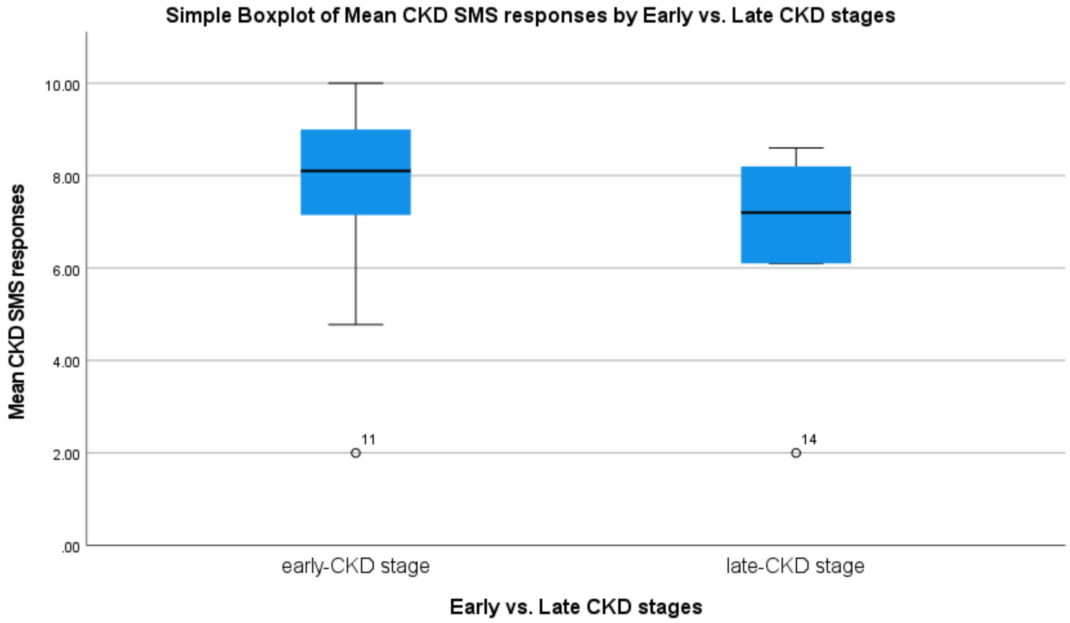
Assumptions testing - Analysis 2:

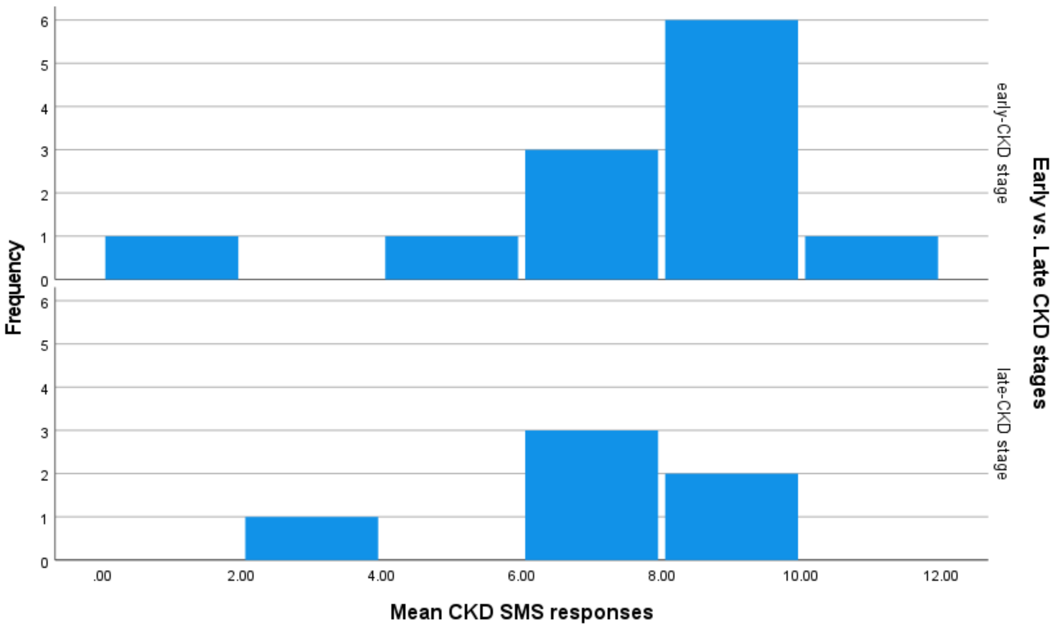
Descriptives

			Statistic	Std. Error
Mean CKD SMS responses	Mean		7.2321	.53854
	95% Confidence Interval for Mean	Lower Bound	6.0959	
		Upper Bound	8.3683	
	5% Trimmed Mean		7.3690	
	Median		7.8500	
	Variance		5.221	
	Std. Deviation		2.28484	
	Minimum		2.00	
	Maximum		10.00	
	Range		8.00	
	Interquartile Range		1.82	
	Skewness		-1.363	.536
	Kurtosis		1.532	1.038

Descriptive Statistics

Early vs. Late CKD stages		N	Minimum	Maximum	Mean	Std. Deviation	Variance
early-CKD stage	Mean CKD SMS responses	12	2.00	10.00	7.5731	2.24755	5.051
	Valid N (listwise)	12					
late-CKD stage	Mean CKD SMS responses	6	2.00	8.60	6.5500	2.40811	5.799
	Valid N (listwise)	6					





Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
Mean CKD SMS responses	Equal variances assumed	.028	.870	.890	16	.193	.387	1.02315	1.14947	-1.41361	3.45991
	Equal variances not assumed			.869	9.486	.203	.406	1.02315	1.17790	-1.62079	3.66708

Test of Homogeneity of Variance

		Levene Statistic	df1	df2	Sig.
Mean CKD SMS responses	Based on Mean	.000	1	16	.992
	Based on Median	.002	1	16	.962
	Based on Median and with adjusted df	**.002**	**1**	**15.848**	**.962**
	Based on trimmed mean	.000	1	16	.983

Two-Sample Independent T-test Analysis 3:

Group Statistics

	Early vs. Late CKD stages	N	Mean	Std. Deviation	Std. Error Mean
Mean CKD SMS responses	early-CKD stage	12	7.5731	2.24755	.64881
	late-CKD stage	6	6.5500	2.40811	.98311

Independent Samples Test

	Levene's Test for Equality of Variances		t-test for Equality of Means							
					Significance				95% Confidence Interval of the Difference	
	F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper

Mean CKD SMS responses	**Equal variances assumed**	.028	**.870**	**.890**	**16**	.193	**.387**	1.02315	1.14947	-1.41361	3.45991
	Equal variances not assumed			.869	9.486	.203	.406	1.02315	1.17790	-1.62079	3.66708

Independent Samples Effect Sizes

		Standardizer[a]	Point Estimate	95% Confidence Interval	
				Lower	Upper
Mean CKD SMS responses	Cohen's d	2.29893	**.445**	-.554	1.430
	Hedges' correction	2.41420	.424	-.527	1.362
	Glass's delta	2.40811	.425	-.607	1.419

a. The denominator used in estimating the effect sizes.
Cohen's d uses the pooled standard deviation.
Hedges' correction uses the pooled standard deviation, plus a correction factor.
Glass's delta uses the sample standard deviation of the control group.

Variances are assumed to be equal, thus using the top row, t=.890 and the *p*-value is .387 (two-tailed) which is > .05, thus the null hypothesis remains.

Appendix GG

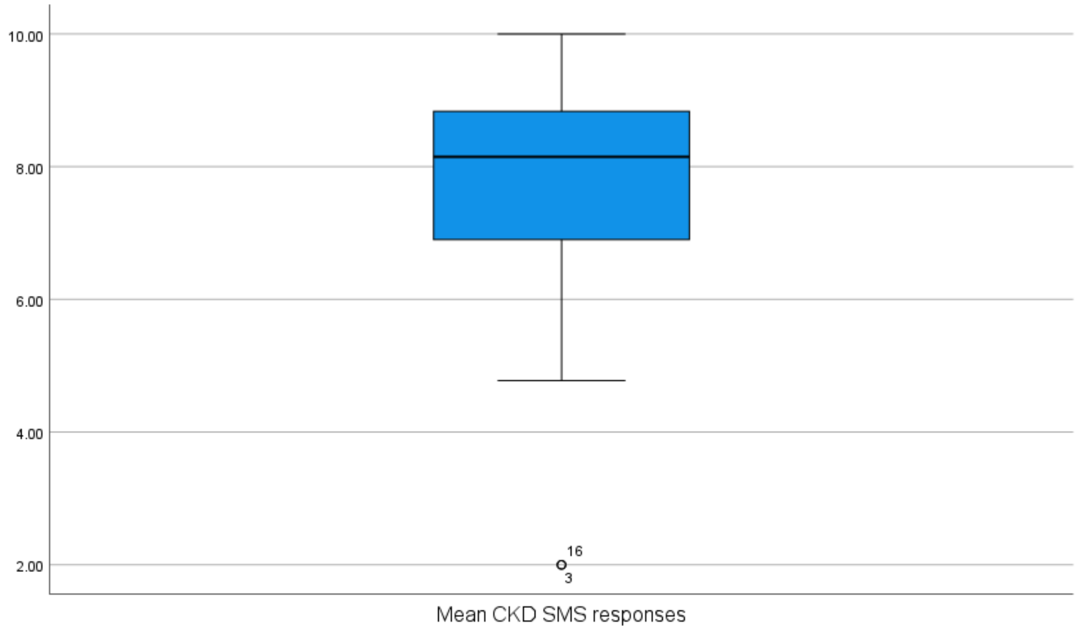
Assumptions Testing and Analysis 4

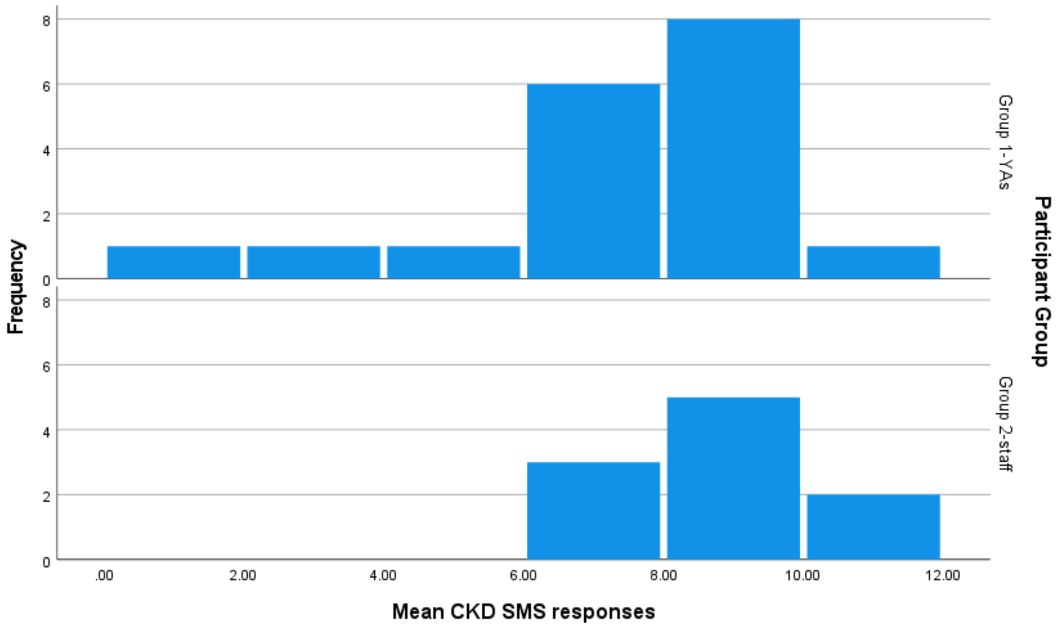
H4: There will be significant differences in responses regarding YAs‘ interest in receiving SMS across 10 areas between YAs and their health and social care professionals
HO: the distribution of the two groups is equal
HA: the mean ranks of the two groups are not equal

A Summary of the Assumption of Independent-Test Analysis 4:

	Assumptions	**Results (SPSS statistics)**	**Reference**
1	Sample size	Based on the Gpower calculation, this assumption was not met	**Thesis Chapter 6, section 6.2.3**
2	One dependent variable measured at the continuous or ordinal level, and the independent variable consist of two categorical, independent groups (e.g., dichotomous variable)	Dependent variable: CKD SMS (ordinal variable, but because the scale includes 10 values, it may be treated as a continuous variable) Independent variables: categorical variable with two independent groups: YAs vs health and social care professionals)	
3	The independence of observations	There was no relationship between the observations in each group of the independent variable or between the groups themselves which was determined by the study design (e.g., the researcher ensured that there are different participants in each group with no participants being in more than one group)	
4	The absence of outliers	No significant outliers were detected as assessed by visual inspection of the boxplot and Histogram	**Analysis 1 and 2**
5	Normality and homogeneity of variance	Levene’s test for Equality of variance was not significant meaning that the null hypothesis can be accepted, meaning that the assumption of equal distribution between two groups is satisfied	**Analysis 2**

<u>Assumptions testing - Analysis 1:</u>





Assumptions testing - Analysis 2:

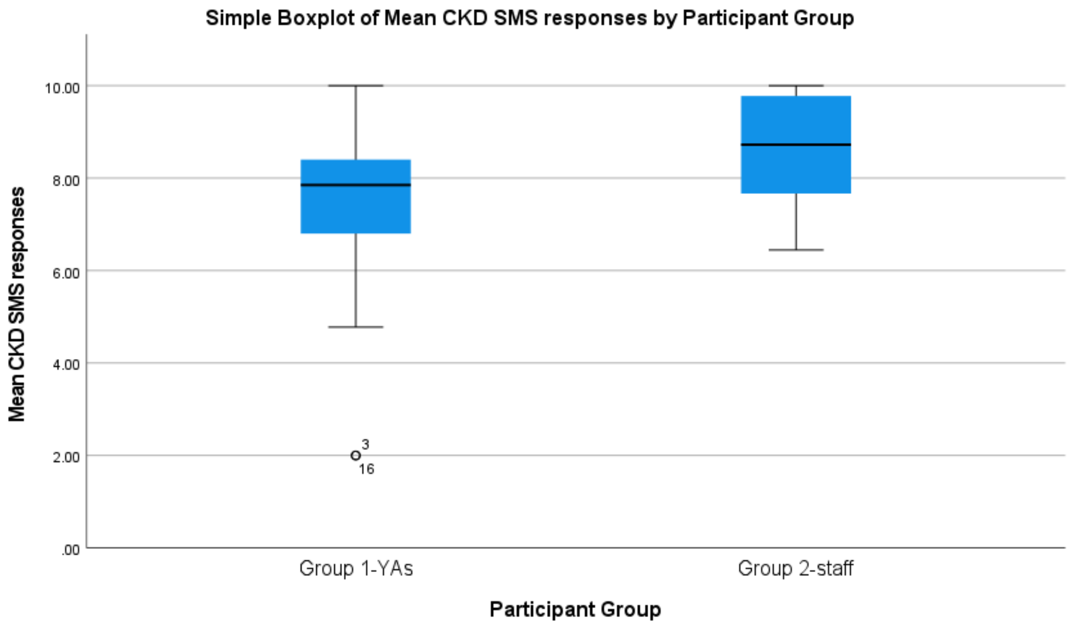
Descriptives

			Statistic	Std. Error
Mean CKD SMS responses	Mean		7.6968	.38882
	95% Confidence Interval for Mean	Lower Bound	6.8990	

		Upper Bound	8.4946	
	5% Trimmed Mean		7.8854	
	Median		8.1500	
	Variance		4.233	
	Std. Deviation		2.05746	
	Minimum		2.00	
	Maximum		10.00	
	Range		8.00	
	Interquartile Range		2.01	
	Skewness		-1.541	.441
	Kurtosis		2.647	.858

Descriptive Statistics

Participant Group		N	Minimum	Maximum	Mean	Std. Deviation	Variance
Group 1-YAs	Mean CKD SMS responses	18	2.00	10.00	7.2321	2.28484	5.221
	Valid N (listwise)	18					
Group 2-staff	Mean CKD SMS responses	10	6.44	10.00	8.5333	1.27635	1.629
	Valid N (listwise)	10					



Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
Mean CKD SMS responses	Equal variances assumed	1.560	.223	-1.654	26	.055	.110	-1.30123	.78657	-2.91805	.31559

	Equal variances not assumed			-1.933	25.979	.032	.064	-1.30123	.67301	-2.68467	.08220

Independent Samples Effect Sizes

		Standardizer[a]	Point Estimate	95% Confidence Interval	
				Lower	Upper
Mean CKD SMS responses	Cohen's d	1.99432	-.652	-1.439	.146
	Hedges' correction	2.05425	-.633	-1.397	.142
	Glass's delta	1.27635	-1.019	-1.901	-.098

a. The denominator used in estimating the effect sizes.
Cohen's d uses the pooled standard deviation.
Hedges' correction uses the pooled standard deviation, plus a correction factor.
Glass's delta uses the sample standard deviation of the control group.

Test of Homogeneity of Variance

		Levene Statistic	df1	df2	Sig.
Mean CKD SMS responses	Based on Mean	1.688	1	26	.205
	Based on Median	1.026	1	26	.321
	Based on Median and with adjusted df	**1.026**	**1**	**19.986**	**.323**
	Based on trimmed mean	1.358	1	26	.254

Two-Sample Independent T-test Analysis 4:

Group Statistics

	Participant Group	N	Mean	Std. Deviation	Std. Error Mean
Mean CKD SMS responses	Group 1-YAs	18	7.2321	2.28484	.53854
	Group 2-staff	10	8.5333	1.27635	.40362

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
Mean CKD SMS responses	**Equal variances assumed**	**1.560**	**.223**	**-1.654**	26	.055	**.110**	-1.30123	.78657	-2.91805	.31559
	Equal variances not assumed			-1.933	25.979	.032	.064	-1.30123	.67301	-2.68467	.08220

Independent Samples Effect Sizes

		Standardizer[a]	Point Estimate	95% Confidence Interval	
				Lower	Upper
Mean CKD SMS responses	Cohen's d	1.99432	**-.652**	-1.439	.146
	Hedges' correction	2.05425	-.633	-1.397	.142
	Glass's delta	1.27635	-1.019	-1.901	-.098

a. The denominator used in estimating the effect sizes.
Cohen's d uses the pooled standard deviation.
Hedges' correction uses the pooled standard deviation, plus a correction factor.
Glass's delta uses the sample standard deviation of the control group.

Variances are assumed to be equal, thus using the top row, t= -1.654 and the *p*-value is .110 (two-tailed) which is > .05, thus the null hypothesis remains.

Appendix HH

Qualitative Data - Worked Example

The worked example of the analytical process below illustrates data extracted from the interview with Participant 1. This example is based on one interview question-answer from topic 1 and presents different initial themes (colour-coded) and single potential codes (using the comment function in a Word document):

Worked Example of the Analytical Process

	Comment
Interviewer: What makes it harder to live with chronic kidney disease, what areas of your life are most impacted or limited by the condition and how?	
Interviewee (participant 1, female): There are a few. So, when I was younger, because I got diagnosed when I was at university, drinking, the social life. Obviously, they said, you have to be really careful with alcohol because it does make obviously a lot worse. And also, alcohol drops your blood pressure even more, so when I was on this medication it was quite serious that I could be at risk of passing out. So, I had to be careful and try to tell my friends that I couldn't drink as much as they, kind of you know what university people can be like that "No no, you are fine". And I think them not understanding was really difficult. Because it is that sort of culture. So that was quite difficult when I was younger.	**Socialising and peer pressure**
And now that I'm growing up, the other side effect that I never really thought about was having kids. So, I got told when I was 19 that if I wanted to think about having children it's basically up to my kidneys if I have them or not. Because obviously when a woman is pregnant, it puts a lot of pressure on their kidneys and they don't know until I'm pregnant, how much it's going to put on them and obviously you can't regain that function. So it's kind of been a ticking time bomb in the back of my head, every day, especially being a woman, you know we don't really have that much time anyways. So my specialist said you kind of got to find the right time, where your kidneys are in a good position and you're not too old as they put it, which always makes you feel great when you're 19 (laughs).	**Having children**
So I never really thought about it until they kind of set those to me, and they said that I could die younger. And they said that is indefinite if I'll ever come off my medication and I will quite possibly need a transplant because of how young I am, which yeah it was all very daunting it wasn't the best appointment I could have in the world, but yeah it's sort of stuff you don't really see every day, I act absolutely normal with everyone and there are only certain people who see me on a bad day, which is my mom and my partner. But it's this other stuff that are consequences that some people don't even have to worry about. And I think another challenge is	**Daunting and lonely illness**

stereotypes. So a lot of people think that kidney disease is an older person’s illness and when I used to go to my renal appointments I would be the youngest person there. And they kind of would look at me, I’m like yes I’m here.	**Invisible and misjudged disability**

Appendix II

Thematic Analysis - Young Adults (YAs; Group 1)

Initial Codebook and Thematic Map, and Revised Codes:

The research question for phase 2: *Among YAs living with CKD stages 1 to 5, what aspects of the existing CKD self-management interventions need improvement and what additional aspects may they benefit from?*

The Research question for phase 2, part 2:

How does CKD affect YAs and what do they require to effectively self-manage their condition?

Table II1

Initial Priori Codes/Themes - Interviews with YAs:

	Priori codes:
Topic 1	**Living with CKD** **Impact of CKD** **Challenges associated with CKD**
Topic 2	**Current self-management support** **CKD self-management knowledge** **CKD self-management skills** **CKD self-management confidence**

CKD Chronic Kidney Disease.

Initial Posteriori codes/themes:

YAs with CKD

Advice for other YAs

YAs Young Adults.

Note that: the above (Table II1) are initial themes/codes which were later revised. The following information includes the initial codebook (for YA; Table II2), as well as the initial thematic map (Figure II1) and revised codes (for both groups of participants; Table II3), respectively. The following Appendix JJ includes the initial codebook for health and social care professionals. Both codebooks for YAs and their health and social care professionals provide one example of the participants’ quotes for each code. Both codebooks with more examples of data extracts are available upon request. More examples of the data extract can also be seen in Table BBB1 in Appendix BBB.

Table II2

Initial Codebook - YAs:

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 1 (female)	Participant nr. 2 (male)	Participant nr. 3 (male)	Participant nr. 4 (male)
		Example (citation/ raw data):			
Living with CKD (Statements that describe CKD and what is like to live with CKD)	**Invisible and misjudged disability**	“It is kind of an invisible disability”	“It's a silent disease, that’s a big part of it, that is the challenging part to be fair”	“Just because you can't see it, it doesn't mean it's not happening internally. People assume that CKD is a very old person's illness”	“I’d say it's very much a silent condition and that you don't really feel it until you get sort of towards the end stage where you start just to feel really tired, and you want to sleep a bit and just feel like it's harder to do things”
	Daunting and lonely illness	“Just knowing that you're not alone. I think it can be incredibly daunting to be diagnosed as”		“You do feel down, and you can feel very isolated and alone”	
	Lack of CKD awareness and understanding (from teachers	“I find it important to tell someone that I have CKD because I have to carry a card around with me just in case I have to get any medication that needs to not interfere with mine”	“Education is a big one, challenging a bit in school”	“It would be nice if employers understood that chronic illnesses like CKD affect similarly as it would affect other serious illnesses like cancer or heart problems”	“I guess work and career have been majorly affected..it can be hard to try and explain that, and it seems as well that the burden and the explanation is kind of put on the person to explain to

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 1 (female)	Participant nr. 2 (male)	Participant nr. 3 (male)	Participant nr. 4 (male)
	and employers)				the employer and you almost feel like you're defending yourself, for being ill. When you shouldn't really have"
YAs with CKD (Statements that describe the YA population who suffer from CKD)	**Invincible and naïve**	"I think when you're young, you think you're invincible"			
	"We are more than just our condition" (Code for YAs only)	"I think once you're past 18, doctors should treat you like an adult, maybe they should start actually treating you like you deserve to know everything, you are the patient"		"They (doctors) were talking at me rather than with me and I think they need to learn the difference between listening to me and hearing me. If you hear me, you're going to take action on what I said, if you're listening, you're just ticking boxes: yes, we listened to the patient. I'm not a box.. and I think those are big points that should and can and do make a difference in people's lives"	
	"Want to live a	"There's a side of me where I want to live my		"Our aim at the end of the day is to lead as normal	"It stopped me from doing more things than I'd like

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 1 (female)	Participant nr. 2 (male)	Participant nr. 3 (male)	Participant nr. 4 (male)
	normal life”	normal life. I still go out and drink. I don't drink that much, but when I do, I have to drink a lot anyway in fluids, which can be challenging at times”		life as possible, and work is part of a normal life”	to do. I used to do Thai boxing and sort of contact sport and I can't really do that now because of the transplants.. I can do it I just need to avoid contact”
Impact of CKD (Statements that indicate how CKD impacts or limits YAs' lives)	**Physical and mental well-being**	“Once I remember, I had one week off work because I just couldn't get out of bed. I was that lethargic and I couldn't drive, because I couldn’t actually focus and see straight”	“I mean on the anxiety side of it, which is a big part of my problems, with the kidney disease to treat anxiety. I think the biggest thing is to help me to live with it, live my life”	“Not only can it affect you physically, whether that’s pain, anaemia, not feeling great, feeling ill, feeling sick, having infections things like that, I think the mind, the mental aspect also can be affected. I don’t think it’s really understood very well, the mental side of it”	“The mental side of it, managing your own mental state”
	Socialising and peer pressure (Code for YAs only)	“I think their not understanding was really difficult. Because it is that sort of culture. So that was quite difficult when I was younger”	“Socialising is a big one, it put me back on socialising quite a lot. I think exercising, or joining in team sports compared to doing		

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 1 (female)	Participant nr. 2 (male)	Participant nr. 3 (male)	Participant nr. 4 (male)
			individual sports on my own”		
	Having children (Code for YAs only)	“And now that I’m growing up, the other side effect that I never really thought about was having kids. So, I got told when I was 19 that if I wanted to think about having children, it was basically up to my kidneys if I had them or not. Because obviously when a woman is pregnant, it puts a lot of pressure on their kidneys and they don’t know until I’m pregnant, how much it’s going to put on them and obviously you can’t regain that function. So it's kind of been a ticking time bomb in the back of my head, every day, especially being a woman, we don’t really have that much			

Codes/ Themes (description)	**Codes/ Sub-themes**	**Participant nr. 1 (female)**	**Participant nr. 2 (male)**	**Participant nr. 3 (male)**	**Participant nr. 4 (male)**
		time anyways. So, my specialist said you kind of got to find the right time, where your kidneys are in a good position and you're not too old as they put it, which always makes you feel great when you're 19 (laughs)"			
Challenges associated with CKD (Statements that describe the challenges associated with CKD)	**The transition process and taking ownership**			"I think a big part of that as well, can be the transition from paediatric to adult. When you are in paediatrics, generally, your parents take a lot of the brunt of the responsibilities, you're under their care. But when you hit that kind of threshold and you have to move on and then you understand all the stuff your parents were dealing with and how to deal with and that can be a really big change for a young person"	

Current self-management support (Comments that describe the current self-management support)	**Family and peer support**	"I've heard that there are some renal units and hospitals that have like focus groups for young people where they just meet up every week and say how are things, do you need anything. I've not really had any of that and I think I'd be one of these people who, if I knew there was a focus group, at my local hospital or even anywhere really, where there are young people with the same condition or even old, I don't really mind just anyone. Maybe just to go along once in a while and just say: yeah I need help with this, could anyone help and just be a community"	"I would say, definitely get champs to use one of the youth workers. Use a youth worker who is on the team or a psychologist to work with, mine work perfectly, brilliantly. Yeah that's one thing, definitely make use of youth work"	"As much as family and lovers care for us and try to look after us, I think there's a different aspect when you meet people who are like you. We all have our individual stories and our individual journeys of where we are in that kind of chronic illness but I think we can relate more to each other because we've lived it. Kind of peer patients or like champion patients (from ethnic minorities)"	"It'd be good if there was more sort of exercise, more groups within the sort of kidney community of people who have been through or going through what we're all going through, it would be good to engage a bit more with those sorts of things. I mean I'm based over in Northwest of Wales so it's pretty sort of rural and stuff like that, so we don't really have much of that around here. I don't know whether it's the same where you are down south or in England, I don't know. On a day-to-day basis, it would be great to share ideas on health and diet and just other sorts of different tips stuff really"

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 1 (female)	Participant nr. 2 (male)	Participant nr. 3 (male)	Participant nr. 4 (male)
	Effective communication and relationship with HCPs	“Maybe standing up for yourself. I think that's a skill in itself, to have that innocent confidence, which links your other point to actually say you might be a doctor but you're not living with it, and therefore I think I deserve to have the amount that I deserve (talking about medication), in a sense”		“And if you can self-advocate, and you can self-care that means you don’t potentially, unless of course, it’s an emergency or something, have to always go into the hospital for every little thing because it freaks you out which will then less than burden on the renal team”	“It’s not a case of sort of, just being a good boy and doing what they say, just taking their word as Gospel it’, I would challenge if I thought something was wrong”
	PCC approach	“Every person is different”	“I mean, I think it might help.. we’ve spoken in the email about it, about the research side of everything we need to probably have that because the more research is done, the more it can make easier for YAs, YAs	“If you can teach me things in a way that is appropriate to teach me, I will absorb that information better. It’s a very individual illness”	“It’d be great if someone like me and other people that want to do exercise if we can have a more personalised program or something like that, around exercise, because it’s such an important thing in managing the condition that would be great if I could have said to a doctor, this is what I do week to week basis, would you consider that

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 1 (female)	Participant nr. 2 (male)	Participant nr. 3 (male)	Participant nr. 4 (male)
			more than older generations”		healthy or is that too much? But obviously, that support isn’t available as far as I’m aware”
	Consistency in care			“I’ve had different experiences with different hospitals because I’ve been through a couple.. One was not so successful and one was absolutely amazing.. I’ve kind of seen how it should be and kind of how horribly it can make you feel”	
CKD self-management knowledge (Statements that describe YAs’ knowledge of CKD self-management)	**Adequate information**	“I think that (being provided with knowledge on CKD) would do a massive thing to actually get to acceptance of it and, yeah, I definitely not got enough information in my book”	“No, it is really down to you. Whatever stage you are in, get booklets and everything. I think that’s good self-management, to look at the booklets and keep track what their advice that’s been given to you”	“They don't have that knowledge and understanding, and I think the sooner we have that connection with patients and their carers if they have carers to understand the illness and the signs and symptoms, to look out for what could happen, what can happen. Sometimes you don't need to panic about everything,	“My own research sort of stuff. I know there's information on websites which I might have read, but I can't remember, and I’m sure I could go to the renal nurses and consultant at the hospital and ask, but otherwise. I suppose, unofficially being part of Facebook groups with other people and getting information

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 1 (female)	Participant nr. 2 (male)	Participant nr. 3 (male)	Participant nr. 4 (male)
				give them that peace of mind that sometimes, he or she will not feel great. But that is part of the illness”	off them, as well as, it is another source, or be it sort of unofficial, so there are the resources available”
CKD self-management skills (Comments that describe YAs’ CKD self-management skills)	**“Being born with it is better than being diagnosed later on”**			“I've been quite lucky that I was, I know it's really weird, but yeah I was lucky that I was born with this so I’ve learned through my life. I’m about all these little things and because I’ve had to have several transplants I’ve kind of learned about different dialysis and diet and fluid management and all these different things and different drugs and rejection and biopsies. But not everyone is going to be like me, not everyone is going to be born with it and learn through it, as some may present late, for example, they may present in the middle of the	

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 1 (female)	Participant nr. 2 (male)	Participant nr. 3 (male)	Participant nr. 4 (male)
				university and think: like what the hell, like my life is upside down.. they might present in their mid-20s, for example when they're starting their career and they're settling down and thinking: okay like this, my life I'm good. And then it'll hit them and then, like crap, what do I do with my life"	
CKD self-management confidence (Statements that describe YAs' confidence in CKD self-management)	**Confident "now" but not "then"** (Code for YAs only)	"I'm very confident in day-to-day, drinking, taking my medication and not eating a certain food. I am very confident in that aspect. But I'm not so confident in the reality of living with CKD, sounds really silly because I am living with it, but, like the future is quite daunting and that's what I'm not confident with.. It's those little questions that I get in my	"I think I do sometimes struggle with a bit, especially on transplant medication, that's a little bit harder, you've got to remember to take them in a certain time period, otherwise, certain drugs will.. you know, you wouldn't get the	"The patient will feel more confident to look after themselves because they have been informed, spoken to with respect and listened to. And I think these kinds of things will help change in the long run. If you kind of had that relationship with the patient at the beginning and had that communication at the beginning, you could have potentially helped that	"I'd say I've got the skills and confidence to manage it at the stage now because it's fairly easy to manage at this stage, and because I've known about it for 13 years of I've had a lot of time. But certainly, when I first was diagnosed, I was nowhere near confidence, particularly with the exercise and because I was unsure about what I could do and what I

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 1 (female)	Participant nr. 2 (male)	Participant nr. 3 (male)	Participant nr. 4 (male)
		head now and again, and I don't have the answers, and therefore I don't feel confident about my future in a sense”	kidney function as good as it would be or the transplant would fail. And I think that's one area that I do still struggle on that bit at the moment”	patient to not have to go in all the time and not take up bed space, etc. So, not only does it benefit the patient it benefits the system.. it will make them pawns better and stronger and we will have the confidence to reach out to you and you will have that confidence to reach out to us”	couldn't do, so in the end I just thought I just almost do what I want to do, which is what I did”
	Empowerment, partnership, and respect			“I think it will give patients that confidence that they can manage themselves, they can have that confidence to live as normally as they can, prepare for things, whether that be seasonal changes, etc. And it empowers us because then we feel we have more control over our condition. And I think is about partnership and empowerment and having	

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 1 (female)	Participant nr. 2 (male)	Participant nr. 3 (male)	Participant nr. 4 (male)
				that independence and knowledge”	
Advice for other YAs with CKD [sub-theme for YAs only] (Statements conveying advice for other YAs who suffer from CKD)	**“Be brave”**	“If I had to give someone who was young advice and they were just about to find out that they have CKD, is to be brave, to not take things too personally, even though it'll feel like it. And to be patient with people because people will not understand and your friends will let you down because they don’t understand”			
	“Keep going and keep on track”		“Keep going on, that's it, carry on, do as you do, and you'll get there, whatever stage of kidney disease you are at. And I definitely say, just focus on it, focus on eating, taking medication, focus	“Just keeping on top of everything.. like keeping on top of your regime, keeping on top of your tablets keeping on top of your appointments your blood tests what you’re eating what you’re drinking. And that can be every day. Just trying to keep on top of everything,	

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 1 (female)	Participant nr. 2 (male)	Participant nr. 3 (male)	Participant nr. 4 (male)
			on that make sure you do that every day, or if it's dialysis and you do it at home, keep a routine, make sure you do that, I think that's a big thing keeping on track”	as well as making sure you’re feeling okay and you’re mentally feeling okay”	
	“Get support and take one step at a time”			“I think it is advisable, I guess, if possible, to get a support system, whether that be a peer support system with other young people around your age or reaching out to charities.. whatever kind of charities they're available to help you with that” “There can be many ups, there can be many downs. I think it's finding the right kind of support for yourself. Whatever works for that person to help them through the downs and to	

Codes/ Themes (description)	**Codes/ Sub-themes**	**Participant nr. 1 (female)**	**Participant nr. 2 (male)**	**Participant nr. 3 (male)**	**Participant nr. 4 (male)**
				celebrate the ups with them as well. I think I've learned during my years to take it one step at a time"	
Miscellaneous codes (not included in synthesis)	**Hidden challenges**	"Those are the challenges that are hidden (talking about the misconception of CKD and having kids), and that shocked me the most, things that I had to really think ahead of and plan my life really"			
	Unforeseen Changes (e.g., COVID outbreak)			"A lot had changed and yes, I understand that at the time, Covid, I totally respect that. But Covid doesn't give you an excuse not to treat me like a human being. Covid is not an excuse not to take me seriously if I know what I'm talking about. Covid is not an excuse to repeatedly do stuff for weeks and keep telling me it'll happen. I'm sorry but I've	

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 1 (female)	Participant nr. 2 (male)	Participant nr. 3 (male)	Participant nr. 4 (male)
				just been transplanted. It’s my third time, I kind of know what I’m talking about, we’re also going through a worldwide pandemic I respect that, yes, it’s very difficult. But I’m patient, and I know that I need A B to make sure C is OK. But if you’re not helping me with A B then C will mess up and for whatever reason, they (HCPs) didn’t seem to get that”	
	Time management		“I think one thing that I’m struggling with is that I’ve got a lot of time on my hands. She’s (psychologist) helped me try to start looking into getting things, you know, I’m just under a year		

Codes/ Themes (description)	**Codes/ Sub-themes**	**Participant nr. 1 (female)**	**Participant nr. 2 (male)**	**Participant nr. 3 (male)**	**Participant nr. 4 (male)**
			post-transplant and start getting back into lifestyle, looking for jobs and things. I think that's management, keep yourself occupied, if you're in a situation like mine"		
	Motivation to keep healthy and to "see your future"	"My biggest influence slash motivation is to keep healthy. I think when you are my age or younger all you want to do is see your future in a way, that's your aim, that's your motivation to actually get old and have a family and all that stuff, so that's my biggest motivation"			"It's the thought of, if I get into bad shape not only what I look so bad but, it's going to lead to failure quicker. So yeah for me, it's the thought of going into failure rather than having to have dialysis which I was lucky enough to not actually have"

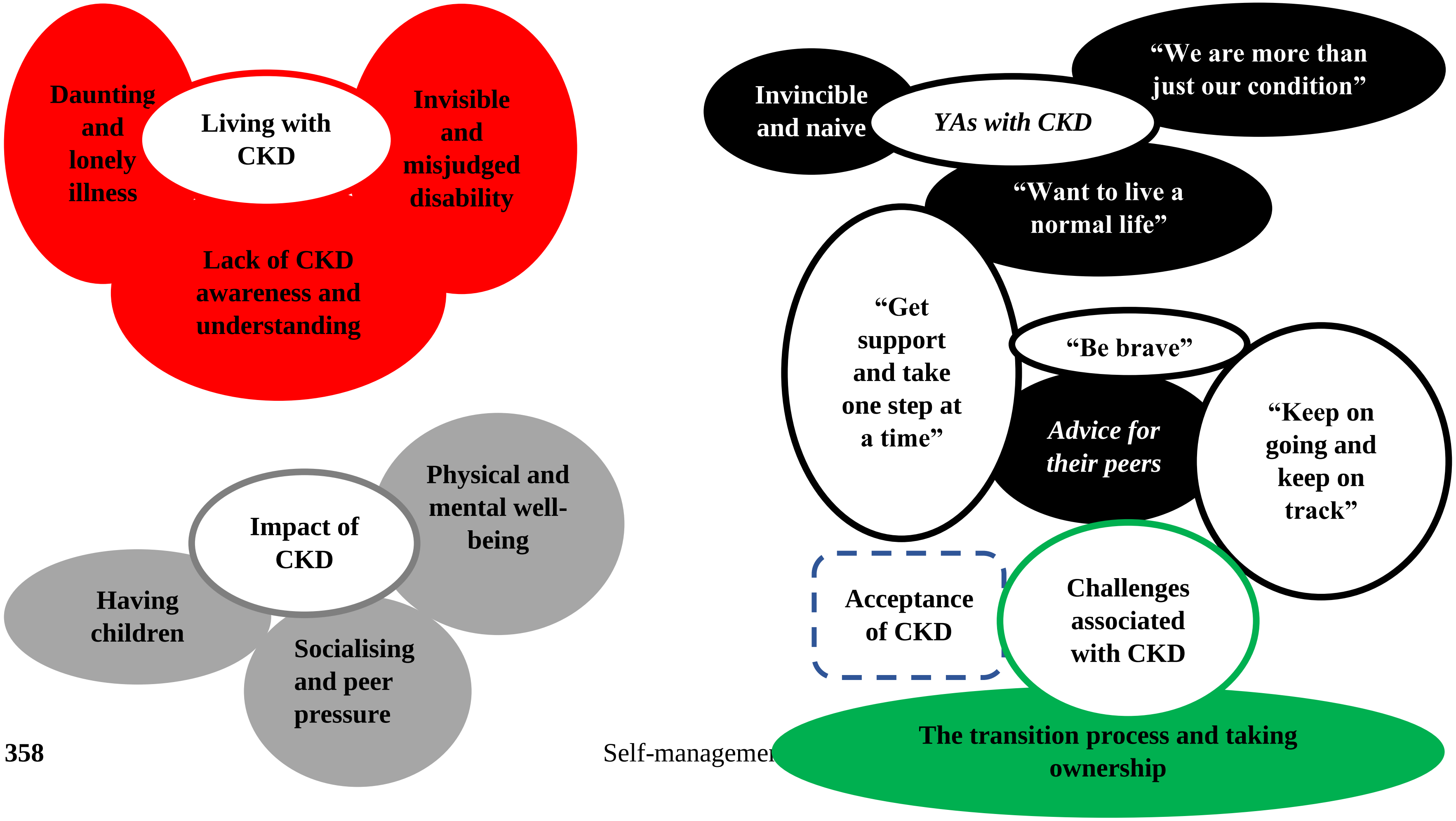
Note: Priori codes and *Posteriori codes (in Italics). CKD* Chronic Kidney Disease; *HCP* Healthcare Professional; *MDT* Multidisciplinary Team; *PCC* Person-Centred Care; *YA* Young Adult.

Figure II1

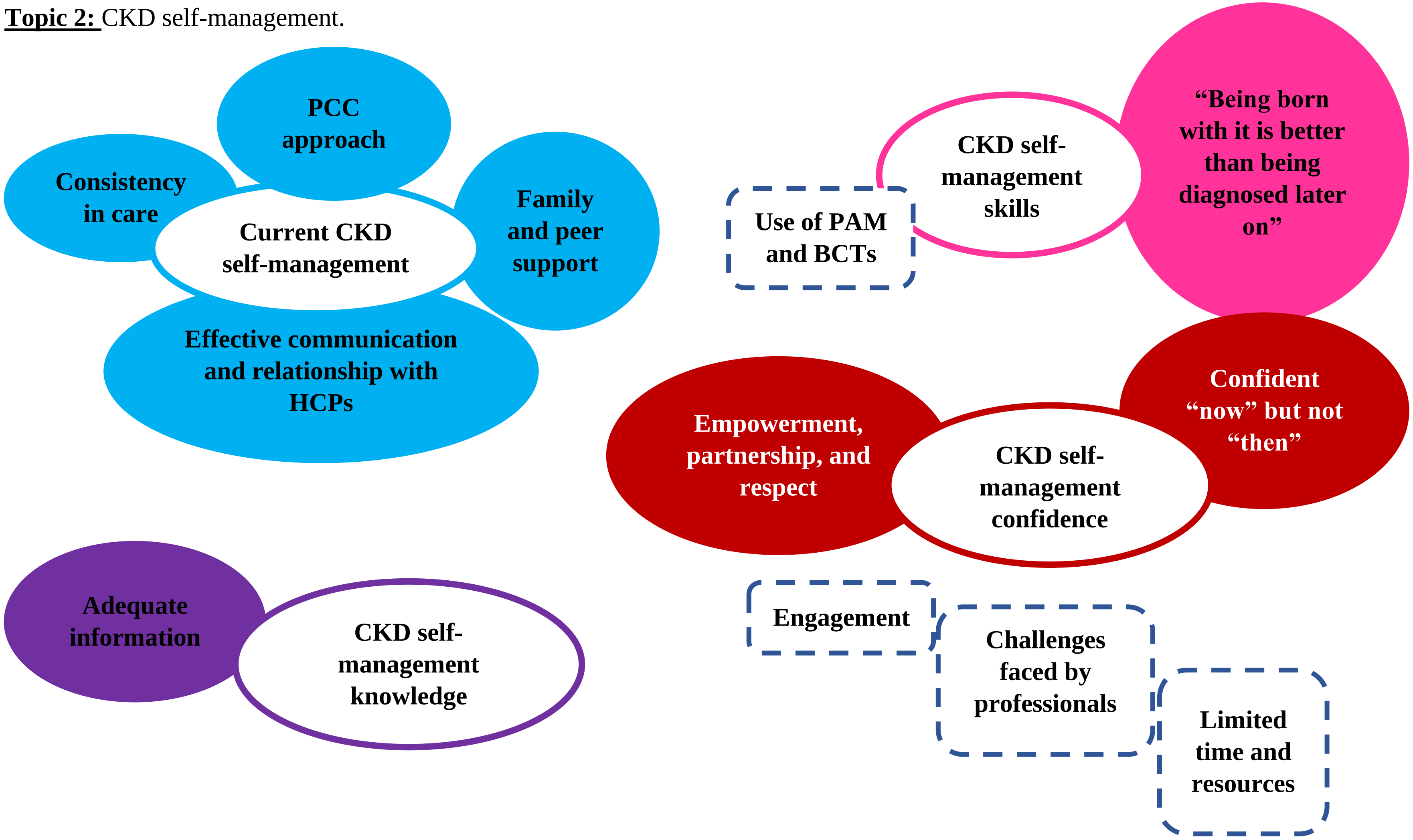
Initial Thematic Map

Thematic map showing main themes and sub-themes organised by topic:

Topic 1: YAs' experiences and perspectives of living with CKD and the challenges associated with managing their condition.



Topic 2: CKD self-management.



- - - - - - Theme/code derived from interviews with staff only (see next Appendix for staff' codebook)

Table II3

Revised Codes/ Themes

Initial codes/ themes:	Revised codes/ themes	Main themes and description:	Final codes for each reviewed theme
Living with CKD Impact of CKD Challenges associated with CKD	**CKD and its associated impact and challenges**	**Theme 2** Family of codes that describe YAs' perception of living with CKD, its impact, and associated challenges	Invisible and misjudged disability/ Daunting and lonely illness/ Lack of CKD awareness and understanding/ Physical and mental well-being/ The transition process and taking ownership/ Socialising and peer pressure/ Acceptance of CKD (staff only)/ Having children
This theme was generated from interviews with staff only		**Theme 3** Family of codes that describe challenges faced by professionals when supporting YAs with CKD	Engagement/ Limited time and resources
Current self-management support	**Considerations for effective CKD self-management**	**Theme 4** Family of codes that identify aspects of CKD self-management that YAs recognised as important to effectively self-manage their condition	Family and peer support/ Consistency in care/ Effective communication and relationship with HCPs/ PCC approach
CKD self-management knowledge CKD self-management skills CKD self-management confidence	**Improving activation**	**Theme 5** Family of codes that highlight YAs' areas of knowledge, skills and confidence necessary to improve their activation	Adequate information/ "Being born with it is better than being diagnosed later on"/ Confident "now" but not "then"/ Empowerment, partnership and respect/ Use of PAM and BCTs (staff only)
YAs with CKD		**Theme 1 (and sub-theme)**	

Advice for other YAs	**YA' with CKD and** *advice for their peers (sub-theme)*	Family of codes that describe the YA population who suffer from CKD as well as their advice for their peers	Invincible and naïve/ "We are more than just our condition"/ "Want to live a normal life" Sub-theme: "Be brave"/ "Keep going and keep on track"/ "Get support and take one step at a time"

*BCT B*ehaviour Change Technique; *CKD* Chronic Kidney Disease; *HCP* Healthcare Professional*; MDT* Multidisciplinary Team; *PAM* Patient Activation Measure, PCC Person-centred Care, *YA* Young Adult.

Appendix JJ

Thematic Analysis - Health and Socialcare Professionals (Group 2)

Codebook:

Table JJ1

Initial Priori Codes/Themes - Interviews with health and social care professionals

	Priori codes:
Topic 1	**Living with CKD**
	Impact of CKD
	Challenges associated with CKD
Topic 2	**Current self-management support**
	CKD self-management knowledge
	CKD self-management skills
	CKD self-management confidence
	Use of PAM and BCTs (group 2 only)

BCT Behaviour Change Techniques; *CKD* Chronic Kidney Disease; *PAM* Patient Activation Measure.

Posteriori codes/themes:

Challenges faced by professionals

Note that: the above (Table JJ1) are initial themes/codes which were later revised. The following information includes the initial codebook (for health and social care professionals; Table JJ2). Both codebooks, for YAs and their health and social care professionals, provide one example of the participants' quote for each code. Both codebooks with more examples of data extracts are available upon request.

Table JJ2

Codebook - Health and Social Care Professionals

Codes/ Themes (description)	**Codes/ Sub-themes**	**Participant nr. 5 (female)**	**Participant nr. 6 (male)**	**Participant nr. 7 (female)**	**Participant nr. 8 (female)**	**Participant nr. 9 (male)**
		Example (citation/ raw data):				
Living with CKD (Statements that describe CKD and what is like for YAs to live with CKD)	**Daunting and lonely illness**			"All the appointments you've got to attend or the surgical treatments, the procedures you've got to have, it just becomes a life that you share with a hospital and a team, rather than your own personal illusion, independence and freedom"	"Chronic health conditions are really difficult to try and manage because they can be unpredictable and I think that's a difficulty that for some people, they might be able to keep going for a certain time and then they may just have like an infection or an illness that's kind of sets them back"	"They are trying to find, kind of, their place in the world, which we all kind of do that at that age, but on top of it, they are also having to learn to manage for what is going to be the rest of their life with a complicated condition. So, for me, that's one of the biggest impacts"
	Lack of CKD awareness and understanding (from teachers		"We support people trying to get back into education or trying to get work, and if they are on	"It is about spreading the word about renal failure and all the available treatments and kind of normalising it"	"Sometimes their peers can't understand if they're really tired and that trying to explain to their work that although they look really well they're actually not	"But it also makes it very hard for them to be able to explain to other people and to feel that they really understand it"

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
	and employers)		dialysis, it's difficult to do"		feeling that well and then if they're on dialysis the impact that's had so they drew some really insightful drawings, which helped us remember that as well"	
	Invisible and misjudged disability				"We've run arts projects, we did kind of a drawing out workshop to help YAs to be able to draw their feelings around their health condition and that was really insightful for us because lots of them talked about it being an invisible illness"	
Impact of CKD (Statements that indicate how CKD impacts or	**Physical and mental well-being**	"It just impacts every area of life"	"I think there is an impact on everything, it is so holistic. On family life, it's, on the personal life, it's, on the	"Trying to tackle all the complexities of young adult life and long-term treatments and the effects of transplant	"Then you might only be able to cut hours as you may be too exhausted to do it"	"Because of how complicated kidney disease is and all of the various treatments, medications, and diet, the impact it can

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
limits YAs' lives)			work life and education. And it depends on the diagnosis of it as well, because obviously as young adults you form your own opinions on the world.. just impact on absolutely everything"	medication, it's just complicated, it's so complicated"		have on their physical appearance, their sexual relationships all different matter of things, it's really yeah quite a complicated thing for them to wrap their head around"
Challenges associated with CKD (Statements that describe the challenges associated with CKD)	**Acceptance of CKD** (Code for staff only)		"People tend to manage well, people that have got acceptance to their health condition"	"I think the majority of younger people I've worked with have found it really difficult to accept treatments, so it's about acceptance, coming to terms with the fact that you've got this condition and this		"Because they did not come to terms with that [CKD] yet that's probably one of the most challenging things, and for that, they're in a bit of chaos and in crisis and there are lots of things going on, as well in their life that's also which very

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
				condition will remain for life”		often, is tied up part of the same thing”
	The transition process and taking ownership		“It can be quite difficult, I think, especially when people are literally transferring over from children's services when they are used to the parent making all choices, that's another barrier for them to make all the choices”	“I’m sure coming into a hospital, having been in a smaller unit and in children's unit, come into an adult unit must be so overwhelming and so frightening for so many people”	“For some people actually taking that ownership of the condition is difficult transitioning, I’m just thinking of the transition specifically and having to take that ownership of taking your medications and trying to fit it around college and fitted around work and fitting around everything”	“Making sure that they understand all the things that they need to before they move across to adult services, and that includes their condition, but it also includes understanding what the differences are going to be for paediatrics’ going up to adults services, and what might be expected from them”
Challenges faced by professionals (Statements that describe the challenges that health and social care	**Engagement**		“Getting their engagement and getting them on the side, getting them to feel like you're an ally, rather than just another sort of	“So my experience of working with young adults has been quite traumatic really that there's been a lot of young deaths, I mean	“I guess, the aim is to try and help people to be able to live “normal life”, but what we know is sometimes with a chronic health condition, some things	“Their families are very worried about them and they kind of wrap them in bubble wrap and then it becomes like an over protection and perhaps not letting

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
professionals face when supporting YAs with CKD) (code for staff only)			health professional, it's kind of like telling them what to do. Sort of walk the journey with them a little bit and be that support, but not dictating to them: you need to do this, you need to do that"	generally you don't see that many young people on haemodialysis within the units, but those who have dialysed there have been very many people who died young. I find it really difficult to engage people"	are out of their control with illnesses or maybe needed new medication, that's lots of different things so I think that's kind of a struggle that we've come across a really difficult one of just wanting to be able to do the same things not having to take loads of medication all the time"	them have the experiences and taking the risks to manage it themselves"
	Limited time and resources			**"**I find it really tricky because we don't have the time as social workers to commit and I think there's a lot of misunderstanding from the clinical teams, they kind of the treatment often is the same for	"They are good resources but it's I guess some of the barriers of the time to fill it out and maybe some young people don't want to have to go through it"	"Some members of the team haven't found that it's, that they don't have the time to be able to deliver it on top of trying to do all of the other stuff"

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
				older people and a young person and there's no kind of thoughts given not complete thought given to the needs of the younger person.. I think seeing people outside of the clinics out of the hospital is also crucial. And I think having more staff”		
Current self-management support (Comments that describe the current self-management support)	**PCC approach**	“Have a full understanding of how best to meet their needs”	“It's different things for different people. Some people don't want and need support, they want to manage it themselves, they want to be independent, so they want to write it all down	“Person-centred care is the way forward isn't it that's again understanding what is important to the individual and tailoring care around that”	“It’s really person specific. It's just remembering that chronic conditions can affect so many different parts of someone's life and I just think the more holistically we can work and recognise that it's not just the medical side of it, that it can impact lots of	“Lots of them will manage it differently it's lots to do with their individual ways that they have learnt to manage it over the years”

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
			themselves and then present it every now and again. But for other people, they do need that more hands-on approach"		different things so I just think as long as we can work really person-centred and try and adapt and recognise that one size doesn't fit all"	
	Effective communication and relationship with HCPs	"Having that relationship with, whichever medical professional that you link to and that one person of trust. Really good communication and getting that information about what support is out there"	"People they trust, therefore, when they do hit the crisis point if they get to that stage but they've got some of the concern to a little bit and they won't feel judged"	"I think it depends on the member of staff dealing with the person and what connection they have with the person, I think that that is fundamental. If you can connect and build a relationship of trust with a young person, then I think that's going to be a good strategy moving forward"	"I think you can't figure it out until you have those really good conversations with someone about what's actually going on. And I found that sometimes it's been "oh I didn't think I really needed to take this and I haven't really had any side effects from not taking it" and then it's just about education"	

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
	Family and peer support	“The football session [talking about an “activity day”] was great and everybody enjoys it, and I guess there's an opportunity to meet new people and things like that, networking and all that”	“It’s better done [talking to someone] through peers from the charitable sector but there isn't really as much of that is needed for people”	“If you put people in touch with each other that's going to be kind of such valuable assets and also empower people to manage things more and manage things in the way that they want to, rather than it being driven by professionals”	“It's about looking at things like you know does someone need some peer support, do we need to speak to someone who's kind of been through that and to talk to them about that, do they want more support”	“They meet other young patients and they realise that they are not the only ones going through it. And they get the chance to yet to really learn about it. Perhaps see it more positively and hopefully just take away different tools to use every day to kind of keep themselves well and physically and mentally”
	Consistency in care	“Continuity of a worker”	“Living in rural areas, as we do in North Wales, it's harder, if you live in a city, you can go meet for coffee or something and there might be like 10, 20, 30 YAs within	“My advice to any units would be there's a couple of different resources that you can use now but use one of them, and just be consistent with it. And that's what we're still trying to get right.. that's	“It's about making things universal I guess isn't, it's making sure that everyone has the same opportunity to have that evaluation and review when having kind of processes in place”	“So yes in theory. We would start it as young as 11 process, so 11 to 13 is when we would start the transition process in the hospital at the moment. But that's depending on their readiness, how their family feel as well,

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			the same city where is up here it's kind 2 or 3 maybe, there's less chance you will find somebody you click with that you can get that support from"	what I think one of the main important things is to just pick one and use it and put something in place which is going to make sure that each person who comes into the service has this type of support offered to them, whether they're ready to accept it or not, it's just about having that consistency there and making sure that there is something in place"		and how the conditions and the rest of the team feel about starting that process with them, so it's quite fluid in terms of, it doesn't have to start at 11 but if somebody is perhaps a little bit more ready and they wanted to take on that independence earlier, or their family wanted to, can start as young as that so yeah. But does it happen consistently enough in the way it should? Probably there is still work to do there if I am totally honest"
CKD self-management knowledge	**Adequate information**	"My daughter has her phone in her hand constantly so		"It would just be the educational materials we have.. we've got a		"I'm in the process of trying to develop and it doesn't seem like there's much out

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
(Statements that describe YAs' knowledge of CKD self-management)		an app.. getting across that knowledge about, depends on what stage and how you can prevent and maintain your health now so like the exercise.. Even if the exercise can be done on the app, like a fit fitness"		welcome booklet.. to support younger people to access things to self-manage their condition, to access charities, peer support.. to explore forums in their own rights and to kind of the more information, I feel, somebody has the kind of better equipped, they are, but that is not accessible through units, that is something we would work on with people on an individual basis, and again that's, not to say that every young adult is referred to us, it's only when you		there with us at the booklet is an APP based around self-management for young patients.. but COVID kind of happened and we haven't been able to get a designer to actually make the first prototype of the APP yet, but that's kind of where it's at. Within that, there is the idea that there'd be sections where they could learn about their health condition via different videos and games. The whole APP was kind of, I wanted to have a little bit of a gaming element to it, so there were some ways that we were trying to

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
				know another professional finds that they might need support, so it's not routine"		encourage them to kind of learn about their condition, how to manage it themselves, but in a way that hopefully wasn't too laborious and it was quite interesting and kept them engaged, so we thought about things like them having an Avatar character" [Further described the app]
CKD self-management skills (Comments that describe YAs' CKD self-management skills)	***"Being born with it is better than being diagnosed later on"***		"I think people have got a lot more if they've been through CKD as a child and come through children's services they're a bit more informed about what's going on,		"I really think it depends on the treatment, I think it really depends on what point they've come into to try and manage it so whether they're transitioning up or whether they actually have a newly diagnosed condition.. when they're in their	PAM overall: "There's the independence side of things which I think is very different, perhaps to the independence that their healthy peer maybe goes through it at that time, so I think helping them do that and helping

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			doesn't mean they make the choices that the professionals want them to do. But I think they kind of used to live with it and it's kind of how things are.. Later-onset diagnosis, when they're in their late teens or early 20s, can be a real shock, and obviously, they established their life pattern and how things are going and they've gotten their expectations about what was going to		20s and suddenly they've had to try and change the whole lifestyle around this so it's all trying to get used to it"	them understand how to manage their condition and feel empowered to do so would help them, ultimately, I think, moving forward into young adulthood. So it's the education side of things and dependence"

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
			happen, I think that can be hard.. and have a much bigger impact on how they make their choices, it's automatically kind of rebel against it, and a lot of people do"			
CKD self-management confidence (Statements that describe YAs' confidence in CKD self-management)	**Empowerment, partnership, and respect**		"I mean there are things that the renal patient can check the blood results of things like that, so these affiliates they have got some control over the treatment"		"It's about I guess empowering people to be able to come in with that knowledge or with the ability to ask for support as well" "Empower them to keep that going and build on the strengths they already have"	"Trying perhaps initially to support them with things that are going on outside of the hospital that is nothing very often, particularly as a youth worker, to do with their kidney disease but help them feel for themselves that it's important to them and things that will build their confidence and in

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
						doing so, hopefully, and help them feel empowered to kind of start to take on some of the challenges of thinking about coming to terms with their condition and asking for help”
Use of PAM (Statements that describe the use of both PAM)	***Awareness of the use of PAM***	[Not aware]	“I don't think so, not in adult services. I know they doing schemes coming through like ready steady go that I mentioned earlier when they assess where a person is up to and that can gauge when they transition across to adult services. But nothing direct,	[Aware] “I don't think, so I think again it's driven by the relationship between members of staff and the younger person, I don't think there are any patient activation measures used, not that I can think of, not that I’ve come across”	“So there's work being undertaken at the moment to try and look at kind of a transition program which will do that, so when, for example, when someone first comes in, if let's say if they've come in and it hasn't necessarily been transitioned across but they're new, and they're like the people who have come in over 18, they would get support through	“Yeah. So we haven't really used it, to be honest, hugely, I suppose, to some extent, like the ready steady go program has that built into it, because you're having patients say how empowered they feel with certain areas of their condition and how they manage it, so I guess there is patient activation built into that.. but we don't use

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
			kind of like not for any way that it is an ongoing measurement to understand how will people get on, what their understanding is, what their engagement is”		this like education pathways so, for example, there is CKD pathway, so they would get information about all the different types of treatment, but within that, they also get information about diet exercise about social support about groups and a lot of them are run alongside with peers, and so they will come along and talk about their experiences with it, so there are kind of education pathways that are there”	one of the formal patient activation tools as such, so that might be, you are very right, something that should go into one of those programs because you can then perhaps measure it at the start and at the end, as well as now, or for any at any point along that way to check how well are they taking in this information yeah..They do use the quality of life score, and things like that already, but, again, I wouldn't say that's totally consistent”
Use of BCTs (Statements that describe	***Awareness of the***	[Not aware]	“Unfortunately no, but things like that will be	“I’ve done some motivational	“So I’m trained in health and wellness coaching. I did a	“There are certainly approaches and things that we use on

Codes/ Themes (description)	**Codes/ Sub-themes**	**Participant nr. 5 (female)**	**Participant nr. 6 (male)**	**Participant nr. 7 (female)**	**Participant nr. 8 (female)**	**Participant nr. 9 (male)**
the use of BCTs)	***use of BCTs***		beneficial, I think, because then you can start to train them for the interview so they got the skills and confidence to do it"	interviewing.. I do find it useful"	course last year, so I have a certificate in health and wellness coaching, and from previous work, motivational interviewing.. I'm really passionate about well-being so I put myself forward for that. I'm a strong believer in coaching, I think it's very much about empowering and helping to guide and working with someone at their own pace, motivational interviewing, the chase cycle of change, trying to find out where someone's at and helping them to move through that, but not trying to jump too far, so knowing where someone is starting	a daily basis but it would be good, I think, for more staff to attend training and understanding. yeah, particularly the behaviour change stuff is really important, and yeah motivational interviewing is fantastic as well, and I think if more staff had an awareness and understanding of those approaches that would really help them support people. So I think that could be really good"

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
					from and what support they need to help guide them through that and it's really strength-based and empowerment focus and that's why I'm really passionate about it. But I don't think it's generally rolled out across everybody, it's something we're talking about in adults and we've had lots of conversations and we are hoping that's where we're going forward with it"	
YAs with CKD	**Invincible and naïve**	"Thinking you're invincible"	"Risky behaviour at that age when you're pushing boundaries. Some YAs rebel against it or do not want to fit	"Want to be free.. younger people need that sense of freedom"		

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
			into the treatment”			
	“Want to live a normal life”	“Be able to sort of have some normal life alongside it”	“A lot though just want a normal life, whatever a normal life is. They want to see their friends during this really difficult for them to then have all these restrictions put on them”	“Trying to live day-to-day and trying to live a normal life”	“They'll just want to be able to lead that kind of the same lifestyle as their peers that can be really difficult. I think that wanting to be able to do the same things as others or maybe being restricted by fluid or even trying to go out somewhere and maybe not being able to eat the same things or feeling tired or, it’s that wanting to just be able to get on with things the same as everyone else”	“It's a really difficult time in their life where they are wanting to have some normality, wanting to be like their friends, wanting to go off to uni, wanting to move out and all sorts of these different complications and it's just a very challenging time to have to learn to manage what is a really complicated condition”
Miscellaneous codes (not included in synthesis)	**YA clinics**					“I think the young adult clinics are really good. I think they're there. But again, they have to have the focus of

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
						getting them ready to move on to the next kind of stage, and not just because they just come to this clinic because they're young, it has to have that focus of encouraging them to take on independence and feel empowered to their condition”
	The appropriate type of treatment					“There are certain treatments which will be a lot more beneficial for them in terms of being affected around their life and to be being able to work in terms of being able to carry on going to college and invasive early careers and things like that”
	“Medical scare”			“When they have a scare, a kind of a		

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
				medical scare, something really bad happens that will influence somebody to take more responsibility or to do what is asked of them. But then, that's so detrimental and kind of on a psychological and physical level, that's kind of a crisis.. a crisis will determine what people and how people change their attitude”		
	Changes (e.g., Covid outbreak)		“At the moment with covid, we are not able to see people as much, it does make it much harder to get			

Codes/ Themes (description)	Codes/ Sub-themes	Participant nr. 5 (female)	Participant nr. 6 (male)	Participant nr. 7 (female)	Participant nr. 8 (female)	Participant nr. 9 (male)
			that face-to-face contact”			

Note: Priori codes and *Posteriori codes (in Italics). BCT* Behaviour Change Technique*; CKD* Chronic Kidney Disease; *HCP* Healthcare Professional*; MDT* Multidisciplinary Team; *PAM* Patient Activation Measure*; PCC* Person-Centred Care; *YA* Young Adult.

Appendix KK

Summary of Ethical Considerations

There was no current relationship between the researcher, gatekeepers, and potential participants and, as such, the risk of participants feeling obligated to take part in the study was minimised. Participants were given full details of what participation would involve before they agreed to take part. It was not anticipated that the participants would become distressed during the study, however, to minimise this possibility, care has been taken to limit the possible distressing materials that the participants were exposed to. Only positively worded, standardised, and psychometrically robust measures were considered during the selection process.

In addition, the researcher has worked as an Assistant Psychologist and Support Worker in Mental Health settings with individuals in distress and gained experience in how to provide support in such circumstances. Although the research was important, participants were reassured that it is their well-being that is the priority. If the participants did become distressed during the study, they would be reassured that they could withdraw from the research if they wished and the researcher would be on hand (or communicating via email) to take care of them by debriefing them and encouraging them to speak with their HCP, such as GP, or signposting them to other relevant agencies that offer support. The participants also could contact for support one of the research external supervisors who is a Clinical Psychologist in case there were any concerns. If a participant wished to withdraw from the research before the data was anonymised, they would be thanked for their interest and their data would be destroyed. If a participant wished to withdraw from the research, any data which has already been collected and anonymised could not be withdrawn, however further data collection would not take place. At the end of the study, a debrief information sheet was provided to all participants in order to inform them of the nature and outcome of the research as well as the potential risks and information about relevant agencies that offer support. The debrief sheet also contained the contact details of the researcher and the research supervisor should they have any further questions or concerns about the study.

Furthermore, the participant's confidentiality and anonymity were ensured by coding data, using a participant identification number. No names were recorded on the measures used, only some participants' demographic information such as age, gender and so on, was documented. The researcher safeguarded that all the questionnaires were completed anonymously. The researcher also ensured that qualitative transcripts and quotations were anonymised using the participant's identification number, group of participants (YA or staff/ST), and gender, respectively. All digital data was stored on a secure, password-protected computer which was only accessible by the researcher. Additionally, the participants were informed that all audio recordings would be erased once coded. Only the researcher and the research supervisors had access to quantitative and qualitative data. All participants were informed in the participant information sheet that both data will be archived for up to 5 years and destroyed after this period.

Finally, the researcher also foresaw a possibility that during the data collection process, a poor practice could have been recognised. It was made clear to all participants that any identified poor or dangerous practice may require confidentiality to be broken in order to report this to the appropriate responsible practitioner or governing body. However, any decision to do so would be discussed with the participants and the project team. In anticipation of any risks, it was planned that the researcher would receive regular supervision in case there were any issues that needed to be addressed or if participants disclosed upsetting or distressing events. If a participant was at risk of harm the researcher would report this to the relevant authorities. The researcher was able to contact the lead supervisor directly if there were any pressing issues.

Appendix LL

Keywords and MeSH Terms

Keywords and MeSH Terms Related to CKD, Self-Management, and RCT

TOPIC 1 Chronic Kidney Disease	**TOPIC 2** Self-management	**Topic 3** Randomised-controlled trial
Keywords: CKD OR chronic kidney disease OR chronic kidney failure OR chronic kidney illness OR chronic kidney disorder OR chronic kidney insufficiency OR chronic kidney diseases OR chronic kidney failures OR chronic kidney illnesses OR chronic kidney disorders OR chronic kidney insufficiencies OR chronic renal disease OR chronic renal failure OR chronic renal illness OR chronic renal disorder OR chronic renal diseases OR chronic renal failures OR chronic renal illnesses OR chronic renal disorders OR chronic renal insufficiencies OR kidney injury OR kidney injuries OR renal injury OR renal injuries OR kidney transplantation OR kidney transplant OR kidney transplants OR renal transplantation OR renal transplant OR renal transplants OR dialysis OR dialyses OR hemodialysis OR hemodialyses OR haemodialysis OR haemodialyses OR HD OR predialysis OR pre-dialysis OR pre-dialyses OR PD OR end-stage kidney disease OR end stage kidney disease OR ESKD OR end stage renal disease OR end-stage renal disease OR kidney replacement therapy OR kidney replacement therapies OR renal replacement therapy OR renal replacement therapies OR mild to moderate kidney disease OR MMKD OR nephropathy OR nephropathies OR estimated glomerular filtration rate	**Keywords:** Self management OR self-care OR self care OR selfcare OR self-monitoring OR self monitoring OR self-monitor OR self monitor OR self-control OR self control OR self-manage OR self manage OR self-management support OR self management support OR SMS OR self-management intervention OR self management intervention OR self-management interventions OR self management interventions OR self-examination OR self examination OR self-examine OR self examine OR self-medication OR self medication OR self-medicate OR self medicate OR self-evaluation OR self evaluation OR self-evaluate OR self evaluate OR self-efficacy OR self efficacy	**Keywords:** RCT OR RCTs OR randomized controlled trial OR randomized controlled trials OR randomized-controlled trial OR randomized-controlled trials OR randomised controlled trial OR randomised controlled trials OR randomised-controlled trial OR randomised-controlled trials OR controlled clinical trial OR controlled clinical trials OR clinical trial OR clinical trials OR randomized OR randomised OR placebo OR placebos OR drug therapy OR drug therapies OR randomly OR trial OR trials OR groups OR randomisation OR randomization OR random allocation OR double-blind procedure OR double-blind method OR single-blind procedure OR single-blind method OR crossover procedure OR prospective studies OR follow-up studies
MeSH terms: "renal insufficiency, chronic"[MeSH] OR “Glomerular Filtration Rate”[Mesh] OR "kidney glomerulus"[MeSH Terms] OR “Kidney diseases”[Mesh]	**MeSH terms:** "self-management"[MeSH]	**MeSH terms:** "randomized controlled trial"[Publication Type] OR "randomized controlled trials as topic"[MeSH]

MeSH Medical Subject Headings.

Appendix MM

PRISMA 2020 Checklist

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	✓ Entire Chapter 3
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	N/a for thesis
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	✓ (Chapter 3, section 3.1.1)
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	✓ (Chapter 3, section 3.1.2)
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	✓ (Chapter 3, section 3.2.1)
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	✓ (Chapter 3, section 3.2.2)
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	✓ (Chapter 3, section 3.2.3)
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	✓ (Chapter 3, section 3.2.4)

Section and Topic	Item #	Checklist item	Location where item is reported
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	✓ (Chapter 3, section 3.2.4)
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g., for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	✓ (Chapter 3, section 3.2.1)
	10b	List and define all other variables for which data were sought (e.g., participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	✓ (Chapter 3, section 3.2.5) and the relevant appendices, inducing the data extraction and the characteristics of included studies
Study risk of bias assessment	11	Specify the methods used to assess the risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	✓ (Chapter 3, section 3.2.6) and Appendix with the characteristics of included studies which include the risk of bias assessment and author's judgments
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	✓ (Chapter 3, section 3.2.7)
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	✓ (Chapter 3, section 3.2.8)
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/a - e.g., meta-analysis not included.

Section and Topic	Item #	Checklist item	Location where item is reported
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	✓ (Chapter 3, section 3.2.8)
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	✓ (Chapter 3, section 3.2.7 and 3.2.8)
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	✓ (Chapter 3, section 3.2.7); no meta-analysis was conducted
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/a (out of scope for this review)
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/a (out of scope for this review)
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	✓ Chapter 3, section 3.2.9 GRADE approach
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	✓ Chapter 3, section 3.3.1 - Figure 3.1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	✓ Reasons for exclusion included in the characteristics of included studies document (in Appendices)
Study	17	Cite each included study and present its characteristics.	✓ The characteristics of

Section and Topic	Item #	Checklist item	Location where item is reported
characteristics			the included studies document (in Appendices)
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	✓ The characteristics of the included studies document and Chapter 3, section 3.3.3
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	✓ Chapter 3, section 3.3.4
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	✓ Chapter 3, section 3.3.4
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	✓ Chapter 3, section 3.3.4
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/a
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/a
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/a but critically reflected on the synthesis process (e.g., review's strengths and limitations in section 3.5)
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	✓ Chapter 3, section 3.3.4; GRADE in SoF table

Section and Topic	Item #	Checklist item	Location where item is reported
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	✓ (Chapter 3, section 3.5)
	23b	Discuss any limitations of the evidence included in the review.	✓ (Chapter 3, section 3.5)
	23c	Discuss any limitations of the review processes used.	✓ (Chapter 3, section 3.5)
	23d	Discuss implications of the results for practice, policy, and future research.	✓ (Chapter 3, section 3.5)
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	N/a - protocol not registered
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	✓ Protocol available in the additional file 1 - “protocol for literature review”
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	✓ Amendments to the protocol are listed in Chapter 3, section 3.4
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	✓ Reported in the protocol (Additional file 1)
Competing interests	26	Declare any competing interests of review authors.	N/a
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/a

Retrieved from: Page et al., (2021).

Appendix NN

Example of a Full Database Search

Example of a Full Database (PubMed) Search Using Keywords and MeSH Terms

Search on	Query	Results
#4	(("CKD"[Title/Abstract] OR "chronic kidney disease"[Title/Abstract] OR "chronic kidney failure"[Title/Abstract] OR (("chronic"[All Fields] OR "chronical"[All Fields] OR "chronically"[All Fields] OR "chronicities"[All Fields] OR "chronicity"[All Fields] OR "chronicization"[All Fields] OR "chronics"[All Fields]) AND "kidney illness"[Title/Abstract]) OR "chronic kidney disorder"[Title/Abstract] OR "chronic kidney insufficiency"[Title/Abstract] OR "chronic kidney diseases"[Title/Abstract] OR "chronic kidney failures"[Title/Abstract] OR ((("chronic"[All Fields] OR "chronical"[All Fields] OR "chronically"[All Fields] OR "chronicities"[All Fields] OR "chronicity"[All Fields] OR "chronicization"[All Fields] OR "chronics"[All Fields]) AND ("kidney"[MeSH Terms] OR "kidney"[All Fields] OR "kidneys"[All Fields] OR "kidney s"[All Fields])) AND "illnesses"[Title/Abstract]) OR "chronic kidney disorders"[Title/Abstract] OR (("chronic"[All Fields] OR "chronical"[All Fields] OR "chronically"[All Fields] OR "chronicities"[All Fields] OR "chronicity"[All Fields] OR "chronicization"[All Fields] OR "chronics"[All Fields]) AND "kidney insufficiencies"[Title/Abstract]) OR "chronic renal disease"[Title/Abstract] OR "chronic renal failure"[Title/Abstract] OR "chronic renal illness"[Title/Abstract] OR "chronic renal disorder"[Title/Abstract] OR "chronic renal diseases"[Title/Abstract] OR "chronic renal failures"[Title/Abstract] OR (("chronic"[All Fields] OR "chronical"[All Fields] OR "chronically"[All Fields] OR "chronicities"[All Fields] OR "chronicity"[All Fields] OR "chronicization"[All Fields] OR "chronics"[All Fields]) AND "renal illnesses"[Title/Abstract]) OR "chronic renal disorders"[Title/Abstract] OR "chronic renal insufficiencies"[Title/Abstract] OR "kidney injury"[Title/Abstract] OR "kidney injuries"[Title/Abstract] OR "renal injury"[Title/Abstract] OR "renal injuries"[Title/Abstract] OR "kidney transplantation"[Title/Abstract] OR "kidney transplant"[Title/Abstract] OR "kidney transplants"[Title/Abstract] OR "renal transplantation"[Title/Abstract] OR "renal transplant"[Title/Abstract] OR "renal transplants"[Title/Abstract] OR "dialysis"[Title/Abstract] OR "dialyses"[Title/Abstract] OR "hemodialysis"[Title/Abstract] OR "hemodialyses"[Title/Abstract] OR "haemodialysis"[Title/Abstract] OR "haemodialyses"[Title/Abstract] OR "HD"[Title/Abstract] OR "predialysis"[Title/Abstract] OR "pre-dialysis"[Title/Abstract] OR "pre-dialyses"[Title/Abstract] OR "PD"[Title/Abstract] OR "end stage kidney disease"[Title/Abstract] OR "end stage kidney disease"[Title/Abstract] OR "ESKD"[Title/Abstract] OR "end stage renal disease"[Title/Abstract] OR "end stage renal disease"[Title/Abstract] OR "kidney replacement therapy"[Title/Abstract] OR "kidney replacement therapies"[Title/Abstract] OR "renal replacement therapy"[Title/Abstract] OR "renal replacement therapies"[Title/Abstract] OR "mild to moderate kidney disease"[Title/Abstract] OR "MMKD"[Title/Abstract] OR "nephropathy"[Title/Abstract] OR "nephropathies"[Title/Abstract] OR "estimated glomerular filtration rate"[Title/Abstract] OR "renal insufficiency, chronic"[MeSH Terms] OR "Glomerular Filtration Rate"[MeSH Terms] OR "kidney glomerulus"[MeSH Terms] OR "Kidney diseases"[MeSH Terms]) AND ("2011/05/02 00:00":"3000/01/01 05:00"[Date - Publication] AND "humans"[MeSH Terms] AND "english"[Language] AND "adult"[MeSH Terms]) AND (("self-management"[Title/Abstract] OR "self-	**244**

Search on	Query	Results
	care"[Title/Abstract] OR "self-care"[Title/Abstract] OR "selfcare"[Title/Abstract] OR "self-monitoring"[Title/Abstract] OR "self-monitoring"[Title/Abstract] OR "self-monitor"[Title/Abstract] OR "self-monitor"[Title/Abstract] OR "self-control"[Title/Abstract] OR "self-control"[Title/Abstract] OR "self-manage"[Title/Abstract] OR "self-manage"[Title/Abstract] OR "self management support"[Title/Abstract] OR "self management support"[Title/Abstract] OR "SMS"[Title/Abstract] OR "self management intervention"[Title/Abstract] OR "self management intervention"[Title/Abstract] OR "self management interventions"[Title/Abstract] OR "self management interventions"[Title/Abstract] OR "self-examination"[Title/Abstract] OR "self-examination"[Title/Abstract] OR "self-examine"[Title/Abstract] OR "self-examine"[Title/Abstract] OR "self-medication"[Title/Abstract] OR "self-medication"[Title/Abstract] OR "self-medicate"[Title/Abstract] OR "self-medicate"[Title/Abstract] OR "self-evaluation"[Title/Abstract] OR "self-evaluation"[Title/Abstract] OR "self-evaluate"[Title/Abstract] OR "self-evaluate"[Title/Abstract] OR "self-efficacy"[Title/Abstract] OR "self-efficacy"[Title/Abstract] OR "self-management"[MeSH Terms]) AND ("2011/05/02 00:00":"3000/01/01 05:00"[Date - Publication] AND "humans"[MeSH Terms] AND "english"[Language] AND "adult"[MeSH Terms])) AND (("RCT"[Title/Abstract] OR "RCTs"[Title/Abstract] OR "randomized controlled trial"[Title/Abstract] OR "randomized controlled trials"[Title/Abstract] OR "randomized controlled trial"[Title/Abstract] OR "randomized controlled trials"[Title/Abstract] OR "randomised controlled trial"[Title/Abstract] OR "randomised controlled trials"[Title/Abstract] OR "randomised controlled trial"[Title/Abstract] OR "randomised controlled trials"[Title/Abstract] OR "controlled clinical trial"[Title/Abstract] OR "controlled clinical trials"[Title/Abstract] OR "clinical trial"[Title/Abstract] OR "clinical trials"[Title/Abstract] OR "randomized"[Title/Abstract] OR "randomised"[Title/Abstract] OR "placebo"[Title/Abstract] OR "placebos"[Title/Abstract] OR "drug therapy"[Title/Abstract] OR "drug therapies"[Title/Abstract] OR "randomly"[Title/Abstract] OR "trial"[Title/Abstract] OR "trials"[Title/Abstract] OR "groups"[Title/Abstract] OR "randomisation"[Title/Abstract] OR "randomization"[Title/Abstract] OR "random allocation"[Title/Abstract] OR "double blind procedure"[Title/Abstract] OR "double blind method"[Title/Abstract] OR "single blind procedure"[Title/Abstract] OR "single blind method"[Title/Abstract] OR "crossover procedure"[Title/Abstract] OR "prospective studies"[Title/Abstract] OR "follow up studies"[Title/Abstract] OR "randomized controlled trial"[Publication Type] OR "randomized controlled trials as topic"[MeSH Terms]) AND ("2011/05/02 00:00":"3000/01/01 05:00"[Date - Publication] AND "humans"[MeSH Terms] AND "english"[Language] AND "adult"[MeSH Terms]))) AND ((y_10[Filter]) AND (humans[Filter]) AND (english[Filter]) AND (alladult[Filter]))	
#3	(("RCT"[Title/Abstract] OR "RCTs"[Title/Abstract] OR "randomized controlled trial"[Title/Abstract] OR "randomized controlled trials"[Title/Abstract] OR "randomized controlled trial"[Title/Abstract] OR "randomized controlled trials"[Title/Abstract] OR "randomised controlled trial"[Title/Abstract] OR "randomised controlled trials"[Title/Abstract] OR "randomised controlled trial"[Title/Abstract] OR "randomised controlled trials"[Title/Abstract] OR "controlled clinical trial"[Title/Abstract] OR "controlled clinical trials"[Title/Abstract] OR "clinical trial"[Title/Abstract] OR "clinical trials"[Title/Abstract] OR "randomized"[Title/Abstract] OR "randomised"[Title/Abstract] OR "placebo"[Title/Abstract] OR "placebos"[Title/Abstract] OR "drug therapy"[Title/Abstract] OR "drug	1899

Search on	Query	Results
	therapies"[Title/Abstract] OR "randomly"[Title/Abstract] OR "trial"[Title/Abstract] OR "trials"[Title/Abstract] OR "groups"[Title/Abstract] OR "randomisation"[Title/Abstract] OR "randomization"[Title/Abstract] OR "random allocation"[Title/Abstract] OR "double blind procedure"[Title/Abstract] OR "double blind method"[Title/Abstract] OR "single blind procedure"[Title/Abstract] OR "single blind method"[Title/Abstract] OR "crossover procedure"[Title/Abstract] OR "prospective studies"[Title/Abstract] OR "follow up studies"[Title/Abstract]) AND "randomized controlled trial"[Publication Type] AND "randomized controlled trials as topic"[MeSH Terms]) AND ((y_10[Filter]) AND (humans[Filter]) AND (english[Filter]) AND (alladult[Filter]))	
#2	(("self-management"[Title/Abstract] OR "self-care"[Title/Abstract] OR "self-care"[Title/Abstract] OR "selfcare"[Title/Abstract] OR "self-monitoring"[Title/Abstract] OR "self-monitoring"[Title/Abstract] OR "self-monitor"[Title/Abstract] OR "self-monitor"[Title/Abstract] OR "self-control"[Title/Abstract] OR "self-control"[Title/Abstract] OR "self-manage"[Title/Abstract] OR "self-manage"[Title/Abstract] OR "self management support"[Title/Abstract] OR "self management support"[Title/Abstract] OR "SMS"[Title/Abstract] OR "self management intervention"[Title/Abstract] OR "self management intervention"[Title/Abstract] OR "self management interventions"[Title/Abstract] OR "self management interventions"[Title/Abstract] OR "self-examination"[Title/Abstract] OR "self-examination"[Title/Abstract] OR "self-examine"[Title/Abstract] OR "self-examine"[Title/Abstract] OR "self-medication"[Title/Abstract] OR "self-medication"[Title/Abstract] OR "self-medicate"[Title/Abstract] OR "self-medicate"[Title/Abstract] OR "self-evaluation"[Title/Abstract] OR "self-evaluation"[Title/Abstract] OR "self-evaluate"[Title/Abstract] OR "self-evaluate"[Title/Abstract] OR "self-efficacy"[Title/Abstract] OR "self-efficacy"[Title/Abstract]) AND "self-management"[MeSH Terms]) AND ((y_10[Filter]) AND (humans[Filter]) AND (english[Filter]) AND (alladult[Filter]))	1655
#1	(("CKD"[Title/Abstract] OR "chronic kidney disease"[Title/Abstract] OR "chronic kidney failure"[Title/Abstract] OR (("chronic"[All Fields] OR "chronical"[All Fields] OR "chronically"[All Fields] OR "chronicities"[All Fields] OR "chronicity"[All Fields] OR "chronicization"[All Fields] OR "chronics"[All Fields]) AND "kidney illness"[Title/Abstract]) OR "chronic kidney disorder"[Title/Abstract] OR "chronic kidney insufficiency"[Title/Abstract] OR "chronic kidney diseases"[Title/Abstract] OR "chronic kidney failures"[Title/Abstract] OR ((("chronic"[All Fields] OR "chronical"[All Fields] OR "chronically"[All Fields] OR "chronicities"[All Fields] OR "chronicity"[All Fields] OR "chronicization"[All Fields] OR "chronics"[All Fields]) AND ("kidney"[MeSH Terms] OR "kidney"[All Fields] OR "kidneys"[All Fields] OR "kidney s"[All Fields])) AND "illnesses"[Title/Abstract]) OR "chronic kidney disorders"[Title/Abstract] OR (("chronic"[All Fields] OR "chronical"[All Fields] OR "chronically"[All Fields] OR "chronicities"[All Fields] OR "chronicity"[All Fields] OR "chronicization"[All Fields] OR "chronics"[All Fields]) AND "kidney insufficiencies"[Title/Abstract]) OR "chronic renal disease"[Title/Abstract] OR "chronic renal failure"[Title/Abstract] OR "chronic renal illness"[Title/Abstract] OR "chronic renal disorder"[Title/Abstract] OR "chronic renal diseases"[Title/Abstract] OR "chronic renal failures"[Title/Abstract] OR (("chronic"[All Fields] OR "chronical"[All Fields] OR "chronically"[All	57

Search on	Query	Results
	Fields] OR "chronicities"[All Fields] OR "chronicity"[All Fields] OR "chronicization"[All Fields] OR "chronics"[All Fields]) AND "renal illnesses"[Title/Abstract]) OR "chronic renal disorders"[Title/Abstract] OR "chronic renal insufficiencies"[Title/Abstract] OR "kidney injury"[Title/Abstract] OR "kidney injuries"[Title/Abstract] OR "renal injury"[Title/Abstract] OR "renal injuries"[Title/Abstract] OR "kidney transplantation"[Title/Abstract] OR "kidney transplant"[Title/Abstract] OR "kidney transplants"[Title/Abstract] OR "renal transplantation"[Title/Abstract] OR "renal transplant"[Title/Abstract] OR "renal transplants"[Title/Abstract] OR "dialysis"[Title/Abstract] OR "dialyses"[Title/Abstract] OR "hemodialysis"[Title/Abstract] OR "hemodialyses"[Title/Abstract] OR "haemodialysis"[Title/Abstract] OR "haemodialyses"[Title/Abstract] OR "HD"[Title/Abstract] OR "predialysis"[Title/Abstract] OR "pre-dialysis"[Title/Abstract] OR "pre-dialyses"[Title/Abstract] OR "PD"[Title/Abstract] OR "end stage kidney disease"[Title/Abstract] OR "end stage kidney disease"[Title/Abstract] OR "ESKD"[Title/Abstract] OR "end stage renal disease"[Title/Abstract] OR "end stage renal disease"[Title/Abstract] OR "kidney replacement therapy"[Title/Abstract] OR "kidney replacement therapies"[Title/Abstract] OR "renal replacement therapy"[Title/Abstract] OR "renal replacement therapies"[Title/Abstract] OR "mild to moderate kidney disease"[Title/Abstract] OR "MMKD"[Title/Abstract] OR "nephropathy"[Title/Abstract] OR "nephropathies"[Title/Abstract] OR "estimated glomerular filtration rate"[Title/Abstract]) AND "renal insufficiency, chronic"[MeSH Terms] AND "Glomerular Filtration Rate"[MeSH Terms] AND "kidney glomerulus"[MeSH Terms] AND "Kidney diseases"[MeSH Terms]) AND ((y_10[Filter]) AND (humans[Filter]) AND (english[Filter]) AND (alladult[Filter]))	

Appendix OO

Title and Abstract Level 1 Screening Form

Citation, Title, and Abstract Screening

1. Does the **citation** indicate publication on or after 2011?
    a. Yes: continue screening
    b. No: stop screening
2. Is the **abstract** available?
    a. Yes: continue screening
    b. No: stop screening
3. Does the **title and abstract** use English?
    a. Yes: continue screening
    b. No: stop screening
4. Does the **title or abstract NOT** indicate that the study is a systematic review or another literature review?
    a. Yes: continue screening
    b. No: stop screening

Abstract Screening

5. Does the **abstract** indicate that this study was a primary randomised-controlled trial (RCT)? [Refer to keywords for RCT]
    a. Yes or Unsure/Unclear: continue screening
    b. No: stop screening
    -For example: any studies other than primary RCT
    -Key point: studies that say they used “only wave 3” indicate that the abstract is cross-sectional
6. Does the **abstract** indicate that the intervention involved comparator: care as usual/ standard care?
    a. Yes or Unsure/Unclear: continue screening
    b. No: stop screening
7. Does the **abstract** indicate that the sample studied was adults over 18 years old with chronic kidney disease (CKD; stages 1 to 5)? [Refer to keywords for CKD and classification of CKD]
    a. Yes or Unsure/Unclear: continue screening
    -Key point: patients on dialysis/hemodialysis indicate that they have CKD (stage 4 or 5)
    b. No: stop screening
    -For example: the study samples participants below 18 years old and/or with other conditions than CKD
8. Does the **abstract** indicate that intervention involved CKD self-management? [Refer to keywords for self-management]
    a. Yes or Unsure/Unclear: continue screening
    -For example: self-management; CKD self-management; person-centred self-management; theory-based self-management. Self-management interventions

included strategies, resources or tools in any format of delivery (such as face-to-face, electronic, print, and so on) that aimed to lessen the burden of the disease including the ability to self-manage the CKD, management of symptoms, treatment, the physical and psychological consequences of the disease, and other associated comorbidities, and/or making lifestyle changes.

b. No: stop screening

-For example: no intervention or any intervention other than specified in the inclusion criteria

9. Does the **abstract** indicate that the study assessed at least one of the primary and/or secondary outcomes?

Primary outcomes: self-efficacy; CKD knowledge; CKD self-management; adverse events (such as complaints, side effects, levels of dissatisfaction, increased inequalities, or death), and clinical indicator (particularly, alteration in eGFR)

Secondary outcomes: other clinical indicators (including, blood pressure; BP, and weight) and behavioural and patient outcomes, including health-related behaviours (including, smoking, alcohol consumption, diet, and physical activity); psychological distress (particularly, anxiety and depression); Health-Related Quality of Life (HRQoL) or Quality of Life (QoL); and Patient activation

a. Yes or Unsure/Unclear: continue screening

b. No: stop screening

***Decision*: Should this article be included?**

a. **Yes**, all 9 screening questions answered Yes or Unsure/Unclear

b. **No**, at least one answers definitely "No"

Appendix PP

Data Extraction Form

Data Extraction Form (including the “cheat sheet” at the end of the document) adapted from Ryan, Synnot, Prictor, and Hill (2016)**.**

Section 1: General review information:
Form version/date: Version 1/ 10/07/2021 **Revised version:** Version 2/ 08/01/2021
Review Title:
Study ID (Author & Publication Year):
Name of review author completing this form:
Date form completed:
Name of review author checking the data extracted to this form:
Other information and notes – if contact with author/s required:

Author contact details for study	
Further information required	
Correspondence with authors successful or not; what information was received and when	
Will any additional unpublished data supplied by the authors be included in the review? **If so, note that the study will include unpublished data**	
Notes *(Unpublished – for own use) e.g. references to be followed up, source of information especially if multiple reports of the same trial or unpublished data/personal communication included.*	

Section 2: Methods of the study:
Aim of study (As stated in the trial report/s. What was the trial designed to assess?)**:**
Study design:
The number of arms or groups (including control groups; briefly describe each):
Consumer involvement (e.g., In the design of the study and/or intervention; in delivery of intervention; in the evaluation of intervention; in the interpretation of study findings):
Funding source (also include any details about possible or explicit conflicts of interest)
Informed consent obtained? *(Yes/No/Unclear)*
Ethical approval *(Yes/No/Unclear)*

Section 3: Risk of Bias assessment: See the link to guide on how to conduct R0B 2 in the “cheat sheet” at the end of this document.
Assessment of Risk of Bias for RCT studies – RoB 2
Primary outcomes: self-efficacy; CKD knowledge; CKD self-management; adverse events (such as complaints, side effects, levels of dissatisfaction, increased inequalities, or death), and clinical indicators (particularly, alteration in eGFR).
Secondary outcomes: other clinical indicators (including, blood pressure; BP, and weight) and behavioural and patient outcomes, including health-related behaviours (including, smoking, alcohol consumption, diet, and physical activity); psychological

distress (particularly, anxiety and depression); Health-Related Quality of Life (HRQoL) or Quality of Life (QoL); and Patient activation.
See the link to guide on how to conduct R0B 2 in the "cheat sheet" at the end of this document.

Study design

X Individually-randomised parallel-group trial
☐ Cluster-randomised parallel-group trial
☐ Individually randomised cross-over (or other matched) trial

For the purposes of this assessment, the interventions being compared are defined as

Experimental: ☐ Comparator: ☐

Specify which outcome is being assessed for risk of bias ☐

Specify the numerical result being assessed. In case of multiple alternative analyses being presented, specify the numeric result (e.g. RR = 1.52 (95% CI 0.83 to 2.77) and/or a reference (e.g. to a table, figure or paragraph) that uniquely defines the result being assessed. ☐

Is the review team's aim for this result…?

☐ to assess the effect of *assignment to intervention* (the 'intention-to-treat' eff
☐ to assess the effect of *adhering to intervention* (the 'per-protocol' effect)

If the aim is to assess the effect of *adhering to intervention*, select the deviations from intended intervention that should be addressed (at least one must be checked):

☐ occurrence of non-protocol interventions
☐ failures in implementing the intervention that could have affected the outcome
☐ non-adherence to their assigned intervention by trial participants

Which of the following sources were <u>obtained</u> to help inform the risk-of-bias assessment? (tick as many as apply)

☐ Journal article(s) with results of the trial
☐ Trial protocol
☐ Statistical analysis plan (SAP)
☐ Non-commercial trial registry record (e.g. ClinicalTrials.gov record)
☐ Company-owned trial registry record (e.g. GSK Clinical Study Register record)
☐ "Grey literature" (e.g. unpublished thesis)
☐ Conference abstract(s) about the trial
☐ Regulatory document (e.g. Clinical Study Report, Drug Approval Package)
☐ Research ethics application
☐ Grant database summary (e.g. NIH RePORTER or Research Councils UK Gateway to Research)

☐	Personal communication with trialist
☐	Personal communication with the sponsor

Risk of bias assessment:

Responses underlined in green are potential markers for a low risk of bias, and responses in red are potential markers for risk of bias. Where questions relate only to signposts to other questions, no formatting is used.

Domain 1: Risk of bias arising from the randomization process

Signalling questions	Comments	Response options
1.1 Was the allocation sequence random?		Y / PY / PN / N / NI
1.2 Was the allocation sequence concealed until participants were enrolled and assigned to interventions?		Y / PY / PN / N / NI
1.3 Did baseline differences between intervention groups suggest a problem with the randomization process?		Y / PY / PN / N / NI
Risk-of-bias judgement		Low / High / Some concerns
Optional: What is the predicted direction of bias arising from the randomization process?		NA / Favours experimental / Favours comparator / Towards null /Away from null / Unpredictable

Domain 2: Risk of bias due to deviations from the intended interventions (*effect of assignment to intervention*)

Signalling questions	Comments	Response options
2.1. Were participants aware of their assigned intervention during the trial?		Y / PY / PN / N / NI
2.2. Were carers and people delivering the interventions aware of participants' assigned intervention during the trial?		Y / PY / PN / N / NI
2.3. If Y/PY/NI to 2.1 or 2.2: Were there deviations from	*(If answered Y or PY to above questions about*	NA / Y / PY / PN / N / NI

the intended intervention that arose because of the trial context?	*blinding, then questions 2.3, 2.4, 2.5 do not need to be answered*)	
2.4 If Y/PY to 2.3: Were these deviations likely to have affected the outcome?		NA / Y / PY / PN / N / NI
2.5. If Y/PY/NI to 2.4: Were these deviations from intended intervention balanced between groups?		NA / Y / PY / PN / N / NI
2.6 Was an appropriate analysis used to estimate the effect of assignment to intervention?		Y / PY / PN / N / NI
2.7 If N/PN/NI to 2.6: Was there potential for a substantial impact (on the result) of the failure to analyse participants in the group to which they were randomised?		NA / Y / PY / PN / N / NI
Risk-of-bias judgement		Low / High / Some concerns
Optional: What is the predicted direction of bias due to deviations from intended interventions?		NA / Favours experimental / Favours comparator / Towards null /Away from null / Unpredictable

Domain 2: Risk of bias due to deviations from the intended interventions (*effect of adhering to intervention*)

Signalling questions	**Comments**	**Response options**
2.1. Were participants aware of their assigned intervention during the trial?		Y / PY / PN / N / NI
2.2. Were carers and people delivering the interventions aware of participants' assigned intervention during the trial?		Y / PY / PN / N / NI
2.3. [If applicable:] If Y/PY/NI to 2.1 or 2.2: Were important non-protocol interventions balanced across intervention groups?		NA / Y / PY / PN / N / NI
2.4. [If applicable:] Were there failures in		NA / Y / PY / PN / N / NI

implementing the intervention that could have affected the outcome?		
2.5. [If applicable:] Was there non-adherence to the assigned intervention regimen that could have affected participants' outcomes?		NA / Y / PY / PN / N / NI
2.6. If N/PN/NI to 2.3, or Y/PY/NI to 2.4 or 2.5: Was an appropriate analysis used to estimate the effect of adhering to the intervention?		NA / Y / PY / PN / N / NI
Risk-of-bias judgement		Low / High / Some concerns
Optional: What is the predicted direction of bias due to deviations from intended interventions?		NA / Favours experimental / Favours comparator / Towards null /Away from null / Unpredictable

Domain 3: Missing outcome data

Signalling questions	**Comments**	**Response options**
3.1 Were data for this outcome available for all, or nearly all, participants randomised?		Y / PY / PN / N / NI
3.2 If N/PN/NI to 3.1: Is there evidence that the result was not biased by missing outcome data?		NA / Y / PY / PN / N
3.3 If N/PN to 3.2: Could missingness in the outcome depend on its true value?		NA / Y / PY / PN / N / NI
3.4 If Y/PY/NI to 3.3: Is it likely that missingness in the outcome depended on its true value?		NA / Y / PY / PN / N / NI
Risk-of-bias judgement		Low / High / Some concerns
Optional: What is the predicted direction of bias due to missing outcome data?		NA / Favours experimental / Favours comparator /

		Towards null /Away from null / Unpredictable

Domain 4: Risk of bias in the measurement of the outcome

Signalling questions	Comments	Response options
4.1 Was the method of measuring the outcome inappropriate?		Y / PY / PN / N / NI
4.2 Could measurement or ascertainment of the outcome have differed between intervention groups?		Y / PY / PN / N / NI
4.3 If N/PN/NI to 4.1 and 4.2: Were outcome assessors aware of the intervention received by study participants?		NA / Y / PY / PN / N / NI
4.4 If Y/PY/NI to 4.3: Could assessment of the outcome have been influenced by knowledge of intervention received?		NA / Y / PY / PN / N / NI
4.5 If Y/PY/NI to 4.4: Is it likely that assessment of the outcome was influenced by knowledge of intervention received?		NA / Y / PY / PN / N / NI
Risk-of-bias judgement		Low / High / Some concerns
Optional: What is the predicted direction of bias in measurement of the outcome?		NA / Favours experimental / Favours comparator / Towards null /Away from null / Unpredictable

Domain 5: Risk of bias in selection of the reported result

Signalling questions	Comments	Response options
5.1 Were the data that produced this result analysed in accordance with a pre-specified analysis plan that was finalized before unblinded outcome data were available for analysis?		Y / PY / PN / N / NI

Is the numerical result being assessed likely to have been selected, on the basis of the results, from...		
5.2. ... multiple eligible outcome measurements (e.g. scales, definitions, time points) within the outcome domain?		Y / PY / PN / N / NI
5.3 ... multiple eligible analyses of the data?		Y / PY / PN / N / NI
Risk-of-bias judgement		Low / High / Some concerns
Optional: What is the predicted direction of bias due to selection of the reported result?		NA / Favours experimental / Favours comparator / Towards null /Away from null / Unpredictable

The overall risk of bias

Risk-of-bias judgement		Low / High / Some concerns
Optional: What is the overall predicted direction of bias for this outcome?		NA / Favours experimental / Favours comparator / Towards null /Away from null / Unpredictable

Section 4: Study characteristics - Participants:

Description (e.g., Patients/consumers; carers; parents of patients/consumers; health professionals; well people in the community):

Geographic location (e.g., City/State/Country):

Setting (e.g., Community, home, primary health centre, acute care hospital, extended care facility):

Methods of recruitment of participants (How were potential participants approached and invited to participate?):

Inclusion/exclusion criteria for participation in the study:

Age: range, mean (standard deviation):

Gender:
Ethnicity:
Have important populations or groups been excluded from the study (*eg people with more than one concurrent health problem (multimorbidity) or disability, those from any socioeconomic groups*)?
Numbers involved:

Study numbers	**Number**
Eligible for inclusion	
Excluded	
Refused to take part	
Randomised to the intervention group(s)	
Randomised to control group	
Excluded post-randomisation (for each group; with reasons if relevant)	
Withdrawn (for each group; with reasons if relevant)	
Lost to follow up (for each group; with reasons)	Intervention group (with reasons)
	Control group (with reasons)
Included in the analysis (for each group, for each outcome)	Outcome 1 Intervention Control
	Outcome 2 Intervention Control
	Outcome 3 Intervention Control
	Outcome 4 Intervention Control
	Outcome 5 Intervention Control
	Outcome 6 Intervention Control

Principal health problem or diagnosis:
Stage of problem/illness:
Other health problem/s/comorbidities:

Section 5: Study characteristics – Interventions and compressions:

Item	**Explanation, notes**	**Intervention**	**Control or usual care**

1. Intervention name	Include a brief name or phrase that describes the intervention (including the definition of any acronyms or abbreviations).		
2. Aims and rationale ('why?')	Aim(s) of intervention (as stated in the trial report/s. What was the problem that this intervention was designed to address?). Describe any theory (with key references) or rationale relevant to the intervention. (Note that for a complex intervention with different components, each component may have a different aim or rationale). Describe any information on the quality of the intervention, assessed by study authors, others, or by you - such as the evidence base supporting the intervention.		
3. What was done?	Materials: Describe the content, format(s) or media, source of materials (if possible, where they can be accessed), and any other information relevant to the physical or information materials provided to participants or in training providers of the intervention. Procedures: Describe each of the processes used in delivering the intervention (e.g., education, telephone follow-up, case management) Note that some complex interventions require additional support activities to be implemented and if so details of these should also be reported. Note also that some complex interventions require sequencing of activities, whereas for others the order of delivery is less critical. Mode of delivery: Describe the mode of delivery of the intervention, such as whether it was delivered face-to-face (e.g., inpatient consultation, educational session, training) or at a distance (e.g., via phone, internet, mail); and whether the delivery was to individuals or groups of participants.		

	Co-interventions: Describe the delivery of any co-interventions (Co-interventions may be separate to the intervention of interest, or they may be other similar elements in a suite of interventions that have a common purpose).		
4. Who delivered the intervention?	Describe who was involved in the delivery of each component of the intervention and/or each different intervention provider. 'Intervention provider' could for example be taken to mean a health professional or it could mean a consumer peer advocate. Include a description of any specific training given to providers to deliver the intervention, numbers of providers, professional background, specific pre-existing skills or experience required, quality of any specific training received to deliver the intervention, and any measures of competence or consistency in delivering the intervention recorded before or during the study.		
6. Where was the intervention provided?	Describe the features of the setting (location) that might be relevant to intervention delivery (e.g., country, type of clinic, primary or hospital care). If the location varied this should be described, with relevant features that might affect the intervention delivery; as should any requisite features of the location that might impact on intervention delivery or feasibility (e.g., location close to participants' usual doctor, availability of equipment).		
7. When and how often or how much of the intervention was provided?	Describe how the intervention was delivered, such as stages, timing, frequency, number of sessions, intensity and duration of intervention delivery.		

8. Was the intervention tailored?	If the intervention was meant to be tailored or personalised in the course of the study, describe the rationale for this and the major features of what was done - such as: • how? • why? • when? and • what? was done to tailor the intervention. If particular decision rules were used to determine when or how to tailor the intervention details should be provided.		
9. Was the intervention modified or adapted?	If the intervention was changed during the study, this should be described (e.g., unforeseen modifications required, changes in study circumstances requiring modifications to the intervention). If such modifications happen, why, what, how and when the intervention was changed should be described.		
10. How well was the intervention delivered?	<u>Assessment</u> of fidelity: if intervention fidelity was assessed, describe the extent to which the intervention was delivered as intended. (i.e., the amount or type of intervention planned for delivery might differ from what was actually delivered). If strategies to maintain intervention fidelity was <u>planned</u> before intervention delivery or were used during the study, describe these, along with any materials or tools used.		

*Table adapted from Hoffman et al., (2014)

<u>**Section 6:** Study characteristics – Outcomes:</u>
Primary outcomes for this systematic review - self-efficacy; CKD knowledge; CKD self-management; adverse events (such as complaints, side effects, levels of dissatisfaction, increased inequalities, or death), and clinical indicator (particularly, alteration in eGFR).

Primary outcomes			
Outcome	Method of assessing outcome measures e.g.,	Method of follow-up for non-respondents	Timing of outcome assessment (including

	phone survey, questionnaire		frequency, length of follow-up)

Primary outcomes – adverse events		
Adverse event	Methods of assessment	Timing of assessment

Secondary outcomes for this systematic review - other clinical indicators (including, blood pressure; BP, and weight) and behavioural and patient outcomes, including health-related behaviours (including, smoking, alcohol consumption, diet, and physical activity); psychological distress (particularly, anxiety and depression); Health-Related Quality of Life (HRQoL) or Quality of Life (QoL); and Patient activation.

Secondary outcomes			
Outcome	Method of assessing outcome measures e.g., phone survey, questionnaire	Method of follow-up for non-respondents	Timing of outcome assessment (including frequency, length of follow up)

<u>**Section 7:** Data and results:</u>

***** *All data are numbers (of patients/units), not percentages*

Dichotomous outcomes

Outcome	Timing of outcome assessment (days/months)	Intervention group*		Control group		Notes
		Observed (n)	Total (N)	Observed (n)	Total (N)	

**Note: add additional columns if there is more than one intervention group, eg. Intervention Group A, Intervention Group B…*

Continuous outcomes:

		Intervention group			Control group			
Outcome	Timing of outcome assessment (days/months)	*Mean / Mean change	Standard deviation (SD)	N	*Mean / Mean change	Standard deviation (SD)	N	Notes

*Delete as appropriate

Cheat sheet:

Instructions and decision rules:

- When extracting information, please record the source of each piece of information, including the precise location within a document.
- Highlight any missing information and report it as “unclear” or “not described”
- If any assumptions were made about how the study was conducted, please report it by using: “probably done” or “probably not done”, and provide a rationale for the assumption
- If adverse effects were not reported by the included study, it should be clearly reported whether adverse effects were investigated or not by the study.

Instructions for assessing Risk of Bias - RoB 2:

See full guidance:
https://drive.google.com/file/d/19R9savfPdCHC8XLz2iiMvL_71lPJERWK/view
See CRIBSHEET:
https://drive.google.com/file/d/1Q4Fk3HCuBRwIDWTGZa5oH11OdR4Gbhdo/view

Appendix QQ

Characteristics of Included Studies

Please note that this document consists of the worked examples of the characteristics of included studies (summarised below in Tables QQ1- QQ5 and Figures QQ1-QQ4), organised into studies involving non-dialysis patients (N=12) and studies involving patients on dialysis (N=11), risk of bias, as well as reasons for excluding studies after the title and abstract screening and after the full-text screening (at the end of this document). It includes three worked examples each (for non-dialysis and dialysis studies) and full data is available upon request.

***Note fields:** report, if for example, contact with the author was made [Yes (information obtained)/No]; record if the study was translated from a language other than English; record if the study was a duplicate publication; record if there is information on the study funding.

Table QQ1

Total of Included Studies (N=23)

Non-dialysis population N=12	Dialysis population N=11
Barahimi et al. (2017)	Cho (2012)
Blakeman et al. (2014)	Griva et al. (2018)
Chen et al. (2011)	Hare, Clark-Carter, & Foreshaw (2014)
Humalda et al. (2020)	Huang et al. (2018)
Li et al. (2020)	Kauric-Klein, Peters, & Yarandi (2017)
Meuleman et al. (2017)	Lee et al. (2020)
Nelson et al. (2018)	Liu et al. (2016)
Nguyen, Douglas, and Bonner (2019)	Luo et al. (2019)
Wu et al. (2018)	Motarri et al. (2012)
	Shad et al. (2018)
Articles retrieved from the reference list of included studies	
Flesher et al (2011)	Sevick et al. (2016)
Ishani et al. (2016)	
Teng et al. (2013)	

Table QQ2

Characteristics of Included Studies - Non-Dialysis Patients (N=12):
Barahimi et al. (2017)

Methods	***Study design:*** A controlled Clinical Trial ***Unit of allocation/analysis:*** Tehran University of Medical Sciences at centres for treating noncommunicable diseases/participants ***Follow-up:*** 6 months ***Duration:*** 6 months

	Providers: online
Participants	***Participants:*** IG: (N=39); CG: (N=92**)** ***Age range, mean (SD):*** the inclusion criteria do not mention criteria for age but reported in results that “the mean age was 58±9 years in the IG and 67±9 years in the CG (P<.001)” ***Gender:*** CG: F=35(36.1); M=57(61.9); IG: F=16(48.0); M=23(59.0) ***Country/ Ethnicity:*** Iran ***Principal health problem or diagnosis:*** CKD ***Stage of problem/illness:*** GFR less than 60 mL/min/1.73m^2 ***Other health problem/s/comorbidities:*** ” The participants should have diabetes mellitus”
Interventions and comparisons	***Aims:*** “to determine the effectiveness of virtual training in terms of its impact on physiological measures affecting the development of kidney dysfunction” ***Intervention***: ” Self-care education through e-learning on improving kidney function among individuals with CKD” ***Comparator***: “CG received typical treatment without using this model” ***Was the theoretical framework included?*** ND ***Was the intervention tailored?*** ND
Outcomes *(i) outcomes and time-points from the study that are considered in the review *(ii) outcomes and time-points measured (or reported) in the study	***(i)** eGFR **Time points:** at baseline and 6 months ***(ii)** improvement of kidney function based on eGFR
Notes	“This research has been supported by the Tehran University of Medical Sciences and Health Services. No conflict of interest.”

Risk of Bias

Bias:	**Reviewer’s judgment**	**Support for judgment**
Bias arising from the randomization process	High Risk	E.g., **“**Individuals were not selected randomly” and ND on whether the allocation sequence was adequately concealed; and unwell-balanced groups
Bias due to deviations from intended interventions	High Risk	Most information was not provided or unclear; e.g., participants or providers were not blinded; the protocol was available

Bias due to missing outcome data	Some concerns	E.g., data for this outcome were available for all, or nearly all, participants randomised; ND on dropouts
Bias in the measurement of the outcome	High Risk	E.g., the method of measuring the outcome was appropriate but unclear information and ND on dropouts and the possibility that “outcome assessors were aware of the intervention received by the study participant”
Bias in the selection of the reported results	Some concerns	E.g., trail protocol is not available, analysis intentions are not available
Overall bias	**High Risk**	The study is judged to be at high risk of bias in at least one domain for this result.

Blakeman et al. (2014)

Methods	***Study design:*** “a pragmatic, two-arm, patient-level RCT” ***Unit of allocation/analysis:*** 24 general practices in Greater Manchester/ participants ***Follow-up:*** 6 months ***Duration:*** 4 weeks/ April 2012 and November 2012 (recruitment and follow-up) ***Providers:*** lay health workers (“8 telephone support workers: 3 members of staff, 4 postgraduate students, and 1 undergraduate student at the University of Manchester”)
Participants	***Participants:*** IG: (N=215); CG: (N=221**)** ***Age range, mean (SD):*** Mean age=72.1; CG: <75 years 132(59.7); 75 years or older 89(40.3); and IG: <75 years 118(54.9); 75 years or older 97(45.1) ***Gender:*** CG: F= 130(58.8); M= 91(41.2); IG: F= 125(58.1); M= 90(41.9) ***Country/ Ethnicity:*** white and non-white (1.4%) ***Principal health problem or diagnosis:*** CKD ***Stage of problem/illness:*** stage 3 (both 3a and 3b) with and without proteinuria ***Other health problem/s/comorbidities:*** 41.7% (N= 182) of patients had co-morbid established cardiovascular disease
Interventions and comparisons	***Aims:*** “The primary aim of the trial was to test whether an intervention which provides information about self-management, tailored access to local community resources and telephone guidance can improve health outcomes for patients with stage 3 CKD”, intervention effectiveness ***Intervention:*** “The BRIGHT intervention entailed the provision of a kidney information guidebook; a booklet and interactive website that tailored access to community resources; and telephone-guided help from a lay health worker”

	Comparator: CG (usual care) "Participants in the control arm were sent the kidney information guidebook and the PLANS booklet with links to the website at the end of the trial period. Both arms had usual access to primary care." ***Was the theoretical framework included?*** ND ***Was the intervention tailored?*** yes - "tailoring access to local community resources"
Outcomes *(i) outcomes and time-points from the study that are considered in the review *(ii) outcomes and time-points measured (or reported) in the study	***(i)** BP; HRQoL; anxiety; self-care activities **Time points:** at baseline and 6 months ***(ii)** "Primary outcomes: positive and active engagement in life, BP control; and HRQoL. Secondary outcomes: an additional five domains of the Health Education Impact Questionnaire (social integration and support, skill and technique acquisition, emotional wellbeing, self-monitoring and insight, and health service navigation); the Summary of Diabetes Self-Care Activities Measure; the anxiety sub-scale from HADS-A, and as a measure of CKD-specific anxiety the Emotional Response item from the Brief Illness Perception Questionnaire in relation to the patient's CKD; four physical and psychological well-being health education outcome measures taken from the Medical Outcomes Study (general health, social role/limitation, energy/ vitality and psychological wellbeing); the UCLA Loneliness Scale; the Medication Knowledge and Medication Motivation subscales from the Modified Morisky Medication Adherence Scale; Social capital service use (frequency of contact with primary care services and hospital outpatient services); and levels of Illness, practical everyday and emotional work done by social network members"
Notes	"The study was conducted as part of the NIHR Collaboration for Leadership in Applied Health Research and Care Greater Manchester"

Risk of Bias

Bias:	**Reviewer's judgment**	**Support for judgment**
Bias arising from the randomization process	Low Risk	E.g., "the participant was allocated to receive either the intervention or usual care (1:1) via a minimisation algorithm. The minimisation procedure ensured that within each practice, as each subsequent patient was recruited the two trial arms remained well-balanced" "The method also includes a degree of random allocation to avoid complete determination" "used robust allocation concealment, achieved high levels of retention overall, and used appropriate imputation to account for missing data"

Bias due to deviations from intended interventions	Some concerns	E.g., "neither the researchers nor health care practitioners were blinded to allocation" but, "the two trial arms remained well-balanced" intention-to-treat analysis was not conducted
Bias due to missing outcome data	Low Risk	E.g., "in total, 436 patients completed baseline data and 374 (85.7%) patients returned 6 months follow-up data" "all results remained unchanged under both sensitivity analyses, with the exception of a significant (p,0.05) increase in energy/vitality scores for intervention patients under complete cases analysis" "Where either sensitivity analysis produced a result differing in significance from the primary analysis, this is indicated in the text and tables"
Bias in the measurement of the outcome	High Risk	E.g., the assessor was probably aware of the intervention received, and "we recognise there is potential for bias in patient self-report outcomes in an unblinded trial"
Bias in the selection of the reported results	Low Risk	E.g., "Analysis followed intention to treat principles and a pre-specified plan" and trial registration available - protocol
Overall bias	**High Risk**	The study is judged to be at high risk of bias in at least one domain for this result.

Chen et al. (2011)

Methods	***Study design:*** an open-label, RCT ***Unit of allocation/analysis:*** "an outpatient clinic in the Nephrology Department of Chang Gung Memorial Hospital at Keelung, Taiwan"/ participants ***Follow-up:*** 12 months ***Duration:*** January 2008 to December 2008 (recruitment) ***Providers:*** management nurses, dietitians, peers and volunteers
Participants	***Participants:*** IG (N=27); CG (N=27) ***Age range, mean (SD):*** between 18 and 80 years old; CG: 68.85±14.56; IG: 67.93±12.87 ***Gender:*** CG: F= 12 (44.4%); M= 15 (55.6%); IG: F= 12 (44.4%); M= 15 (55.6%) ***Country/ Ethnicity:*** Taiwan ***Principal health problem or diagnosis:*** incidental CKD ***Stage of problem/illness:*** stages 3 to 5 ***Other health problem/s/comorbidities:*** ND

Interventions and comparisons	***Aims:*** “ to investigate the effect of SMS on CKD progression. to examine the impact of a standardised SMS program on the progression and morbidity of CKD” ***Intervention:*** SMS - interactive individualised education sessions. SMS comprised health information, patient education, telephone-based support and the aid of a support group ***Comparator:*** non-SMS. The non-SMS patients received customary care from a nephrologist ***Was the theoretical framework included?*** standardised SMS ***Was the intervention tailored?*** not specified (but, individualised education sessions)
Outcomes *(i) outcomes and time-points from the study that are considered in the review *(ii) outcomes and time-points measured (or reported) in the study	***(i)** eGFR (at baseline, 6 and 12 months); CKD knowledge (at baseline and 12 months) [-*Note that*: the study assessed CKD knowledge using a standardised checklist before and after the intervention, but it was not included as their primary or secondary outcome] Time-points: at baseline, 6 and 12 months ***(ii)** “The primary endpoints were absolute eGFR alteration and number of hospitalization events during the 1-year follow-up. The secondary endpoints were an eGFR decrease of up to 50%, ESRD requiring RRT, all-cause mortality or composite secondary endpoints”
Notes	“Funding. Chang Gung Memorial Hospital provided grant support (CMRPG260323) to this study”

Risk of Bias

Bias:	**Reviewer’s judgment**	**Support for judgment**
Bias arising from the randomization process	Low Risk	E.g., “a centre research nurse who randomised patients into SMS and non-SMS group at a 1:1 ratio by using a random table”
Bias due to deviations from intended interventions	Low Risk	E.g., open-label RCT - both the researchers and participants knew which treatment was being administered, but deviations from the intended intervention were unlikely to arise because of the experimental context; and they were balanced between groups, unlikely to have affected the outcome.
Bias due to missing outcome data	Low Risk	E.g., “4 participants lost to follow-up “, ITT analysis not reported but missingness in the outcome was unlikely to depend on its true value; data for this outcome were available for

		all, or nearly all, participants randomised
Bias in the measurement of the outcome	Low Risk	E.g., “A single nephrology nurse completed all pre-and post-education evaluations to limit information bias”
Bias in the selection of the reported results	Low Risk	E.g., pre-specified intentions not reported but protocol available
Overall bias	**Low Risk**	The study is judged to be at low risk of bias for all domains for this result.

Footnotes:

BP Blood Pressure; *BRIGHT* Bringing Information and Guided Help Together; *CG* Control Group; *CKD* Chronic Kidney Disease; *eGFR* estimated; *F* Female; *HADS-A* Hospital Anxiety and Depression Scale- Anxiety; *HRQoL* Health-Related Quality of Life; *IG* intervention Group; *ITT* Intention-To-Treat; *M* Male; *ND* No Data; *PLANS* Patient-Led Assessment for Network Support; *RCT* Randomised Control Trial; *SD* Standard Deviation; *SMI* Self-Management Intervention; *SMS* Self-Management Support.

Figure QQ1

Risk of Bias for Studies that Included Non-Dialysis Patients (N=12) - Summary Plot:

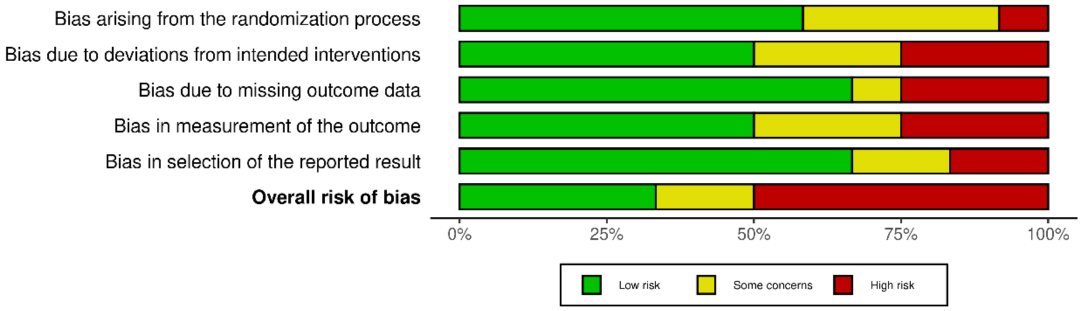
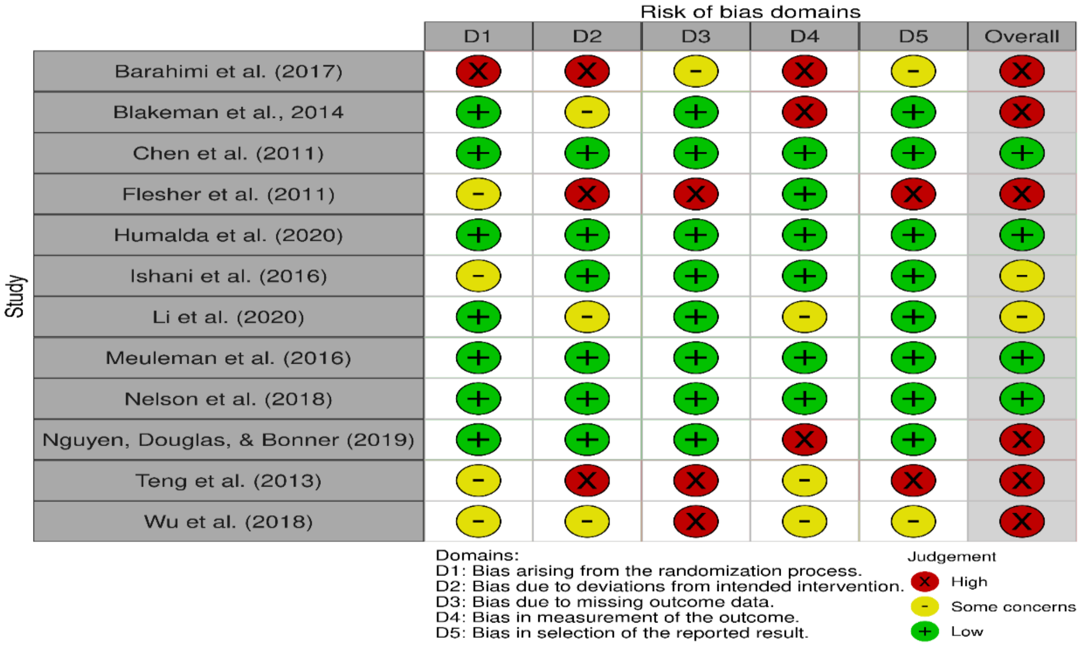


Figure QQ2

Risk of Bias for Studies that Included Non-Dialysis Patients (N=12) - Traffic-Light Plot:



Risk of bias domains

Study	D1	D2	D3	D4	D5	Overall
Barahimi et al. (2017)	X	X	-	X	-	X
Blakeman et al., 2014	+	-	+	X	+	X
Chen et al. (2011)	+	+	+	+	+	+
Flesher et al. (2011)	-	X	X	+	X	X
Humalda et al. (2020)	+	+	+	+	+	+
Ishani et al. (2016)	-	+	+	+	+	-
Li et al. (2020)	+	-	+	-	+	-
Meuleman et al. (2016)	+	+	+	+	+	+
Nelson et al. (2018)	+	+	+	+	+	+
Nguyen, Douglas, & Bonner (2019)	+	+	+	X	+	X
Teng et al. (2013)	-	X	X	-	X	X
Wu et al. (2018)	-	-	X	-	-	X

Domains:
D1: Bias arising from the randomization process.
D2: Bias due to deviations from intended intervention.
D3: Bias due to missing outcome data.
D4: Bias in measurement of the outcome.
D5: Bias in selection of the reported result.

Judgement
X High
- Some concerns
+ Low

Table QQ3

Characteristics of Included Studies - Patients on Dialysis (N=11):

Cho (2012)

Methods	***Study design:*** RCT ***Unit of allocation/analysis:*** participants were dialysis outpatients at Seoul National University Hospital in Korea/ participants ***Follow-up:*** 4 weeks ***Duration:*** the health contract intervention for 4 weeks/ recruitment between November 2007 and January 2008 ***Providers:*** study researcher
Participants	***Participants:*** IG (N=21); CG (N=22**)** ***Age range, mean (SD):*** ≥ 20 years of age; CG: 64.23±12.19; IG: 56.52±12.50 ***Gender:*** CG: F=13 (59.1); M=9 (40.9); IG: F=6 (28.6); M=15 (71.4) ***Country/ Ethnicity:*** Korea/ Korean ***Principal health problem or diagnosis:*** receiving dialysis twice or 3 times a week for at least 3 months ***Stage of problem/illness:*** ND ***Other health problem/s/comorbidities:*** ND

Interventions and comparisons	***Aims:*** "The aim of this study was to examine the effect of the HCI on the self-care behaviour of renal dialysis patients and physiological indices" ***Intervention:*** the HCI 4-week intervention ***Comparator:*** routine care ***Was the theoretical framework included?*** yes, the goal attainment theory ***Was the intervention tailored?*** ND
Outcomes *(i) outcomes and time-points from the study that are considered in the review *(ii) outcomes and time-points measured (or reported) in the study	***(i)** self-care behaviour, and the mean weight gain **Time points:** at baseline and 4 weeks follow-up (pre-test and post-test) ***(ii)** self-care behaviour, the serum phosphorus and serum potassium measurements, the mean weight gain
Notes	

Risk of Bias

Bias:	**Reviewer's judgment**	**Support for judgment**
Bias arising from the randomization process	Some Concerns	E.g., "A random numbers table was used to allocate the participants to either the IG or CG", but ND on whether the allocation sequence was adequately concealed
Bias due to deviations from intended interventions	Some Concerns	E.g., ND on blinding and protocol or registry; ITT not conducted
Bias due to missing outcome data	Low Risk	E.g., Data for this outcome were available for all, or nearly all, participants randomised
Bias in the measurement of the outcome	Low Risk	E.g., The method of measuring the outcome was appropriate; measurement or ascertainment of the outcome did not differ between intervention groups; outcome assessors were not aware of the intervention received by the study participant: "research assistant was responsible for the assessment of outcome measures. The research assistant was not aware of the allocation of the participants"

Bias in the selection of the reported results	Some Concerns	E.g., ND on whether the trial was analysed in accordance with a pre-specified plan or whether a statistical analysis plan was conducted
Overall bias	**Some Concerns**	The study is judged to raise some concerns in at least one domain for this result, but not to be at high risk of bias for any domain.

Griva et al. (2018)

Methods	***Study design:*** multi-centre parallel (1:1) design, blinded RCT ***Unit of allocation/analysis:*** "14 of the 24 dialysis centres run by the National Kidney Foundation Singapore, a non-profit charitable organisation, which serves socioeconomically disadvantaged and middle-income patients with ESRD in Singapore"/ participants ***Follow-up:*** 2 weeks, 6- and 9 months post-intervention ***Duration:*** recruitment between January 2009 and June 2012/ over 3 core 7 sessions plus 1 booster session (total contact 8 hours). An additional telephone follow-up call was scheduled in the interim between the core curriculum and booster session ***Providers:*** 2 renal health care professionals
Participants	***Participants:*** IG: (N=101); CG: (N=134**)** ***Age range, mean (SD):*** over 21 years old; CG: 53.9 (10.4); IG: 53.1 (10.5) ***Gender:*** CG: F= 38.3% (51); IG: F= 46.1% (47) ***Country/ Ethnicity:*** Singapore/ Chinese, Malay, Indian, and others ***Principal health problem or diagnosis:*** adult patients on HD for a minimum of 6 months ***Stage of problem/illness:*** ND ***Other health problem/s/comorbidities:*** ND
Interventions and comparisons	***Aims:*** "to assess the short- and long-term effects of a practical, low-intensity self-management intervention for HD patients who are socioeconomically disadvantaged and from a diverse ethnic background" ***Intervention:*** the HED-SMART intervention ***Comparator:*** usual care ***Was the theoretical framework included?*** yes, the principles of problem-solving and SCT ***Was the intervention tailored?*** ND
Outcomes *(i) outcomes and time-points from the study that are	***(i)** IDWG, self-efficacy, and self-management skills **Time points:** at baseline, 1-week post-intervention (after completion of the core curriculum), 3 months (following telephone call and booster session), and 9 months post-intervention (no contact/maintenance phase)

considered in the review *(ii) outcomes and time-points measured (or reported) in the study	***(ii)** Primary outcomes: serum potassium, phosphate levels, and IDWG. Secondary outcomes: self-reported adherence, self-efficacy, and self-management skills.
Notes	The study was funded by the NKF Research Fund [NKFRC2008/07/24] and the Ministry of Education-NUS Academic Research Fund [FY2007-FRC5-006]. The 18 funding sources had no role in the study design or intervention, recruitment of patients, data collection, analysis, or interpretation of the results, writing of the manuscript, or decision to submit the manuscript for publication. Incentives: All participants received S$10 at each evaluation completed (S$40 total). Intervention participants received an additional travel reimbursement of S$25 for each intervention session attended, to cover travel on non-dialysis days (S$100 total)

Risk of Bias

Bias:	**Reviewer's judgment**	**Support for judgment**
Bias arising from the randomization process	Low Risk	E.g., "computerised randomisation (1:1 allocation ratio)/ Healthcare professionals delivering the intervention were notified of the allocation after baseline assessment and before the first session; however, research assessors and all other staff remained blind to allocation at all assessment points

Bias due to deviations from intended interventions	Low Risk	E.g., "the allocation of randomization was concealed from study participants until consent and baseline assessment was completed. Consenting patients indicated their preferred language for intervention at baseline to guide subsequent arrangements for those allocated to HED-SMART. Healthcare professionals delivering the intervention were notified of the allocation after baseline assessment and before the first session; however, research assessors and all other staff remained blind to allocation at all assessment points"/ Primary analyses were based on ITT population, (all randomly assigned participants, including those without post-baseline observations)"
Bias due to missing outcome data	Low Risk	E.g., "Overall retention through study completion was 82.1% (n=193). Complete case data (per protocol) for all clinical markers and questionnaires across all time points was 80% (n=189). Attrition rates were significantly greater in the IG (25.7%; n=26) than in CG (11.9%; n=16) (p=.01). This was largely due to not being able to form a preferred language group for 6 participants randomised to intervention arm 11 (no commencement rather than discontinuation). There were no differential attrition rates between study arms when these subjects were excluded"
Bias in the measurement of the outcome	Low Risk	E.g., "however, research assessors and all other staff remained blind to allocation at all assessment points"
Bias in the selection of the reported results	Low Risk	E.g., "Moreover, self-selection bias cannot be ruled out. It is possible that volunteers were highly motivated to change their behaviour, thereby influencing the study outcomes in a positive direction." But: the trial was analysed in accordance with a pre-specified plan that was finalised before unblinded outcome data were available for analysis; and appropriate analyses were conducted: "primary analyses

		were based on ITT population, (all randomly assigned participants, including those without post-baseline observations). Missing values were imputed using the last Observation Carried Forward (LOCF) method. As a sensitivity analysis, per protocol approach was used in which participants with missing data were excluded.”
Overall bias	**Low Risk**	The study is judged to be at low risk of bias for all domains for this result.

Hare, Clark-Carter, & Foreshaw (2014)

Methods	***Study design:*** RCT ***Unit of allocation/analysis:*** NHS Renal Service Home Therapies Department in Wolverhampton, UK/ participants ***Follow-up:*** 5 data collection points; “at baseline (T1), post-intervention (T2) and at three follow-up points (T3, T4, T5); providing a true RCT phase and longitudinal analysis phase”/ 6-week follow-up (T1-T3)/ 16-week follow-up IG only ***Duration:*** the study ran for a total of 21 weeks ***Providers:*** a supervised Trainee Health Psychologist
Participants	***Participants:*** IG: (N=8); CG: (N=7**)** ***Age range, mean (SD):*** ≥aged 18 years; CG: 60.1 (SD, 12.2); IG: 60 (SD, 14.1) ***Gender*:** CG: F=1 (14.3); M=6 (85.7); IG: F=0 (0); M=8 (100) ***Country/ Ethnicity:*** UK ***Principal health problem or diagnosis:*** Patients receiving PD (CAPD and APD) for ≥3 months ***Stage of problem/illness:*** PD patients identified as non-adherent to fluid restrictions ***Other health problem/s/comorbidities:*** ND
Interventions and comparisons	***Aims:*** **“**To investigate whether the LIP, an applied and established intervention to enhance HD patient fluid restrictions, would be effective in improving fluid adherence among PD patients” and “to identify whether the group intervention had any effect on the QoL and psychological well-being, as well as the impact on patient health beliefs and attributions” ***Intervention:*** intervention encompassed educational, cognitive and behavioural components, aimed to assist patients’ self-management of fluid ***Comparator:*** “a deferred-entry CG. CG received the intervention in weeks 11–14; providing control in both an extended baseline and replication of an intervention effect” ***Was the theoretical framework included?*** Yes, CBT techniques, encompassing educational, cognitive and behavioural components

	Was the intervention tailored? ND
Outcomes *(i) outcomes and time-points from the study that are considered in the review *(ii) outcomes and time-points measured (or reported) in the study	***(i)** Weight, BP, psychological well-being, QoL **Time points:** "at baseline (T1), post-intervention (T2) and at 3 follow-up points (T3, T4, T5)" ***(ii)** Primary outcomes: weight (kg). Secondary outcomes: SBP, DSBP and observable signs of oedema, as well as, psychological well-being (anxiety and depression), QoL (measured by SF-36 so HRQoL), and health beliefs and attributions
Notes	

Risk of Bias

Bias:	**Reviewer's judgment**	**Support for judgment**
Bias arising from the randomization process	High Risk	E.g., "Participants were allocated a number following recruitment and randomised into the IG or CG by simply drawing numbers out of a bag; allocated to each group in sequential order. This method of randomisation was chosen to ensure the groups had equal sample sizes. There was no form of blinding in this study; due to the active nature of group attendance and participation, this could not be concealed"
Bias due to deviations from intended interventions	Some Concerns	E.g., "There was no form of blinding in this study" - participants were aware of their assigned intervention during the trial; carers and people delivering the interventions were aware of participants' assigned intervention during the trial; ND study protocol or registry
Bias due to missing outcome data	Low Risk	E.g., "An ITT analysis was used for any participants lost to follow-up. In the current study, there were no missing data for those who were retained in the study. Independent t-tests were used to examine any differences between the IG and CG at baseline" "Independent t-tests revealed no significant differences

		between the two groups on any outcome measures”
Bias in the measurement of the outcome	Some Concerns	E.g., No form of blinding in this study, but the method of measuring the outcome was appropriate; assessment of the outcome was unlikely to have been influenced by knowledge of the intervention received
Bias in the selection of the reported results	Some Concerns	E.g., ND on whether the trial was analysed in accordance with a pre-specified plan or whether a statistical analysis plan was conducted
Overall bias	**High Risk**	The study is judged to be at high risk of bias in at least one domain for this result.

Footnotes:

APD Automated Peritoneal Dialysis; *BP* Blood Pressure; *CAPD* Continuous Ambulatory Peritoneal Dialysis; *CBT* Cognitive Behavioural Therapy; *CG* Control Group; *CKD* Chronic Kidney Disease; *ESRD* End Stage Renal Disease; *F* Female; *HCI* Health Contract Intervention; *HD* Haemodialysis; *HED-SMART* Haemodialysis Self-Management Intervention Randomised Trial; *HRQoL* Health-Related Quality of Life; *IDWG* Interdialytic Weight Gain; *IDWGa* Average Daily Interdialytic Weight Gain; *IG* intervention Group; *ITT* Intention-To-Treat; *LIP* Liquid Intake Programme; *M* Male; *ND* No Data; *NHS* National Health Service; *PD* Peritoneal Dialysis; *QoL* Quality of Life; *RCT* Randomised Control Trial; *SBP* Systolic Blood Pressure; *SCT* Social Cognitive Theory; *SD* Standard Deviation.

Figure QQ3

Risk of Bias for Studies that Included Patients on Dialysis (N=11) - Summary Plot:

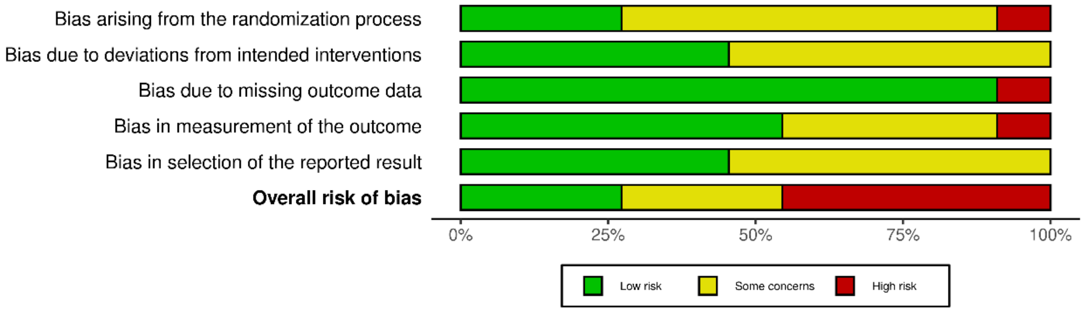
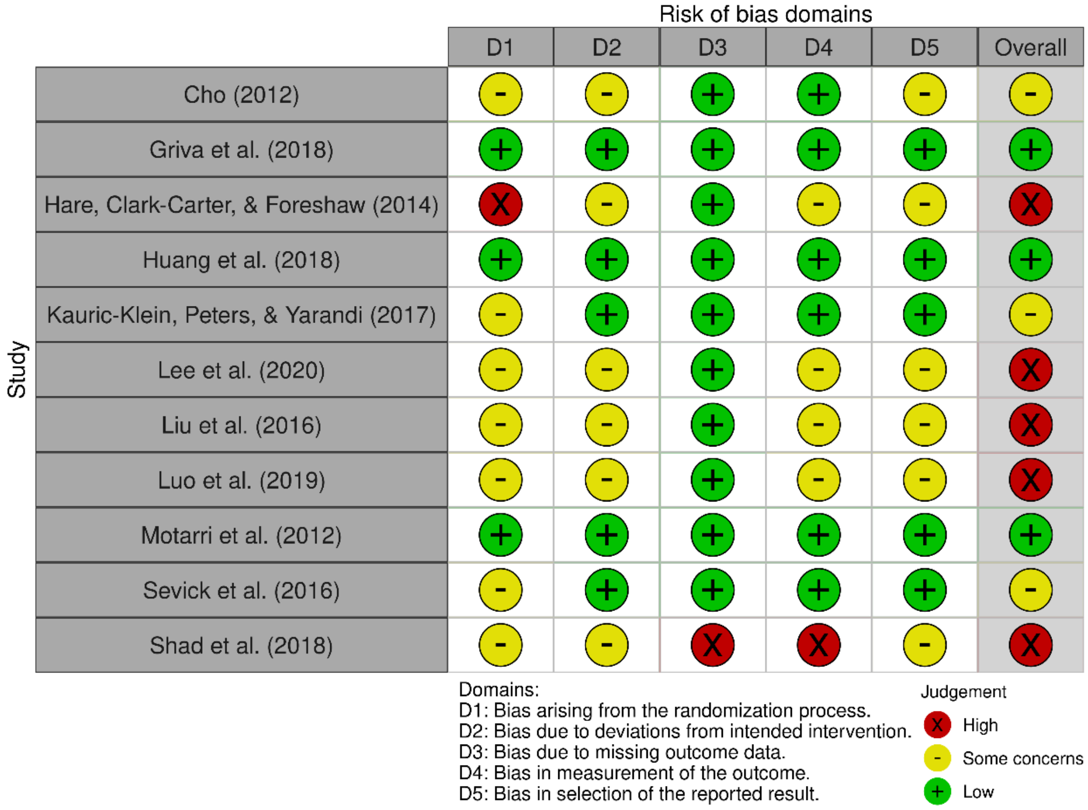


Figure QQ4

Risk of Bias for Studies that Included Patients on Dialysis (N=11) - Traffic-Light Plot:



Risk of bias domains

Study	D1	D2	D3	D4	D5	Overall
Cho (2012)	-	-	+	+	-	-
Griva et al. (2018)	+	+	+	+	+	+
Hare, Clark-Carter, & Foreshaw (2014)	X	-	+	-	-	X
Huang et al. (2018)	+	+	+	+	+	+
Kauric-Klein, Peters, & Yarandi (2017)	-	+	+	+	+	-
Lee et al. (2020)	-	-	+	-	-	X
Liu et al. (2016)	-	-	+	-	-	X
Luo et al. (2019)	-	-	+	-	-	X
Motarri et al. (2012)	+	+	+	+	+	+
Sevick et al. (2016)	-	+	+	+	+	-
Shad et al. (2018)	-	-	X	X	-	X

Domains:
D1: Bias arising from the randomization process.
D2: Bias due to deviations from intended intervention.
D3: Bias due to missing outcome data.
D4: Bias in measurement of the outcome.
D5: Bias in selection of the reported result.

Judgement
X High
- Some concerns
+ Low

Table QQ4

Reasons for Excluding Studies After the Title and Abstract Screening (N=236)

No RCT	89
No CKD	70
No abstract	22
Systematic review	15
No SMI	13
Trial registration- study not yet completed	8
Wrong population	6
Wrong outcome	7
Foreign language	3
Secondary analysis of data from RCT	3

Retrieved from RAYYAN's synthesis (Ouzzani et al., 2016). *CKD* Chronic Kidney Disease; *RCT* Randomised Control Trial; *SMI* Self-management intervention.

Table QQ5

Reasons for Excluding Studies After the Full-Text Screening (N=12):

No RCT	3
No SMI	2
Wrong population	4
Wrong outcome	3

RCT Randomised Control Trial; *SMI* Self-management intervention.

Appendix RR

Effect Direction for Individual Outcomes

Reported Effect Direction for Individual Outcomes

Author year	Final sample in the IG	Physiological outcomes	Cognitions	Individual outcomes	Health status
Barahimi et al. (2017)	39	▴ (eGFR)			
Blakeman et al. (2014)	215	▲ (BP)	▲ (CKD self-management)	▲ (HRQoL/ QoL) ◀▶ (anxiety)	
Chen et al. (2011)	27	▴ (eGFR)	▴ (CKD knowledge)		
Cho (2012)	21	▴ (weight)	▴ (CKD self-management)		
Flesher et al. (2011)	23	◂▸ (eGFR) ▴ (BP)			
Griva et al. (2018)	101	▲ (weight)	◀▶ (CKD self-management) ▲ (self-efficacy)		
Hare, Clark-Carter, & Foreshaw (2014)	8	◂▸ (weight) ▾ (BP)		◂▸ (psychological distress) ◂▸ (HRQoL/ QoL)	
Huang et al. (2018)	46	◂▸ (BP)	▴ (CKD self-management)		
Humalda et al. (2020)	50	▲ (BP)	◀▶ (CKD self-management)	▲ (HRQoL/ QoL)	
Ishani et al. (2016)	450				◀▶ (adverse events)
Kauric-Klein, Peters, & Yarandi (2017)	59	◀▶ (weight) ▲ (BP)	◀▶ (self-efficacy)		
Lee et al. (2020)	28	◂▸ (weight) ◂▸ (eGFR)			
Li et al. (2020)	25	▴ (eGFR) ◂▸ (weight)	▴ (CKD self-management)	▴ (HRQoL/ QoL)	

Author year	**Final sample in the IG**	**Physiological outcomes**	**Cognitions**	**Individual outcomes**	**Health status**
			◂▸ (self-efficacy)		
Liu et al. (2016)	43		▴ (CKD self-management) ▴ (CKD knowledge)		
Luo et al. (2019)	64		▲ (CKD self-management)		
Meuleman et al (2016)	67	◀▶ (BP) ▲ (weight)	▲ (self-efficacy)	◀▶ (HRQoL/ QoL)	
Motarri et al. (2012)	25	▴ (weight) ▴ (BP)	▴ (self-efficacy)	▴ (HRQoL/ QoL)	
Nelson et al. (2018)	50	◀▶ (eGFR) ◀▶ (BP) ▲ (weight)	▲ (patient activation)	◀▶ (HRQoL/ QoL)	
Nguyen, Douglas, & Bonner (2019)	68	◀▶ (BP)	▲ (CKD self-management) ▲ (self-efficacy) ▲ (CKD knowledge)	▲ (HRQoL/ QoL)	
Sevick et al. (2018)	93	◀▶ (weight)			
Shad et al. (2018)	29		▴ (CKD self-management)		
Teng et al. (2013)	52	◀▶ (weight)	▲ (CKD knowledge)		
Wu et al. (2018)	45	◂▸ (eGFR) ◂▸ (BP)	▴ (CKD self-management) ▴ (self-efficacy)	◂▸ (psychological distress)	

BP Blood Pressure; *CKD* Chronic Kidney Disease; *eGFR* estimated Glomerular Filtration Rate; *HRQoL* Health-Related Quality of Life; *IG* Intervention Group; *QoL* Quality of Life.
LEGEND:

Effect direction: upward arrow ▲ =positive health impact, downward arrow ▼ =negative health impact, sideways arrow ◀▶ =no change/mixed effects/conflicting findings. Sample size: final sample size in the IG: large arrow ▲ >300; medium arrow ▲ 50-300; small arrow ▴<50. *IG* Intervention Group.

Appendix SS

Synthesis Without Meta-analysis (SWiM) Reporting Items

Synthesis Without Meta-Analysis

SWiM is intended to complement and be used as an extension to PRISMA		
SWiM reporting item	**Item description**	**The section in the manuscript where the item is reported**
Methods		
1 Grouping studies for synthesis	1a) Provide a description of, and rationale for, the groups used in the synthesis (e.g., groupings of populations, interventions, outcomes, study design)	Chapter 3, section 3.2.8
	1b) Detail and provide the rationale for any changes made subsequent to the protocol in the groups used in the synthesis	Chapter 3 section 3.4
2 Describe the standardised metric and transformation methods used	Describe the standardised metric for each outcome. Explain why the metric(s) was chosen, and describe any methods used to transform the intervention effects, as reported in the study, to the standardised metric, citing any methodological guidance consulted	Chapter 3, section 3.2.7
3 Describe the synthesis methods	Describe and justify the methods used to synthesise the effects for each outcome when it was not possible to undertake a meta-analysis of effect estimates	Chapter 3, section 3.2.8
4 Criteria used to prioritise results for summary and synthesis	Where applicable, provide the criteria used, with supporting justification, to select the particular studies, or a particular study, for the main synthesis or to draw conclusions from the synthesis (e.g., based on study design, risk of bias assessments, directness in relation to the review question)	Chapter 3, section 3.2.1 and 3.2.8

5 Investigation of heterogeneity in reported effects	State the method(s) used to examine heterogeneity in reported effects when it was not possible to undertake a meta-analysis of effect estimates and its extensions to investigate heterogeneity	Chapter 3 section 3.2.7
6 Certainty of evidence	Describe the methods used to assess the certainty of the synthesis findings	Chapter 3, section 3.2.9
7 Data presentation methods	Describe the graphical and tabular methods used to present the effects (e.g., tables, forest plots, harvest plots). Specify key study characteristics (e.g., study design, risk of bias) used to order the studies, in the text and any tables or graphs, clearly referencing the studies included	Described in Chapter 3, sections 3.2.7 and 3.2.8 and presented in section 3.3
Results		
8 Reporting results	For each comparison and outcome, provide a description of the synthesised findings, and the certainty of the findings. Describe the result in language that is consistent with the question the synthesis addresses, and indicate which studies contribute to the synthesis	Chapter 3, section 3.3
Discussion		
9 Limitations of the synthesis	Report the limitations of the synthesis methods used and/or the groupings used in the synthesis, and how these affect the conclusions that can be drawn in relation to the original review question	Chapter 3, section 3.5

Retrieved from*:* Campbell et al. (2020). PRISMA=Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Appendix TT

GRADE Assessment for Each Outcome

GRADE Assessment

GRADE criteria	Rating	Footnotes (Reasons for down- or upgrading)	Quality of the evidence
Outcome: **Self-efficacy**			
Study design	RCT (starts at high quality)		
RoB	No serious RoB, do not downgrade.	All information is from studies at low RoB, thus possible bias is unlikely to seriously change the results.	⊕⊕⊕⊕ **High**
Inconsistency	No, do not downgrade.	In all 3 included studies that assessed self-efficacy, the effect direction was reported as positive (benefit). 2 studies included a medium sample size and 1 involved a small sample. This inconsistency does not seem to be an issue.	
Indirectness	No, do not downgrade.	2 out of 3 studies included patients on dialysis, and 1 study compromised the non-dialysis population. Interventions involved SMIs and 1 empowerment program versus regular/standard care. Outcomes were assessed using standard measures, and 1 self-reported (valid and reliable) measure, and reported as continuous variables. Although some variability was noted, indirectness does not appear to be an issue.	
Imprecision	No, do not downgrade.	The total number of participants across all 3 studies was 421, thus more than 400 (a "rule of thumb"). All 3 trials reported a reduction in self-efficacy outcome.	
Publication bias	Undetected, do not downgrade.	Statistical evaluation of publication bias was not possible. The results come from 1 "small" study and 2 "medium" studies. The number of events was 193. Finally, the search for studies was comprehensive, thus we did not suspect publication bias.	

GRADE criteria	**Rating**	**Footnotes** (Reasons for down- or upgrading)	**Quality of the evidence**
Other (upgrading factors)	n/a	n/a	
GRADE criteria	**Rating**	**Footnotes** (Reasons for down- or upgrading)	**Quality of the evidence**
Outcome: CKD self-management			
Study design	RCT (starts at high quality)		
RoB	No serious RoB, do not downgrade.	All information is from studies at low RoB, thus possible bias unlikely to seriously change the results	⊕⊕OO **Low**
Inconsistency	Serious (-1), downgrade	In 3 included studies that assessed CKD self-management, the effect direction was reported as positive (in a small sample) in 1 study, and 2 studies reported no change/ mixed results (in medium samples). Given the occurrence of some inconsistency, we downgraded this domain by 1 level.	
Indirectness	No, do not downgrade.	The population, intervention, comparator, and outcomes provide evidence for the review's question. 2 studies involved patients on dialysis, and 1 study included non-dialysis patients. Interventions involved similar SMIs compared with routine/ standard care, while 1 study involved a "common intervention group" as care-as-usual. Outcomes were assessed using standard measures, and 1 study used 2 self-administered questions. 2 outcomes were reported as continuous variables and 1 as a binary measure (categorical variable). Some variability was noted; however, the indirectness does not appear to be an issue.	
Imprecision	Serious (-1), downgrade	The total number of participants across all 3 studies was 419, thus more than 400 (a "rule of thumb"), however, 1 study assessed categorical outcome. 1 trial reported a reduction in CKD self-management outcome (in a small sample), while 2 trials reported no change/ mixed results (in medium samples). Due to the occurrence of some imprecision, we decided to downgrade this domain by 1.	

GRADE criteria	Rating	Footnotes (Reasons for down- or upgrading)	Quality of the evidence
Publication bias	Undetected, do not downgrade.	Statistical evaluation of publication bias was not possible. Both, positive and "no change" results were published. The results come from 1 "small" study and 2 "medium" studies. The number of events was 197. Finally, the search for studies was comprehensive, thus we did not suspect publication bias.	
Other (upgrading factors)	n/a	n/a	
GRADE criteria	**Rating**	**Footnotes** (Reasons for down- or upgrading)	**Quality of the evidence**
Outcome: CKD knowledge			
Study design	RCT (starts at high quality)		
RoB	No serious RoB, do not downgrade.	All information is from studies at low RoB, thus possible bias unlikely to seriously change the results	⊕⊕OO **Low**
Inconsistency	No, do not downgrade.	Only 1 study assessed CKD knowledge outcome, thus inconsistency could not be detected. This study reported the effect direction (in a small sample) as positive.	
Indirectness	No, do not downgrade.	The population, intervention, comparator, and outcomes provide evidence for the review's question. The study compared SMI with usual care/ "customary care from a nephrologist". CKD knowledge was assessed using a standardised CKD knowledge checklist with dichotomous responses, evaluated using a 5-point Likert scale.	
Imprecision	Very serious (-2)	The total number of patients included in this trial was 54 (IG=27; CG=27), which means that the small number of participants analysed will not produce enough precise information. Thus, due to insufficient information (mainly because only 1 study assessed this outcome), we decided to downgrade this domain by 2 levels.	
Publication bias	Undetected, do not downgrade.	Statistical evaluation of publication bias was not possible, and given that only 1 trial assessed this outcome, publication bias was not suspected.	

GRADE criteria	**Rating**	**Footnotes** (Reasons for down- or upgrading)	**Quality of the evidence**
Other (upgrading factors)	n/a	n/a	
GRADE criteria	**Rating**	**Footnotes** (Reasons for down- or upgrading)	**Quality of the evidence**
Outcome: eGFR			
Study design	RCT (starts at high quality)		
RoB	No serious RoB, do not downgrade.	All information is from studies at low RoB, thus possible bias unlikely to seriously change the results	⊕⊕OO **Low**
Inconsistency	Serious (-1), downgrade.	2 trials assessed eGFR outcome. 1 study reported a positive effect direction (small sample size) while another study reported no change/ mixed results (medium sample size). Given the occurrence of some inconsistency in the results, we downgraded this domain by 1 level.	
Indirectness	No, do not downgrade.	The population, intervention, comparator, and outcomes provide evidence for the review's question. Both trials included non-dialysis patients. In one study, the intervention involved a home-based kidney care program versus usual care, and in another study, it involved a self-management program versus usual care ("customary care from a nephrologist"). Although some variability in the interventions was noted, indirectness does not appear to be an issue.	
Imprecision	Serious (-1), downgrade.	The total number of participants across both studies was 179, thus less than 400 (a "rule of thumb"), not producing enough information. One trial reported a reduction in eGFR outcome, while another reported no change/ mixed results. Due to insufficient information, we decided to downgrade this domain by 1 level.	
Publication bias	Undetected, do not downgrade.	Statistical evaluation of publication bias was not possible. The results come from 1 "small" study and 1 "medium" study, reporting, both reduction and no change. The number of events was 77. Finally, the search for studies was comprehensive, thus we did not suspect publication bias.	

GRADE criteria	**Rating**	**Footnotes** (Reasons for down- or upgrading)	**Quality of the evidence**
Other (upgrading factors)	n/a	n/a	

Adapted from: Ryan, Santesso, and Hill, (2016). *CKD* Chronic Kidney Disease; *eGFR* estimated Glomerular Filtration Rate; *RCT* Randomised Controlled Trial; *RoB* Risk of Bias; *SMI* Self-Management Interventions.

Appendix UU

Intervention Characteristics (Non-Dialysis Population)

Interventions According to the TIDieR Checklist in Non-Dialysis patients (N=12 studies)

Study ID (author & year)Bookmark; N*	Why (Aim)	What (intervention)	Who (providers)	How (delivery format)	Where (setting)	When & How Much	Tailoring
Barahimi et al. (2017)[1] N=39	"To determine the effectiveness of virtual training in terms of its impact on physiological measures affecting the development of kidney dysfunction"	Educational intervention via the computer-based system - **"**self-care education through e-learning"	ND but the intervention involved online e-learning	Face-to-face, website	Noncommunicable centres and online	6-month intervention and follow-up	ND
Blakeman et al. (2014)[2] N=215	"To test whether an intervention which provides information about self-management, tailored access to local community resources and telephone guidance can improve health outcomes for patients with stage 3 CKD"	BRIGHT intervention: -Kidney information guidebook -PLANS booklet with a link to an interactive website that tailored access to local resources -Telephone-guided help	Lay health workers ("8 telephone support workers: 3 members of staff, 4 postgraduate students, and 1 undergraduate student")	Print, telephone, website	24 general practices in Greater Manchester and online	6-month intervention and follow-up	Tailored information

Study ID (author & year)Bookmark; N*	**Why (Aim)**	**What (intervention)**	**Who (providers)**	**How (delivery format)**	**Where (setting)**	**When & How Much**	**Tailoring**
Chen et al. (2011)[3] N=27	"To examine the impact of a standardised SMS programme on the progression and morbidity of CKD"	Interactive individualised education sessions. SMS comprised: -Health information -Patient education -Telephone-based support -Aid of a support group	Management nurses, dietitians, peers and volunteers	Print, face-to-face, and telephone	Outpatient clinic in the Nephrology Department of Chang Gung Memorial Hospital at Keelung, Taiwan	12-month intervention and follow-up/ telephone support weekly; 1-to-1 monthly and group support twice a month	Unclear, but "education sessions were individualised"
Flesher et al (2011)[5] N=23	"To determine whether a comprehensive nutrition programme of individual counselling group cooking classes and an exercise programme would reduce cardiovascular risk factors and slow the progression of certain CKD parameters"	-Standard care (i.e., individual nutrition counselling) -Group CKD nutrition and cooking classes (2h sessions over 4 weeks) -1 shopping tour led by a dietician -CKD cookbook -Exercise programme	Certified Exercise Physiologist, nurse, dietitian, cook educator and exercise physiologist	Print, face-to-face	Recruited through a nephrologist and general practitioners within the Greater Vancouver area	12-week exercise programme; 3×1h sessions/week /12-month follow-up	ND

Study ID (author & year)Bookmark; N*	Why (Aim)	What (intervention)	Who (providers)	How (delivery format)	Where (setting)	When & How Much	Tailoring
Humalda et al. (2020)[10] N=50	"To examine the efficacy and explored costs, barriers, and facilitators for implementation of SUBLIME intervention into clinical practice"	SUBLIME: self-management and e-health technology intervention: -Routine care -Web-based SMI including individual e-coaching -Group meetings	Dietitians, lifestyle coaches, or research nurses (trained by certified lifestyle professionals)	Print, face-to-face, telephone, website, email	Outpatient clinics	3 months intervention phase (2 scheduled 2h group coaching and 1 to 4 individual e-coaching sessions/ 3- and 9-month follow-up	ND

Study ID (author & year)Bookmark; N*	Why (Aim)	What (intervention)	Who (providers)	How (delivery format)	Where (setting)	When & How Much	Tailoring
Ishani et al. (2016)[11] N=450	To determine whether the intervention can be effectively implemented and "whether it could improve the combined end point of death, hospitalization, emergency department visits, or admission to a nursing home in patients with moderate to severe CKD compared to usual care"	-Second in-home visit - installation of the video monitoring device with peripherals and broadband -Lifestyle modification (physical activity, diet, weight reduction, and smoking cessation). -Customised self-monitoring strategy based on the clinical condition	Interprofessional team (nephrologist, nurse practitioner, clinical pharmacy specialist, psychologist, social worker, telehealth care technician, and dietician)	Telehealth	Minneapolis Veterans Affairs Health Care System, St. Cloud, and affiliated community-based clinics	4.5 months/ 12-month follow-up	Unclear, but "customised education" and "a patient-specific treatment plan"
Li et al. (2020)[14] N=25	"To evaluate the effectiveness of wearable devices, a health management platform, and social media at improving the self-management of CKD, to establish a new SMI model"	LINE app intervention: -Diet, exercise, and self-management education -Dietary diary and suggestions about diet and exercise	IG - primary care nephrologists; CG- case managers	Wearable devices, a health management platform, and social media, print, video	Nephrology outpatient clinic of National Taiwan University Hospital Yunlin branch	90-day intervention and follow-up	Unclear, but "individualised dietary suggestions"

Study ID (author & year)Bookmark; N*	**Why (Aim)**	**What (intervention)**	**Who (providers)**	**How (delivery format)**	**Where (setting)**	**When & How Much**	**Tailoring**
		- Teleconsultations of health information and opportunity to ask questions					
Meuleman et al., (2017)[17] N=67	"To evaluate the effectiveness and sustainability of self-managed sodium restriction in patients with chronic kidney disease"	-Regular care according to the Dutch Federation of Nephrology treatment guidelines -SMI	IG: 4 personal coaches, 3 health psychologists and 1 dietician. CG: nephrologist, and if necessary, dietician	Face-to-face, print, telephone	Nephrology departments of 3 university hospitals and 1 general teaching hospital in the Netherlands	3 months SMI; consultations every 3-6 months/ 6-month follow-up	Unclear, but "tailored intervention according to the needs of patients and HCPs as assessed in a preparatory qualitative study"

Study ID (author & year)Bookmark; N*	Why (Aim)	What (intervention)	Who (providers)	How (delivery format)	Where (setting)	When & How Much	Tailoring
Nelson et al. (2018)[19] N=50	"To examine the efficacy of a home-based kidney care programme versus usual care on patient activation and other clinical measures"	Home-Based Kidney Care: -Lifestyle coaching -Frequent reinforcement about adherence to medicines, diet and exercise, self-monitoring, and coping strategies -Education on healthy lifestyles	Two community health representatives employed by the University of New Mexico	Face-to-face, print	Clinical data obtained from a previously established cohort – Zuni Indians	12-month study/ biweekly home visits/12-month follow-up	No
Nguyen, Douglas, and Bonner (2019)[20] N=68	"To examine the effectiveness of SMI compared with usual care in improving self-management behaviour, knowledge, self-efficacy, HRQoL, and BP in adults with CKD stages 3-5"	- Care as usual - SMI: -CKD booklet and a handout -1 session and 2 brief telephone follow-up sessions	CG - renal medical practitioners and nurses; IG - first author (experienced nurse teacher)	Face-to-face, telephone, print	Renal outpatient clinics at a large general hospital in Hanoi, Vietnam	12 weeks programme/ 1 session and 20-30 min telephone call/ 16-week follow-up	ND

Study ID (author & year)Bookmark; N*	**Why (Aim)**	**What (intervention)**	**Who (providers)**	**How (delivery format)**	**Where (setting)**	**When & How Much**	**Tailoring**
Teng et al. (2013)[23] N=52	"To test the ability of targeted interventions, matched to the TTM stage of change, to modify the diet and exercise behaviours of patients with early CKD"	-Counselling and information according to the self-reported stage of change -Follow-up telephone call to remind of appointment 1 month before each return clinic visit	Clinic case managers, registered nurse research assistants	Print, face-to-face, telephone	Case managers of the nephrology outpatient clinics of four hospitals in southern Taiwan	12-month intervention and follow-up	Tailored based on readiness to change from TTM
Wu et al. (2018)[24] N=45	To explore the effectiveness of SMI based on self-efficacy on the physiological indicators (renal function), psychological parameters (e.g., self-efficacy, anxiety, and depression), and management	-Setting personal goals -Experiences shared by peers -Information manual -Consultative framework -Application of self-confidence and empowerment skills	Nurses, case managers	Face-to-face, video, print	Department of Nephrology in a regional teaching hospital in Taiwan	3 months intervention and follow-up/ Once weekly for 1 month (lasted for 100 min, including 90 min group discussion and 10 min video)	Unclear but "involved problem-centred approaches"

*N= Nr. of participants in the IG that completed the study. *BCTs* Behaviour Change Techniques**;** *BP* Blood Pressure; *BRIGHT* Bringing Information and Guided Help Together; *CG* Control Group; *CKD* Chronic Kidney Disease; *HCPs* Healthcare Professionals; *HRQoL* Health-Related Quality of Life; *IG* intervention Group; *ND* No Data; *PLANS* Patient-Led Assessment for Network Support; *SMI* Self-Management Intervention; *SMS* Self-Management Support; *TTM* Trans-Theoretical Model.

Appendix VV

Intervention Characteristics (Dialysis Population)

Interventions According to the TIDieR Checklist in Dialysis patients (N=11 studies)

Study ID (author & year);Bookmark; N*	Why (Aim)	What (intervention)	Who (providers)	How (delivery format)	Where (setting)	When & How Much	Tailoring
Cho (2012)4 N=21	"To examine the effect of the HCI on the self-care behaviour of renal dialysis patients and physiological indices"	-Introduction -Mutual goal-setting -Contracting/ re-contracting	Study researcher	Face-to-face, print	Dialysis outpatients at Seoul National University Hospital in Korea	Once a week (between 30 and 60 min) for 4 weeks	ND
Griva et al. (2018)6 N= 101	"To assess the short- and long-term effects of a practical, low-intensity SMI for HD patients who are socioeconomically disadvantaged and from a diverse ethnic background"	HED-SMART intervention: -Imparting skills and strategies to support behaviour change -Targeting previously identified needs in this population Involved incentives.	2 renal HCPs (Medical Social Worker; Renal Nurse or Renal Dietician)	Face-to-face, telephone, print	14 of the 24 dialysis centres run by the National Kidney Foundation Singapore	3 core group sessions, 1 booster session (8h) and an additional telephone follow-up call between the core curriculum and booster session	ND

Study ID (author & year);Bookmark; N*	**Why (Aim)**	**What (intervention)**	**Who (providers)**	**How (delivery format)**	**Where (setting)**	**When & How Much**	**Tailoring**
Hare, Clark-Carter, & Foreshaw (2014)7 N=8	**“**To investigate whether the LIP intervention would be effective in improving fluid adherence among PD patients”	-CBT techniques to assist fluid self-management -Structured LIP treatment manual (including record sheets, goal-setting sheets and daily planners for fluid intake) -Relaxation CD -Homework between sessions	Supervised Trainee Health Psychologist	Face-to-face, print, CD, homework	NHS Renal Service Home Therapies Department in Wolverhampton, UK / a hospital education room	1h group (6-8 people) sessions, once a week for 4 weeks	ND
Huang et al. (2018)9 N=46	“To examine the effectiveness of SMS intervention for BP control and health behaviours”	-Self-management education (strategies to restrict salt intake) -Individual goal setting and action planning -Brief motivational interviewing -Self-management tools after intervention	The physicians, research nurses and chief nurses	Face-to-face, print	The Peking Union Medical College Hospital dialysis centre	5 weeks intervention, 3 45-min group sessions (8-10 patients each), once per week before dialysis	“Tailored to educating and motivating patients”

Study ID (author & year);Bookmark; N*	**Why (Aim)**	**What (intervention)**	**Who (providers)**	**How (delivery format)**	**Where (setting)**	**When & How Much**	**Tailoring**
Kauric-Klein, Peters, & Yarandi (2017)12 N=59	"To determine whether an educative, self-regulation intervention would improve BP self-efficacy and whether increased BP self-efficacy was associated with improved BP self-care outcomes, leading to improved BP control"	-Education sessions -Self-regulation counselling	A certified nurse practitioner	Face-to-face, print	6 HD units in Southeast Michigan	2 BP education, individually focused (10-15 min) sessions, followed by 12 weeks of weekly (10-15 min) self-regulation counselling related to participants' BP self-monitoring	Not specified but IG received individualised counselling

Study ID (author & year);Bookmark; N*	Why (Aim)	What (intervention)	Who (providers)	How (delivery format)	Where (setting)	When & How Much	Tailoring
Lee et al. (2020)[13] N=28	"To investigate the longitudinal effect of participating in an SMP on renal function control in patients receiving HD"	-Experience sharing of peers or other patients -Provision of manuals and data -Development of a consultation framework -Application of self-confidence and empowerment skills	Nurses or case managers	Face-to-face, video, print	HD centre of a teaching hospital	1 month, once every week for 100 min (including a 90-min group discussion and a 10-min film), small groups (10-15 patients)	Not specified but "centred on the patient's problems to encourage the patients to develop personal objectives"

Study ID (author & year);Bookmark; N*	**Why (Aim)**	**What (intervention)**	**Who (providers)**	**How (delivery format)**	**Where (setting)**	**When & How Much**	**Tailoring**
Liu et al. (2016)[15] N=43	”To investigate the effects of a knowledge-attitude-behaviour health education model on the acquisition of disease-related knowledge and self-management behaviour by patients undergoing MHD”	-Definitive information and education (including written materials, lectures and time to talk with the nursing staff)	Nursing staff and the panel of experienced physicians and experts in HD	Face-to-face, print, telephone	The Second Affiliated Hospital of Harbin Medical University	5 groups (each of approximately the same size); discussions were conducted every 2 weeks	Not specified but “patients received individualised information and support if necessary”

Study ID (author & year);Bookmark; N*	**Why (Aim)**	**What (intervention)**	**Who (providers)**	**How (delivery format)**	**Where (setting)**	**When & How Much**	**Tailoring**
Luo et al. (2019)16 N=64	"To apply MDT based on 5E's renal rehabilitation to patients undergoing PD and verify its efficacy in improving patients' self-management ability and reducing the incidence of PD"	MDT care based on 5E's renal rehabilitation (Encouragement, Education, Exercise, Employment, and Evaluation) on a self-management level	Nursing-led MDT	Face-to-face, print, telephone	The PD Centre of Nephrology Department in the First Affiliated Hospital of Guangxi Medical University in the Guangxi Zhuang autonomous region, China	Activities once a month; telephone and outpatient follow-up as frequently as the CG; attended PD centre once 3 months; home visit programme once 3 months	Not specified but "individualised dietary prescriptions"
Motarri et al. (2012)18 N=25	"To investigate the effect of empowerment on self-care self-efficacy, QoL, and clinical and laboratory indicators in ESKD patients"	-Individual counselling (goal setting and problem-solving) -Group counselling (stress management, coping strategies, social support and motivation)	The second author, nurse	Face-to-face; print	The Boo Ali Sina Dialysis Center, Shiraz, Iran	6 weeks, 4 individual and 2 group counselling sessions (2 sessions for 1.5-2h)	ND

Study ID (author & year);Bookmark; N*	**Why (Aim)**	**What (intervention)**	**Who (providers)**	**How (delivery format)**	**Where (setting)**	**When & How Much**	**Tailoring**
Sevick et al. (2016)21 N=93	"To evaluate the efficacy of behavioural counselling combined with technology-based self-monitoring for sodium restriction in HD patients"	BalanceWise Study intervention: -6 educational modules on the HD diet -Technology-based self-monitoring -SCT-based behavioural counselling -Diet monitoring	Study dietitian	Laptop computer, face-to-face	3 dialysis chains comprising 17 dialysis units in Western Pennsylvania	1-to-1 counselling twice a week during the first 8 weeks; weekly in weeks 9-12; and every other week during weeks 13–16	ND
Shad et al. (2018)22 N=29	"To determine the effectiveness of a new self-care programme, based on Orem's model, in life satisfaction of HD patients"	-Self-care programme based on Orem's model of self-care -Relevant nursing and medical literature ("supportive educational nursing system")	Nurses	Face-to-face, telephone	Zabol Special Diseases Centre	6 sessions (30-45 min); telephone follow-up for one month, once a week	ND

*N=Nr. of participants in the IG. *BP* Blood Pressure; *CBT* Cognitive Behavioural Therapy; *CD* Compact Disk; *CG* Control Group; *CKD* Chronic Kidney Disease; *ESKD* End Stage Renal Disease; *HCI* Health Contract Intervention; *HD* Haemodialysis; *HED-SMART* Haemodialysis Self-Management Intervention Randomised Trial; HCPs Healthcare Professional; *IG* intervention Group; *LIP* Liquid Intake Programme; *MDT* Multidisciplinary Team; *ND* No Data; *NHS* National Health Service; *PD* Peritoneal Dialysis; *QoL* Quality of Life; *SCT* Social-Cognitive Theory; *SMP* Self-Management Programme; *SMS* Self-Management Support; *UK* United Kingdom.

Appendix WW

Characteristics of the Study Outcomes and Results

The following Tables are presented below:
Table WW1 Outcomes of interest in the included studies - non-dialysis patients (N=12)
Table WW2 Results for included outcomes- non-dialysis patients (N=11)
Table WW3 Outcomes of interest in the included studies - dialysis patients (N=12)
Table WW4 Results for included outcomes - dialysis patients (N=11)

Table WW1

Outcomes of Interest in the Included Studies - Non-Dialysis Patients

Study (non-dialysis patients; N=12)	**Outcome (assessed time-point)**
Barahimi et al. (2017) 1	eGFR (6 months)
Blakeman et al. (2014) 2	BP, HRQoL, anxiety, self-care activities (6 months)
Chen et al. (2011) 3	eGFR, CKD knowledge [-*Note that*: the study assessed CKD knowledge using a standardised checklist before and after the intervention, but it was not included as their primary or secondary outcome] (12 months)
Flesher et al (2011) 5	eGFR, BP (12 months)
Humalda et al. (2020) 10	BP, HRQoL, self-management skills (9 months)
Ishani et al. (2016) 11	Adverse events [-primary endpoints: death, hospitalisation, emergency department visits, or admission to skilled nursing facilities] (12 months)
Li et al. (2020) 14	eGFR, self-efficacy, self-management, weight (BMI), QoL (90 days)
Meuleman et al. (2017) 17	Self-efficacy, HRQoL, weight, BP (6 months)
Nelson et al. (2018) 19	Patient activation, HRQoL, eGFR, BP, weight (BMI) (12 months)
Nguyen, Douglas, and Bonner (2019) 20	CKD self-management, kidney disease knowledge, self-efficacy, HRQoL, BP (16 weeks)
Teng et al. (2013) 23	Renal protection knowledge, weight (BMI) (12 months)
Wu et al. (2018) 24	eGFR, BP, anxiety and depression, self-efficacy, and self-management (3 months)

BMI Body Mass Index; *BP* Blood Pressure; *CKD* Chronic Kidney Disease; *eGFR* estimated Glomerular Filtration Rate; *HRQoL* Health-Related Quality of Life; Quality of Life.

Table WW2

Results for Included Outcomes- Non-Dialysis Patients

Non-dialysis population (N=12)

Outcome of interest	**Population**	**Results:** 🟢 **- outcome improved post-intervention** 🔴 **- outcome worsened post-intervention** 🟡 **- outcome unchanged post-intervention** 🟣 **- outcome had mixed results (some improved/some worsened/some did not change)**
Adverse events	CKD 3-5 (eGFR less than 60 mL/min/1.73 m^2)	**Ishani et al. (2016)** 🟡 "At 1 year, the primary outcome of death, hospitalization, emergency department visits, or admission to a skilled nursing facility occurred for 70(46.7%) patients in the CG and 208(46.2%) in the IG(P=0.9). The unadjusted HA for the primary endpoint in the IG compared to the CG was 0.98 (95%[CI], 0.75- 1.29)" "There was no difference between groups for any component of the primary outcome: all-cause mortality (HR, 1.46; 95% CI, 0.42-5.11), hospitalisation (HR, 1.15; 95% CI, 0.80-1.63), emergency department visits (HR, 0.92; 95% CI, 0.68-1.24), or nursing home admission (HR, 3.07; 95% CI, 0.71-13.24)"
eGFR	CKD 3-5 (eGFR less than 60 mL/min/1.73 m^2)	**Barahimi et al. (2017)** 🟢 "It should be noted that the average GFR changes in the IG was 7.5 ± 8.9 mL/min/1.73 m^2, while it was -2.3 ± 8.5 mL/min/1.73 m^2 for the CG, indicating an improvement in kidney function in the IG compared to the CG (P < .001), while progress was observed in CKD among individuals in the CG. The difference in GFR changes between the two groups remained significant after adjustment for confounding factors" The findings of this study showed that: "e-learning leads to a significant difference between the CG and the IG in terms of kidney function"
	CKD 3-5 ("incidental CKD")	**Chen et al. (2011)** 🟢 "The absolute eGFR was significantly higher in patients in the IG (29.11±20.61 mL/min 1.73 m^2); CG (15.72±10.67 mL/min1.73 m^{-2}; P < 0.05), which suggests a slowdown in the progression of CKD in the IG group"

	CKD (eGFR of 20-60 mL/minute for ≥3 months)	**Flesher et al. (2011)** 🟠 “Overall, the eGFR declined by an average of 1.2% annually within the IG, whereas in the CG declined by 11.2% overall annually” “Although more improved in the IG than the CG, results did not show the significance for individual participants”
	CKD stages 1-4	**Li et al. (2020)** 🟢 “The eGFR of the IG was significantly higher than that of the CG. In other words, the decline in eGFR was significantly slower in the IG (–0.56 vs –4.58 mL/min/1.73 m^2)”
	CKD (a urine albumin-to-creatinine ratio ≥30 mg/g)	**Nelson et al. (2018)** 🟠 No significant differences were observed. Mean difference=4.7 (95% CI=-0.5 to 9.9); p=0.08.
	CKD 3b-5 (patients with pre-ESRD)	**Wu et al. (2018)** 🟠 No significant difference in eGFR; R^2= 0.822 (0.802)
BP	CKD stage 3	**Blakeman et al. (2014)** 🟢 “BP was within NICE guidance for a significantly greater proportion of patients in the IG at 6 months, relative to baseline (adjusted odds-ratio= 1.85; 95% CI = 1.25, 2.72)” “The rate of control remained stable in the IG over the 6 months, but dropped very considerably in CG, suggesting that the effect of the intervention was to help patients maintain, but not increase BP control. Mean SBP and DBP in IG changed very little over the 6 months (from 131.6 to 131.5 and 73.6 to 73.4 respectively), but increased in CG (129.0 to 135.2 and 73.4 to 74.5 respectively)”
	CKD (eGFR of 20 to 60 mL/minute	**Flesher et al. (2011)** 🟢 “BP data changes were noted for individuals, and average changes in BP were noted for both the CG and IG. The mean baseline BP for the CG was 139.5/76 mm Hg, and at the third measure, the mean BP was 143.7/74.5 mm Hg (13%/22% change from baseline average). For the IG, the mean baseline BP was

for ≥3 months)	138.9/78.3 mm Hg and this reduced to 126.6/69.4 mm Hg (29%/211% change from baseline average)”
CKD stage 1-4	**Humalda et al. (2020)** 🟢 After 3 months intervention phase: “BP decreased from baseline, without between-groups differences at 3 months and 9 months post-baseline” “There was a concomitant decrease in SBP (from 140±16 to 131±14 mm Hg) and DBP (from 84±9 to 80±9 mm Hg) in the IG; the estimated marginal mean changing from 140±3 to 132±3 mm Hg (P<0.001 for within-group difference” “In comparison, the change in SBP in the CG (from 139±3 to 136±3mm Hg) was not statistically significant (P=0.2 for within-group difference). The mean difference in SBP across groups was −4.7 (95% CI, −10.7 to 1.3) mm Hg (P=0.1)” (After 6 months maintenance phase: “a decrease in SBP was observed (from 140±16 at baseline to 131±14 mm Hg at 9 months post-baseline) in the IG. The estimated marginal mean changed from 140±3 to 132±3 mm Hg (P<0.001 for within-group difference). In the CG, there was a nominal decrease in SBP from 139±3 to 135±3 mm Hg (P=0.1 for within-group difference). The mean difference in SBP across groups was −4.3 (95% CI, −10.2 to 1.7) mm Hg (P=0.2)”)
CKD (a urine albumin-to-creatinine ratio ≥30 mg/g)	**Nelson et al. (2018)** 🟡 No significant difference was found in BP. SBP= -2.9 (95% CI=-8.6 to 2.8); p= 0.32; DBP=-4.6 (95% CI=-12.3 to 3.1); p=0.24.
CKD 3-5 (not receiving dialysis)	**Nguyen, Douglas, and Bonner (2019)** 🟡 “There was no change found between groups over time for SBP (F=1.15, p=0.28) and DBP (F=0.19, p=0.66)”
CKD 1-4 (kidney function (eGFR)≥20	**Meuleman et al., (2017)** 🟢 🟣 **-no significant differences in ambulatory BP, but differences were reported in SBP and DBS** “No significant differences in ambulatory BP measurements were found at the 6- 6-month follow-up, but several other differences were observed”. “Compared to regular care only, the intervention resulted in -7.3

	mL/min/1.73 m^2)/ Hypertension	(95% CI, -12.7 to -1.9) and -3.8 (95% CI, -6.9 to -0.6) mmHg mean changes in systolic and diastolic office BPs, respectively”
	CKD 3b-5 (patients with pre-ESRD)	**Wu et al. (2018)** 🟡 No significant difference in BP; SBP - R^2= 0.305 (0.217); DBP - R^2= 0.260 (0.166)
HRQoL/ QoL	CKD stage 3	**Blakeman et al. (2014)** 🟢 “Mean HRQoL was significantly higher for the IG (adjusted mean difference=0.05; 95% CI=0.01, 0.08)” “There was an increase in mean score for IG, compared to no change in the CG mean”
	CKD stages 1-4	**Humalda et al. (2020)** 🟢 “At baseline, the PHS score was similar between groups (P=0.9). After the intervention phase, this score was higher in the IG compared with the CG (P=0.04); this difference remained after the maintenance phase (P=0.01). At baseline, the MHS score was similar between groups (P=0.8) and remained so after the intervention phase (P=0.1). After the maintenance phase, the IG reported higher MHS scores than CG (P=0.01)”
	CKD 1-4 (kidney function (eGFR)≥20 mL/min/1.73 m^2)/ Hypertension	**Meuleman et al., (2017)** 🟡 At 3 months: “no significant differences between groups were detected in HRQoL” At 6 months: “no significant differences between groups were detected in HRQoL”

	CKD (a urine albumin-to-creatinine ratio≥30 mg/g)	**Nelson et al. (2018)** 🟢 🟣 **- no significant difference in the physical score of the SF-12 Health Survey measure, but significant difference in the mental score of the SF-12 Health Survey measure** "The average Short-Form 12 Health Survey mental score increased by 5.0 more points (95% CI, 1.8 to 8.2; P=0.002) in the IG than in the CG. None of the remaining differences in clinical measures were statistically significant"
	CKD 3-5 (not receiving dialysis)	**Nguyen, Douglas, and Bonner (2019)** 🟢 **"**There were no differences in mean scores for HRQoL at baseline. However, at 16 weeks compared with the CG, the IG reported improved HRQoL with medium effect sizes for both PCS (mean difference= 6.91, 95% CI= 1.22–12.60, d= 0.72) and MCS (mean difference= 7.83, 95% CI= 1.88–13.78, d= 0.59)"
	CKD stages 1-4	**Li et al. (2020)** 🟢 "Kidney Disease QoL scores were higher in the IG (mean 293.16, SD 34.21 vs mean 276.37, SD 32.21; P=.02)."
Psychological distress (anxiety and/or depression)	CKD stage 3	**Blakeman et al. (2014)** 🟡 HADS Anxiety: "no noticeable increase in anxiety" "Adjusted mean difference^2 (95% CI): -0.51 (-1.05, 0.02); p value^2: 0.060"
	CKD 3b-5 (patients with pre-ESRD)	**Wu et al. (2018)** 🟢 🟣 **- a significant difference in the depression scale but not on the anxiety scale** HADS Anxiety and Depression: "The average score of the IG was 2.39 (SD=2.71), lower than that of the CG (score=4.25, SD=2.88), and the difference between the two groups was statistically significant (F=5.44, P=0.022, partial eta^2=0.065)"
CKD self-management	CKD 3b-5 (patients with pre-ESRD)	**Wu et al. (2018)** 🟢 "The average score for self-management in the IG was 89.14 (SD= 9.45), higher than that in the CG (score= 63.87, SD = 13.66), and the difference was also statistically significant (F= 18.35, P< 0.001, partial eta^2= 0.190)"
	CKD stages 1-4	**Humalda et al. (2020)** 🟡 "At baseline, PIH scores were similar between groups (P=0.1). Likewise, after the intervention and maintenance phases, no significant between-group differences in PIH scores were observed (P=0.6 and P=0.5, respectively)"

	CKD stages 1-4	**Li et al. (2020)** 🟢 “The baseline self-management scores showed no significant difference between the IG and CG. However, after the 90-day intervention, self-management scores were significantly higher in the IG, and this difference was evident for all 4 subscales”
	CKD stage 3	**Blakeman et al. (2014)** 🟢 Self-care activities: “The IG reported significantly higher levels of self-care activity at 6 months compared to CG (adjusted mean difference=0.23; 95% CI=0.04, 0.41)”
	CKD 3-5 (not receiving dialysis)	**Nguyen, Douglas, and Bonner (2019)** 🟢 “Overall, the effect of the intervention on self-management behaviour between groups over time was significant (F=178.84, p< 0.001). Although there was no difference in mean scores for self-management at baseline, there was a large improvement in the IG by week 8 (mean difference=12.44, 95% [CI]=7.48–17.40, d=0.84) and a further improvement by week 16 (mean difference=18.13, 95% CI=13.14–23.11, d=1.25)”
Self-efficacy	CKD 3-5 (not receiving dialysis)	**Nguyen, Douglas, and Bonner (2019)** 🟢 “The overall intervention effect on self-efficacy between groups over time was significant (F=40.81, p<0.001). There was no difference in self-efficacy scores at baseline, which remained unchanged in the CG over weeks 8 and 16. By contrast, the IG had increased in self-efficacy scores at week 8 (mean difference=1.02, 95% CI=0.49–1.55, d=0.64) and a larger increase after 16 weeks (mean difference=1.43, 95% CI=0.90– .96, d=0.96)”
	CKD 1-4 (kidney function (eGFR)≥20 mL/min/1.73 m^2)/ Hypertension	**Meuleman et al., (2017)** 🟢 At 3 months: “there was a 0.5 (95% CI, 0.1-0.9) mean increase in self-efficacy score in the IG compared to the CG” At 6 months: “there was a 0.5 (95% CI, 0.0-0.9) mean increase in self-efficacy score in the IG compared to the CG”

	CKD stages 1-4	**Li et al. (2020)** 🟢 🟣 **- one self-efficacy subscale showed no significant difference** **“**Before the intervention, there was no significant difference in the mean self-efficacy scores between the IG and CG; however, after the 90-day intervention, self-efficacy scores were significantly higher in the IG. Among the self-efficacy subscales, only the infection prevention subscale showed no significant difference between groups. In the other 7 subscales, the IG showed significant improvement, especially in blood sugar or BP, control, partnership, and lifestyle”
	CKD 3b-5 (patients with pre-ESRD)	**Wu et al. (2018)** 🟢 Pre-test before intervention: “Before the intervention, only self-efficacy showed a significant difference between the two groups and there was no significant difference in the other indicators. The average total score for self-efficacy for all on the pre-test was 115.29 (SD=60.33). The average total score for self-efficacy in the IG was 131.33 (SD=54.04), higher than that in the CG (score=104.51, SD=62.33). This statistically significant difference (t=−2.35, P=0.02) indicated that the IG had greater self-confidence in the control of CKD than the CG before the intervention. After intervention: “The average score for self-efficacy in the IG was 220.5 (SD=20.44), higher than that in the CG (score=127.46, SD=61.9), and the difference was statistically significant (F=44.42, P < 0.001, partial eta^2=0.36)”
Patient Activation	CKD (a urine albumin-to-creatinine ratio ≥ 30 mg/g)	**Nelson et al. (2018)** 🟢 “The mean (SD) activation scores at baseline among those completing the study were 64.3 (15.3) and 61.1 (21.2) in the CG and IG, respectively. After 12 months, the mean scores were 62.9 (17.1) and 70.3 (21.6), respectively. After adjusting for baseline scores, the average activation score was 8.7 points higher (95% confidence interval [95% CI], 1.9 to 15.5; P=0.01) in the IG than in the CG, showing a statistically significant beneficial effect of the intervention on the primary outcome. Moreover, the odds that participants randomised to the IG had a post-study activation of level 3 or higher was 4.8 times as high as in those in the CG (95% CI, 1.4 to 16.7; P=0.01) after controlling for their baseline activation level”
Weight	CKD stages 1-4	**Li et al. (2020)** 🟡 “There was no difference in baseline body weight in the CG and IG (P=.84). The baseline BMI and body fat percentage levels were similar between the two groups (P=.73 and P=.51, respectively). At the end of the study, both groups showed modest weight gains with no differences between groups (P=.89). There were no differences in body composition (body fat percentage, basal metabolic rate) between the two groups at the end of the study”

	CKD 1-4 (kidney function (eGFR)≥20 mL/min/1.73 m^2)/ Hypertension	**Meuleman et al., (2017)** 🟢 At 3 months: “the IG had a reduction in body weight compared to the CG (mean change, -1.5 [95% CI, -2.7 to -0.3] kg)” At 6 months: “There was a reduction in body weight in the IG compared to the CG (mean change, -1.7 [95% CI, -2.9 to -0.5] kg)”
	CKD (a urine albumin-to-creatinine ratio ≥ 30 mg/g)	**Nelson et al. (2018)** 🟢 “Mean (SD) BMI declined by 0.2 (1.9) kg/m^2 in the CG and 1.3 (2.1) kg/m^2 in the IG for an average decline that was 1.1 kg/m^2 (95% CI, 0.3 to 1.9; P=0.01) greater in the IG than in the CG after adjusting for baseline BMI”
	CKD 1-3	**Teng et al. (2013)** 🟠 No significant changes (ND) in weight
CKD knowledge	CKD 3-5 (“incidental CKD”)	**Chen et al. (2011)** 🟢 “IG had significantly improved CKD knowledge compared with CG after the 12-month study period (SMS, 10.13±2.49 points and non-SMS, 5.51±3.22 points; P < 0.001”
	CKD 3-5 (not receiving dialysis)	**Nguyen, Douglas, and Bonner (2019)** 🟢 “Compared with the CG, participants in the IG had improvements in kidney disease knowledge over time (F=226.89, p<0.001)” “While knowledge scores were similar at baseline and remained stable in the CG, there was a large improvement in the IG by week 8 (mean difference=5.71, 95% CI=4.80–6.62, d=2.15) and sustained improvement by week 16 (mean difference=7.43, 95% CI=6.50–8.36, d=2.86)”
	CKD 1-3	**Teng et al. (2013)** 🟢 “Over time, there were significant differences in both groups in renal function protection knowledge. The 9-month (p= .008) and 12-month (p = .004) renal function protection knowledge scores were higher than those at 6 months for both groups. The IG showed a significant trend (p= .001) in increasing mean renal function protection knowledge compared with no such trend in the CG”

BMI Body Mass Index; *BP* Blood Pressure; *CG* Control Group; *CI* Confidence Interval; *CKD* Chronic Kidney Disease; *DBP* Diastolic Blood Pressure; *eGFR* estimated Glomerular

Filtration Rate; *ESRD* End Stage Renal Disease; *HA* Hazard Ratio; *HADS* Hospital Anxiety and Depression Scale; *HRQoL* Health-Related Quality of Life; *IG* intervention Group; *MHS* Mental Health Summary; *PHS* Physical Health Summary; *PIH* Partners In health; *QoL* Quality of Life; *SBP* Systolic Blood Pressure; *SD* Standard Deviation; *SMS* Self-Management Support.

Table WW3

Outcomes of Interest in the Included Studies - Dialysis Patients

Study (dialysis patients; N=11)	**Outcome (assessed time-point)**
Cho (2012) **4**	Self-care behaviour, the mean weight gain (4 weeks)
Griva et al. (2018) **6**	IDWG, self-efficacy, self-management skills (9 months)
Hare, Clark-Carter, and Foreshaw (2014) **7**	Weight, BP, psychological well-being, QoL (6 weeks; and 16-week follow-up IG only)
Huang et al. (2018) **9**	BP, consistency of HBPM/ self-management (6 months)
Kauric-Klein, Peters, and Yarandi (2017) **12**	BP self-efficacy (in relation to BP self-care outcomes), BP self-care outcomes including IDWG and BP (12 weeks)
Lee et al. (2020) **13**	eGFR, IDWG (9 months)
Liu et al. (2016) **15**	Disease-related knowledge, self-management behaviours (6 months)
Luo et al. (2019) **16**	Self-management (12 months)
Motarri et al. (2012) **18**	Self-care self-efficacy, QoL, BP, and IDWG (6 weeks)
Sevick et al (2016) **21**	IDWGa (16 weeks)
Shad et al. (2018) **22**	Self-care behaviours (1 month)

BP Blood Pressure; *eGFR* Estimated Glomerular Flirtation Rate; *HBPM* Home Blood Pressure Monitoring; *IDWG* Interdialytic Weight Gain; *IDWGa* Average Daily Interdialytic Weight Gain; *QoL* Quality of Life.

Table WW4

Results for Included Outcomes- Dialysis Patients

Dialysis population (N=11)

Outcome of interest	**Population**	**Results:** 🟢 **- outcome improved post-intervention** 🔴 **- outcome worsened post-intervention** 🟡 **- outcome unchanged post-intervention** 🟣 **- outcome had mixed results (some improved/some worsened/some did not change)**
CKD self-management	Dialysis outpatients (receiving dialysis twice or 3 times a week for at least 3 months)	**Cho (2012)** 🟢 “Significant differences were observed between the two groups in the results of analysis using age and gender as covariates after the application of the HCI (F=7.19, P=0.011). Among the self-care behaviour categories, significant differences were observed between the two groups in diet (F=6.19, P=0.017), exercise and rest (F=12.90, P=0.001), and measurement of BP and body weight (F=8.40, P=0.006)
	Patients on HD for a minimum of 6 months	**Griva et al. (2018)** 🟣 “There were no significant interaction effects for self-monitoring and insight (F=2.20, p=0.1), or constructive attitudes and approaches (F=0.07, p=0.9)” **But**: “There were significant time-by-group interaction effects for skills and technique acquisition (F=3.60, p=0.2), health services navigation (F=5.78, p=0.001)”
	CKD stage 5; patients on MHD (duration >3 months)	**Liu et al. (2016)** 🟢 “Self-management behaviour scores for the CG and IG did not show a significant difference prior to intervention (P>0.05). However, self-management behaviour scores for both groups were significantly higher after, compared with before, intervention (P<0.05). Furthermore, post-intervention scoring for the IG was higher than that for the CG (P<0.05)”

	PD patients (regularly continuous ambulatory PD for at least 3 months)	**Luo et al. (2019)** 🟢 “There were no significant differences between the 2 groups in the 5 subscales at the baseline measures (p > 0.05). However, after 12 months of intervention, the IG gained higher scores in the 5 subscales while the CG declined. And the IG improved statistically significantly compared with the CG on “solution bag replacement (t=3.103, p=0.002),” “troubleshooting during operation (t=3.978, p≤0.001),” “diet management (t=3.201, p=0.002)” and “emotion management and return to social life (t=3.552, p=0.001)” subscales”
	HD patients (a minimum of 6 months of dialysis, 3 times a week	**Shad et al. (2018)** 🟢 “Before applying the intervention, the two groups did not differ significantly with regard to the mean score of life satisfaction (P=0.921) and self-care behaviours (P=0.172). Nevertheless, the results of this test suggested a significant difference in the mean values of life satisfaction between the IG and CG after implementing the Orem-based self-care program (P<0.001), so that the average score of life satisfaction in the IG increased from 16.12 to 41.18; statistically, this incase was significant (P<0.001). This change was based on Cohen’s kappa coefficient of 2.25”
	Patients receiving regular HD 3 times per week for at least 3 months	**Huang et al. (2018)** 🟢 “During the follow-up period, 67% to 80% of the patients receiving SMS regularly monitored their BP at home (P < 0.0001); however, for the patients receiving CG, there were no significant changes in the consistency of HBPM (P > 0.05). Patients in the IG had greater increases in the regular performance of HBPM than those in the CG (P < 0.05)”
Self-efficacy	Patients on HD for a minimum of 6 months	**Griva et al. (2018)** 🟢 “There were significant time-by-group interaction effects for disease-related self-efficacy (F=2.66, p=0.5), and dialysis treatment-related self-efficacy (F=6.63, p<0/001)”

	HD patients (diagnosed with ESRD and treated with HD for at least 3 months)	**Motarri et al. (2012)** 🟢 “A significant change was observed between the groups in terms of stress reduction as well as the decision-making dimension and overall self-efficacy scores”
	HD patients (a 4-week average pre-HD BP>150 mmHg or DBP>90 mmHg)	**Kauric-Klein, Peters, & Yarandi (2017)** 🟣 “No significant improvement in **BP self-efficacy** from baseline to 12 weeks within groups (F=0.51, p=.48) or between the two groups (F=3.5, p=.06).” “Although the intervention did not have a significant effect on self-efficacy in the IG, BP self-efficacy scores were found to be significantly related to a number of BP self-care outcomes at both baseline and 12 weeks in the total sample (N=118). Higher BP self-efficacy scores were moderately related to lower average fluid gains at baseline (r=−.35, p<.001) and 12 weeks (r=−.32, p<.001). BP self-efficacy scores were significantly related to BP medication adherence at 12 weeks (r=−.33, p<.001). Increased BP self-efficacy scores were also significantly related to decreased missed HD treatments at 12 weeks (r=−.36, p<.001). BP self-efficacy scores were also related to lower average diastolic BPs at baseline (r=−.21, p<.001) and at 12 weeks (r=−.318, p<.001). Decreased sodium intake was found to be related to improved self-efficacy scores at baseline in the IG (r=−.60, p<.001)”
CKD knowledge	CKD stage 5; patients on MHD (duration >3 months)	**Liu et al. (2016)** 🟢 “There was no obvious difference in the extent of disease-related knowledge for each group prior to intervention. However, at 6 months postintervention, disease-related knowledge scores were significantly higher for patients in the IG, compared with their baseline levels, and also compared with scores observed in the CG (P<0.05 in each case)”

Weight/ IDWG	Dialysis outpatients (receiving dialysis twice or 3 times a week for at least 3 months)	**Cho (2012)** 🟢 “After the HCI, there was a statistically significant difference in mean weight gain between the two groups (F=6.26, P=0.017)”
	HD patients (a 4-week average pre-HD BP>150 mmHg or DBP>90 mmHg)	**Kauric-Klein, Peters, & Yarandi (2017)** 🟡 “There were no significant differences between or within groups in average fluid gains at 12 weeks” [***<u>But, note that</u>***: BP self-efficacy scores were found to be significantly related to a number of **BP self-care outcomes** at both baseline and 12 weeks in the total sample. “Higher BP self-efficacy scores were moderately related to lower average fluid gains at baseline (r = −.35, p < .001) and 12 weeks (r = −.32, p < .001)”]
	Patients on HD for a minimum of 6 months	**Griva et al. (2018)** 🟢

	“A significant time-by-group interaction effect for mean IDWG (F=6.32, p=0.001) and percentile IDWGs (F=4.59, p=0.005). Post hoc comparisons indicated significant IDWG reductions from baseline (T1) to all follow-up assessments in HED-SMART: at 1 week (T2; pmIDWG<0.001; d=-0.59; p%IDWG<0.001; d=-0.53), 3 months (T3; pmIDWG=0.004; d=-0.42; p%IDWG=0.01; d=0.37) and 9 months post-intervention (T4) for mean (pmIDWG=.002; d=-0.46) and percentile IDWGs (p%IDWG=0.002; d=-0.46). Usual care controls had worsened only at T3 (p=0.02 d=0.29 for mean IDWGs) relative to baseline. Percentile IDWGs for controls remained unchanged (with an improvement between T3 and T4). The reductions in IDWGs were significant relative to usual care at both T2 (pmIDWG=0.04; d= -0.28; p%IDWG=.02; d=-0.31) and at T3 (pmIDWG=0.02; d=-0.31; p%IDWG=0.02; d=-0.32) for mean IDWGs and percentile IDWs respectively. Although there were no longer significant differences between conditions in IDWGs at T4, the patterns differed between groups. Both mean and percentile IDWGs relapsed to baseline levels for usual care (p<.01) whilst for HED-SMART IDWGs remained significantly lower than baseline showing sustained effects at both T3 and T4. The study considered IDWG% of ≥4.0% weight to be indicative of poor fluid control. At baseline 42.4% of participants in the HED-SMART program and 46.6% of those in usual care had IDWG% of ≥4.0%. Post-intervention, 32.7% vs. 48.1%; 30.6% vs. 53.4%, 30.6% vs.45.1% of HED-SMART compared to usual care had high IDWG%, at T2, T3 and T4 respectively. Group effects were significant at all follow up assessments (T2, p=0.02; T3 p=0.001; T4 p=0.03)”
Patients receiving PD for ≥3 months and identified as fluid non-adherent	**Hare, Clark-Carter, & Foreshaw (2014)** 🟡 “No significant difference in weight between the IG and CG at either time-point”
ESRD patients receiving HD 3 times a week	**Lee et al. (2020)** 🟣

	“The IDWG was significantly different in the group main effect (B=0.16, SE=0.23, p<.001), suggesting that compared with the CG, the IDWG was significantly different in the group main effect (B=0.16, SE=0.23, p<.001) and significantly decreased in the IG” “the intervention could effectively control the weight change between dialysis sessions for up to 9 months (B=−1.34, SE=0.30, p<.001)”. **However**, it was not significantly different in the time main effect after the first post-test compared with the pre-test (p=.113). Compared with the pre-test, the IDWG was significantly different in the group main effect (B=0.16, SE=0.23, p<.001) after the second post-test and showed a significant decrease (B=0.52, SE=0.16, p=.001). Compared with the pre-test, the IDWG was significantly different in the group main effect (B=0.16, SE=0.23, p<.001) and showed a significant decrease after the third post-test (B=0.65, SE=0.23, p=.004), suggesting that compared with the pre-test, the IDWG was significantly different in the group main effect (B=0.16, SE=0.23, p<.001) and significantly decreased after the second post-test (at 6 months) and the third post-test (at 9 months). The IDWG was significantly different in the group main effect (B=0.16, SE=0.23, p<.001) and was significantly different in the group-time interaction effect after three post-tests. Compared with the pre-test, the IDWG was significantly different in the group main effect (B=0.16, SE=0.23, p<.001) and significantly decreased after the first post-test (B=−1.17, SE=0.26, p<.001); compared with the pre-test, which after the second post-test significantly decreased (B=−1.08, SE=0.22, p<.001); compared with the pre-test, that after the third post-test significantly decreased (B = −1.34, SE = 0.30, p < .001), suggesting that compared with the pre-test, the IDWG was significantly different in the group main effect (B = 0.16, SE = 0.23, p < .001) and significantly decreased after three post-tests (at 3, 6, and 9 months)”
HD patients (HD for at least 3 months)	**Sevick et al. (2016)** ● “No treatment differences in time-specific IDWGAs were apparent in the random effects model (p>0.79), and the linear spline analysis demonstrated no significant departure from linearity (p=0.18)”

	HD patients (diagnosed with ESRD and treated with HD for at least 3 months)	**Motarri et al. (2012)** 🟢 "Adjusted mean differences between the two groups are significant in IDWG"
eGFR	ESRD patients receiving HD 3 times a week	**Lee et al. (2020)** 🟣 "eGFR was not significantly different in the group main effect, time main effect, and group-time interaction effect" "**However**, the intervention had an effect on increasing the eGFR after 6 months (p=.05) and 12 months (p=.04)"
Psychological distress (anxiety and/or depression)	Patients receiving PD for ≥3 months, and identified as fluid non-adherent	**Hare, Clark-Carter, & Foreshaw (2014)** 🟣 "No significant differences were observed in psychological well-being" **However**, "from baseline to 6-week follow-up, eight significant differences were observed in the desired direction for HADS Anxiety and Total scores"
BP	Patients receiving PD for ≥3 months, and identified as fluid non-adherent	**Hare, Clark-Carter, & Foreshaw (2014)** 🔴 "A significant difference in systolic BP between the groups was found post-intervention; however, this was in the undesired direction; therefore, LIP was ineffective in reducing the BP of the IG significantly more than the CG. Likewise, an undesired but significant effect on diastolic BP was observed between IG and CG at the 6-week follow-up; however, this ceased to be significant following sensitivity analyses ($F_{1,11} = 1.06$; $P = 0.32$)".
	HD patients (a 4-week average pre-HD BP>150 mmHg or DBP>90 mmHg)	**Kauric-Klein, Peters, & Yarandi (2017)** 🟢 [***Note that***: the reported results are for: BP self-efficacy scores in relation to a number of **BP self-care outcomes** (including BP control) at both baseline and 12 weeks in the total sample. "BP self-efficacy scores were also related to lower average diastolic BPs at baseline ($r = -.21$, $p < .001$) and at 12 weeks ($r = -.318$, $p < .001$)"

	Patients receiving regular HD 3 times per week for at least 3 months	**Huang et al. (2018)** 🟣 “The IG showed continuous reductions in systolic BP from baseline: –9.2, 8.7, and 8.4 mmHg at 1, 3 and 6 months after the intervention, respectively (P < 0.01). Compared with the CG, the IG had a greater decrease in systolic BP at 1 month: –5.9 mmHg (P = 0.0388), **but** no significant difference was found at 3 or 6 months (P > 0.05)” “No change in diastolic BP from baseline was found in either group”
	HD patients (diagnosed with ESRD and treated with HD for at least 3 months)	**Motarri et al. (2012)** 🟢 “Adjusted mean differences between the two groups are significant in both systolic and diastolic blood pressure”
HRQoL/ QoL	Patients receiving PD for ≥3 months, and identified as fluid non-adherent	**Hare, Clark-Carter, & Foreshaw (2014)** 🟣 “No significant differences were observed in QoL, with the exception of the SF-36 subscale mental health at follow-up” **However**, “from baseline to 6-week follow-up, eight significant differences were observed in the desired direction for SF-36 Overall score, Mental Health score and subscales of Role Physical and Social Function”
	HD patients (diagnosed with ESRD and treated with HD for at least 3 months)	**Motarri et al. (2012)** 🟢 “A significant difference was found in the overall mean score of QoL and in all dimensions of the QoL between the groups.”

BP Blood Pressure; *CG* Control Group; *CKD* Chronic Kidney Disease; *DBP* Diastolic Blood Pressure; *eGFR* Estimated Glomerular Flirtation Rate; *ESRD* End Stage Renal Disease; *HADS* Hospital Anxiety and Depression Scale; *HBPM* Home Blood Pressure Monitoring; *HCI* Health Contract Intervention; *HD* Haemodialysis; *HED-SMART* Haemodialysis Self-Management Intervention Randomised Trial; *HRQoL* Health-Related Quality of Life; *IDWG* Interdialytic Weight Gain; *IDWGa* Average Daily Interdialytic Weight Gain; *IG* intervention Group; *LIP* Liquid Intake Programme; Maintenance Haemodialysis; *PD* Peritoneal Dialysis; *QoL* Quality of Life; *SBP* Systolic Blood Pressure; *SMS* Self-Management Support.

Appendix XX

GRADE Evidence Profile

GRADE Evidence Profile

Question: Self-management intervention compared to care as usual/ standard care for individuals with CKD

Certainty assessment							**Effect**	**Certainty**	**Importance**
№ of studies	**Study design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**			
Self-efficacy (follow-up: range 6 weeks to 9 months; assessed with: different, but valid and reliable measures used by the studies)									
3	randomised trials	not serious	not serious	not serious	not serious	none	SMI improves self-efficacy outcome	⊕⊕⊕⊕ High	CRITICAL
CKD self-management (follow-up: range 6 months to 9 months; assessed with: different measures used by the studies: 2 standardised measures and 1 self-administered questions)									
3	randomised trials	not serious	serious[a]	not serious	serious[b]	none	SMI may improve CKD self-management outcome	⊕⊕◯◯ Low	CRITICAL
CKD knowledge (follow-up: median 12 months; assessed with: standardised CKD knowledge checklist)									
1	randomised trials	not serious	not serious	not serious	very serious[c]	none	SMI may improve CKD knowledge	⊕⊕◯◯ Low	CRITICAL
eGFR (follow-up: median 12 months; assessed with: no data on assessment measure)									
2	randomised trials	not serious	serious[d]	not serious	serious[e]	none	SMI may improve slightly eGFR outcome	⊕⊕◯◯ Low	IMPORTANT
Adverse events									
0							No studies were found that looked at the outcome of the adverse events	-	IMPORTANT

GRADEpro GDT software (2022). *CKD* Chronic Kidney Disease; *SMI* Self-Management Intervention.

GRADE Working Group grades of evidence:

High certainty: we are very confident that the true effect lies close to that of the estimate of the effect.

Moderate certainty: we are moderately confident in the effect estimate: the true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.

Low certainty: our confidence in the effect estimate is limited: the true effect may be substantially different from the estimate of the effect.

Very low certainty: we have very little confidence in the effect estimate: the true effect is likely to be substantially different from the estimate of effect.

Explanations:

a. In 3 trials that assessed CKD self-management, the effect direction was reported as positive (in a small sample) in 1 study, and 2 studies reported no change/ mixed results (in medium samples). Given the occurrence of some inconsistency, we downgraded this domain by 1 level.

b. The total number of participants across all 3 studies was 419, thus more than 400 (a "rule of thumb"), however, 1 study assessed categorical outcome. 1 trial reported a reduction in CKD self-management outcome (in a small sample), while 2 trials reported no change/ mixed results (in medium samples). Due to the occurrence of some imprecision, we decided to downgrade this domain by 1.

c. The total number of patients included in this trial was 54 (IG=27; CG=27), which means that the small number of participants analysed will not produce enough precise information. Thus, due to insufficient information (mainly because only 1 study assessed this outcome), we decided to downgrade this domain by 2 levels. d. 2 trials assessed eGFR outcome. 1 study reported a positive effect direction (small sample size) while another study reported no change/ mixed results (medium sample size). Given the occurrence of some inconsistency in the results, we downgraded this domain by 1 level. e. The total number of participants across both studies was 179, thus less than 400 (a "rule of thumb"), not producing enough information. One trial reported a reduction in eGFR outcome, while another reported no change/ mixed results. Due to insufficient information, we decided to downgrade this domain by 1 level.

Appendix YY

Certificate of Attendance

Renal conditions: Moving on up together! 11 June 2021 – Online Study Day

Working together to manage paediatric onset renal conditions moving into adult services

Certificate of Attendance

Thank you for attending

RCPCH has approved this activity for CPD in accordance with the current RCPCH CPD Guidelines.

Appendix ZZ

Summary of the Main Findings for Each Previous Study Phase

Summary of the Main Findings for Each Previous Study Phase

Study phase	Main findings
Phase 1: Systematic literature review	-**SMIs improve self-efficacy** (high-quality evidence). Successful interventions to improve self-efficacy used multiple intervention topics, with CKD knowledge, diet, medication, and symptom management being the most common topics, presented in various diverse formats (including, a group and an individual format and/or a combination of both). Interventions included in the review were all delivered face-to-face and in print (while two studies also involved telephone contact in their mode of delivery) and accommodated by nurses or multiple providers. Finally, the theory-based (including self-regulation theory with some BCTs, empowerment counselling, and/or SCT) self-efficacy strategies employed in these successful trials included goal setting, barrier identification, and problem-solving, with the inclusion of social and peer support, and family involvement. -Based on low-quality evidence, it was established that **SMIs may improve CKD knowledge and self-management outcomes** and **may slightly improve eGFR.** -**Evidence-practice gap**: there is a lack of high-quality, person-centred, theory-based interventions aimed at improving YAs' self-management and overall health outcomes.
Phase 2 Part 1: a quantitative study	-**PCC plans:** the majority of both groups reported the absence of PCC plans and those who claimed the availability of PCC plans reported mixed opinions about their personalisation and regular updates (most acknowledging the lack of both). -**Preferences for support delivery:** the most common preference for support delivery reported by YAs was individual face-to-face sessions, during weekends, preferably in the evenings (but most YAs were flexible concerning day and time in the week), at the hospital clinic, delivered by professionals. -**Baseline characteristics** - concerning results: some YAs showed signs of moderate to severe alcohol risk, poor self-regulation of eating behaviour, low physical activity, and the presence of depression and anxiety symptoms.

Study phase	**Main findings**
	-Both groups of participants acknowledged **all 10 areas of CKD SMS** as important. The “Maintaining social and occupational roles" domain was rated as the most important by YAs. -**Statistical analysis 1:** the YAs’ level of self-efficacy was a significant predictor of their level of self-management. However, the YAs’ level of patient activation, and controlling time since diagnosis did not significantly predict their level of self-management. -**Statistical analysis 2:** there was not a significant impact of time since diagnosis across all 10 SMS areas while controlling for self-efficacy. -**Statistical analysis 3:** there was no evidence to support a difference between the mean ratings of CKD SMS of the two CKD stages groups (early-versus-late-stage). - **Statistical analysis 4:** there was no evidence to support a difference between the mean ratings of CKD SMS of the two groups of participants (YAs versus health and social care professionals).
Phase 2 Part 2: a qualitative study	-**YAs with CKD** (i*nvincible and naïve; “we are more than our condition;” “want to live a normal life”*); **advice for their peers** (*“be brave;” “keep going and keep on track;” “get support and take one step at a time”*) -**CKD and its associated impact and challenges** (i*nvisible and misjudged disability; daunting and lonely illness; lack of CKD awareness and understanding; physical and mental well-being; the transition process and taking ownership; socialising and peer pressure; acceptance of CKD; having children*) -**Challenges faced by professionals** (*engagement; limited time and resources*) -**Considerations for effective CKD self-management** (f*amily and peer support; consistency in care; effective communication and relationship with HCPs; PCC approach*) -**Improving activation** (a*dequate information; “being born with it is better than being diagnosed later on;” confident “now” but not “then;” empowerment, partnership, and respect; use of PAM and BCTs*)

BCTs Behaviour Change Techniques**;** *CKD* Chronic kidney disease; *eGFR* estimated Glomerular Filtration Rate; *HCPs* Health Care Professionals; *PAM* Patient Activation Measure; *PCC* Person-Centred Care; *SCT* Social-Cognitive Theory; *SMI* Self-Management Intervention; *SMS* Self-Management Support; *YAs* Young Adults.

Appendix AAA

Certificate of Completion of BCT-Taxonomy

BCT Taxonomy v1

Online Training

CERTIFICATE OF COMPLETION

This is to certify that the holder of this certificate has:

Completed full online training at: www.bct-taxonomy.com and has achieved coding competence in use of BCTTv1 to specify the content of complex behaviour change interventions

Certified by:

The BCTTv1 Project Team

and the UCL Centre for Behaviour Change

For further training opportunities, see www.ucl.ac.uk/behaviour-change

CBC UCL Centre for Behaviour Change

Appendix BBB

Initial Assessment of the Problem

Table BBB1

Barriers and Enablers, Descriptions with Data Extracts, Determinants, and Relevant TDF Domains

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
Target behaviour: *Participation in social activities*					
The desire for normality (*YAs with CKD*)	Barrier	All interviewees agreed that YAs want to "live a normal life." However, YAs expressed that CKD hindered their ability to live a normal life like their peers, preventing them from engaging in activities they enjoy.	*"Our aim at the end of the day is to lead as normal life as possible.. we still have to navigate all that stuff whilst still trying to be normal. And it's a lot"* YA. *"It* (CKD) *stopped me from doing more things that I'd like to do"* YA. *"They'll just want to be able to lead that kind of the same lifestyle as their peers that can be really difficult"* ST. *"We've had some young people who maybe haven't taken their medications as they should, because they just want to lead that: normal life.. and then that's cause difficulties down the line for them"* ST.	To address YAs' desire for normality, they need appropriate information and education to help them understand the potential benefits and consequences of seeking normality, challenging any negative beliefs or misconceptions about what is considered normal, and support in finding a sense of normality that aligns with their goals and values.	**Beliefs about consequences** (*Motivation/ reflective motivation*)

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
Social isolation and loneliness (*CKD and its associated impact and challenges*)	Barrier	Participants described CKD as a "daunting and lonely illness". YAs expressed feeling lonely and isolated, often without the support of friends and family.	*"When you're going through something like that and not having your friends and family for you, that is probably the biggest hurdle that you will ever face because you do feel like you're alone. So yeah, that's what I went through, and I won't wish it on anyone"* YA. *"You do feel down, and you can feel very isolated and alone"* YA.	To reduce the feelings of isolation and loneliness in YA, there is a need for activities and environments that will foster YAs' sense of belonging, encourage social engagement and participation, and help them develop and sustain meaningful social connections.	**Social/ professional role and identity** (*Motivation/ reflective motivation*)
Social judgment, stigma, discrimination, and peer pressure (*CKD and its associated*	Barrier	Participants talked about CKD as an "invisible and misjudged disability". YAs shared being judged by friends and family as they do not understand CKD and make their own	*"It's a silent disease. That's a big part of it that is the challenging part to be fair"* YA. *"Lots of them* (YAs) *talked about it being an invisible illness"* ST. *"The fact that it's seen as an old person illness, I think that kind of mental shift needs to change" "I understand that the majority of CKD patients are probably older than we are but we still do exist and we still do need support and we still are trying to live a life"* YA. *"When you're a little kid and you look*	YAs require skills to deal with social challenges, such as social judgment and discrimination, to effectively navigate their social environments. They also need skills to deal with social pressure (e.g., resisting negative peer influences) and make choices aligned	**Social influences** (*Opportunity / social environment*)

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
impact and challenges)		assumptions. Some even experienced being bullied. YAs also talked about peers pressuring them and not understanding why for example they must watch their alcohol consumption.	*different because of drug side effects, people just see that as bullying and normal kids can be bullied, yeah fair enough, but that's just one layer and then, when they see another thing that's another layer"* YA. *"Because we have this image in our society as a whole that young people are kind of like skivers and don't want to work and are happy to sit at home and do nothing and don't want to contribute to society which is far from the truth. If anything, we want to be more involved, we want to be more engaged, we want to be out there, talking to people, interacting with new members of staff that we've met gaining into a role. That stuff kind of motivates us"* YA. *"Them not understanding was really difficult. Because it is that sort of culture. So that was quite difficult when I was younger"* YA.	with their values and goals.	
Lack of CKD awareness and	Barrier	YAs shared difficulties they experienced from their peers,	*"I find it important to tell someone that I have CKD because I have to carry a card around with me just in case I have to get any medication that needs to not interfere with*	Greater public awareness of CKD, its risk factors and management, and provision of accurate and	**Knowledge** (*Capability/ psychological capability*)

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
understanding (*CKD and its associated impact and challenges*)		family, teachers, and employers who lacked an understanding of CKD and its consequences. Participants emphasised the significance of increasing CKD awareness (e.g., to allow early diagnosis) while acknowledging that constantly explaining the condition is burdening. All interviewees recognised that other diseases, such as cancer are well-known, but	*mine"* YA. *"I feel like actually if you educate people then in a way that self-help because some person could early identify themselves to maybe having kidney disease"* YA. *"But it also makes it very hard for them to be able to explain to other people and to feel that they really understand it"* ST. *"It can be hard to try and explain that, and it seems as well that the burden and the explanation is kind of put on the person to explain to the employer and you almost feel like you're defending yourself, for being ill. When you shouldn't really have to"* YA.	accessible disease-specific information to dismiss misconceptions and improve understanding among individuals and communities.	

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
		noted the evident lack of CKD awareness.			
Negative emotions (anxiety/ worry) (*CKD and its associated impact and challenges*)	Barrier	Participants highlighted the importance of mental health and many reported struggling with their mental well-being, particularly with anxiety. They also reported concerns about future uncertainty, and having had to plan the future early, particularly if they plan to have children.	*"I mean on the anxiety side of it, which is a big part of my problems, with the kidney disease, you know, to treat anxiety. I think the biggest thing is to help me to live with it, live my life"* YA. *"The mental side of it, managing your own mental state, because obviously when I was coming towards a transplant, it was very much playing in my mind on, what's life, going to be like afterwards, and just feeling horrible all the time, and then post-transplant, again it's sort of the mental side of it: great I've had a transplant, it's not functioning as I'd like and I can't do the contact sports that I love to do, so I probably say the mental side of It really"* YA. *"I think that mental health is really precarious so as well as going through all the normal developmental problems that kind of teenagers and young adults do, on top of that they've got to*	YAs need to learn how to manage their anxiety and worries about future uncertainty.	**Emotion** (*Motivation/ automatic motivation*)

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
			deal with the confinements of treatments” ST. *“They* (doctors) *said that I could die younger, and they said that is Indefinite If I’ll ever come off my medication and I’ll quite possibly need a transplant because of how young I am, which yeah it was all very daunting, it wasn’t the best appointment I could have in the world”* YA. “*I’m not so confident in the reality of living with CKD, sounds really silly because I am living with it, but like the future is quite daunting and that’s what I’m not confident with.. It’s those little questions that I get in my head now and again, and I don’t have the answers, and therefore I don’t feel confident about my future in a sense*” YA. *“It’s kind of been a ticking time bomb in the back of my head, every day, especially being a woman, we don’t really have that much time anyways. . That’s kind of always on my mind, even though, I don’t talk about it, it’s always on my mind because yeah I’m 24 now, I’m still young, but I know lots of*		

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
			people my age, my friends, who got kids and getting married" YA.		
Physical symptoms (fatigue) (*CKD and its associated impact and challenges*)	Barrier	During discussions about the physical aspect of CKD, interviewees emphasised fatigue as the most debilitating symptom restricting their physical performance.	*"I think the main thing that affected me is tiredness, that's the biggest part"* YA. *"Once I remember, I had one week off work because I just couldn't get out of bed. I was that lethargic and I couldn't drive, because I couldn't actually focus and see straight" "It's rare that I get days like that now, but when I do, I find it really hard to function"* YA.	YAs need appropriate skills and techniques to manage or alleviate fatigue symptoms to increase performance.	**Skills (physical)** (*Capability/ physical capability*)
Acceptance of CKD (*CKD and its associated impact and challenges*)	Enabler	According to professionals, YAs often face challenges in coming to terms with their diagnosis and treatment, but those who do	*"It's about acceptance, coming to terms with the fact that you've got this condition and this condition will remain for life"* ST.	YAs need to accept their condition. As per Tong et al. (2013), the acceptance of health problems and the development of an identity separate from their condition may lead to feeling a better sense of normality as reported	**Beliefs about capabilities** and **Beliefs about consequences**

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
		accept it, tend to manage it well.		in an interview study with adolescents and YAs.	(*Motivation/ reflective motivation*)
Family and peer support (*Considerations for effective CKD self-management*)	Enabler	The importance of family and peer support was discussed across all interviews by all participants.	*"I've not really had any of that and I think I'd be one of these people who, if I knew there was a focus group, at my local hospital or even anywhere really, where there are young people with the same condition or even old, I would go along once in a while and just say: yeah I need help with this, could anyone help? and just be a community"* YA. *"As much as family and loved ones care for us and try to look after us, I think there's a different aspect when you meet people who are like you. We all have our individual stories and journeys of where we are in that kind of chronic illness but I think we can relate more to each other because we've lived it"* YA.	YAs need to develop skills to make connections with others who share similar experiences. Participating in peer support programs can facilitate connections, provide opportunities to learn coping strategies, receive emotional support, and exchange advice, which may improve confidence in participation in social activities.	**Social influences** (*Opportunity / social environment*)
Living in a rural area (*Considerations for*	Barrier	Participants acknowledged the availability of support, including	*"A renal social worker would be great and again some areas have these, some areas don't, which is why I think it needs to be nationalised. At the moment, it's a very*	Living in rural areas restricts YAs from engaging in many activities. Opportunities	**Environmental context and resources**

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
effective CKD self-management)		peer support, and emphasised its importance, however, they noted that it was location-dependent. They identified that those who live in rural areas are disadvantaged as they do not have as many opportunities, highlighting the issue of "consistency in care" as identified in interviews.	*postcode lottery, if you live in one area and they have it, you're lucky, if you live in the other area and you don't have it, you're buggered"* YA. *"Depending on where you are, depends on what support is available in your hospital, not every hospital has a social or youth worker, or access to psychology counselling or different charities"* ST. *"I'm based over in North Wales so it's pretty sort of rural and we don't have much of that around here"* YA.	should be made available for those locally disadvantaged.	(Opportunity / physical environment)
Lifestyle restrictions (*CKD and its*	Barrier	Interviews talked about managing dietary restrictions,	*"If you've had times where you've been unwell, or you've got quite a lot of health checks, or you might get an infection that again impacts on, how you can work, and*	YAs need appropriate training, and practical guidance on managing their lifestyle restrictions,	**Skills (physical)** (*Capability/*

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
associated impact and challenges)		medications, and fluids, attending medical appointments, and dealing with time missed from school or work (e.g., due to illnesses) as demands that affect socialising opportunities.	*some employees have sick pay, some don't, so you have to rely on statutory sick pay, which is considerably less, so there can be a financial burden"* ST. *"Because of how complicated kidney disease is and all of the various treatments, medications, and diet, the impact it can have on their physical appearance, their sexual relationships all different matter of things, it's really yeah quite a complicated thing for them to wrap their head around"* ST. *"It* (medication) *makes my blood pressure drop so much that I end up having really bad days, where I can't actually function"* YA.	treatment, and medical appointments to be able to navigate these restrictions in social settings.	*physical capability)*
Effective communication and self-advocacy skills (*Considerations for effective*	Enabler	Interviewees talked about the importance of being able to self-advocate. They conveyed that if a person possesses effective communication	*"I think giving those tools to a patient and potentially even their carers and their families, those tools to self-advocate and the tools to have co-production with your renal team so you're working together as opposed to kind of being talked down to and being told what to do"* YA. "*People don't fight their thrones*" YA.	YAs need to develop communication and self-advocating skills to empower them to express their needs, concerns, and boundaries in social interactions, which consequently should enhance their confidence	**Skills (cognitive and interpersonal)** (*Capability/ psychological capability*)

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
CKD self-management)		skills, they will be able to self-advocate which consequently will reduce the burden on the renal team.		and facilitate more meaningful and supportive connections.	
PCC approach, YAs' feedback, and regular reviews (*Considerations for effective CKD self-management*)	Enabler	Staff conveyed that effective communication tailored to YAs' needs is key. Their needs are often overlooked due to their small population size, and they are often treated as older patients. Involving them in research, seeking their feedback, and providing regular reviews	*"Although they are at an early stage, they're in an adult clinic and they are kind of treated like everybody else which works for some people but doesn't work for everybody"* ST. *"They're coming into this environment which is structured, there's not much flexibility to it and they've just got to fit into a system.. I don't think we're flexible enough.. there's only a small number of YAs who attend our clinics and then there's nothing specific put together for them"* ST. "*one size doesn't fit all*" ST. "*PCC is the way forward*" ST. *"I think a lot of patients if they feel empowered and listened to, a lot of us are willing to give back also to the community because we understand this can help future generations and future children*	HCPs' mindset needs to shift to prioritise the individual's preferences, and values. Particularly, there is a need for improving HCPs' confidence in their ability to engage in PCC, promoting reflective practices for self-assessment, and encouraging a culture of consistent reviewing and adaptation based on YAs' feedback.	**Social/professional role and identity** (*Motivation/ reflective motivation*)

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
		can provide valuable perspectives to benefit future generations and support them more effectively.	*who will have to go through similar things to what I went through"* YA. *"It has to be led by young people themselves.. I think any research that looks at that's co-production, that's working with YAs that have been through it or going through it to try and help us to figure out what we can do to change, you know, is really helpful"* ST. *"Having evaluation processes can only help us to adapt and change for not doing something well or to celebrate what we are doing and put more of that into the light"* ST.		
Relationship and partnership with professionals (*Considerations for effective CKD self-*	Enabler	YAs emphasised the significance of being well-informed, actively listened to, spoken to respectfully, and establishing a relationship and partnership with HCPs, to develop	*"We will have the confidence to reach out to you and you will have that confidence to reach out to us"*. *"It empowers us because then we feel we have more control over our condition. And I think is about partnership and empowerment and having that independence and knowledge"* YA. *"It goes to that first appointment. That first time you see someone and then the initial first building blocks are basically going to be the foundation of that relationship with that*	YAs need to develop positive relationships and partnerships with HCPs to improve the patient-professional relationship, build trust, and facilitate a partnership which empowers YAs to actively participate in their care and social settings.	**Social influences** (*Opportunity / social environment*)

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
management)		the necessary confidence to effectively self-manage their condition, benefiting both patients and the system. Staff echoed this by acknowledging that empowering YAs through effective communication will enhance their confidence to self-manage, seek assistance when needed, come to terms with their condition, deal with challenges, and develop trust	*patient. If you don't put down the right foundations it's never going to work.. Those initial steps, consultations, and conversations need to be appropriate for each patient for that foundation to set and be strong"* YA.		

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
		in their healthcare providers, especially during times of crisis. To encourage effective communication, HCPs must establish positive relationships with their patients, which YAs believe starts with the initial consultation. Staff suggested investing time in getting to know the individual and building a solid rapport as this relationship is foundational.			

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
Poor engagement and taking ownership (*Challenges faced by professionals* and *CKD and its associated impact and challenges*)	Barrier	Staff talked about the challenges of engaging and connecting with YAs, highlighting the lived difficulties of creating relationships and bonds with them. They emphasised the importance of finding the right balance between giving YAs advice and telling them what to do. They also discussed the difficulties that YAs face when transitioning and how it can be an	*"Getting their engagement and getting them on the side, getting them to feel like you're an ally, rather than just another sort of health professional"* ST. *"I find it really difficult to engage people"* ST. *"Probably when they're not ready to accept help or they don't know what they need, which is very often, and part of our role is helping people understand that and building up a relationship with somebody to be able to give them that support and identify things they're needing, what treatment would help, but when people put up a barrier because they don't want to even engage with the idea of learning about their condition"* ST. *"When you are in paediatrics, generally, your parents take a lot of the brunt of the responsibilities because obviously they are your parents and you're under their care. But I think when you hit that kind of threshold and you have to move on and then, you kind of understand all the stuff your parents were dealing with and how to deal*	YAs need strategies and education about the positive benefits of engagement and encouragement, fostering a sense of ownership and empowerment in managing their health.	**Beliefs about consequences** and **Beliefs about capabilities** (*Motivation/ reflective motivation*)

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
		overwhelming and frightening experience. YAs expressed their concerns about taking responsibility for their own health, mentioning the differences between paediatric and adult services, and how this transition process could be improved. They also disclosed that some YAs wish to manage their CKD themselves but are unsure of how to go about	*with and that can be a really big change for a young person"* YA. *"I think attitudes with paediatrics and adults are very different. Paediatrics seem to be a lot more nurturing and a lot more understanding, and they seem to talk to us at our level, they tend not to use as much jargon. They try to explain things in more accessible ways, they could use toys, for example, Lego or drawing. Whereas with adults, I find they don't really consider the language, you kind of get a leaflet about something and that's it"* "*Having someone there helps a lot"* YA.		

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
		it, while others are not yet ready to take on this responsibility.			
Flexible scheduling and accommodations (*CKD and its associated impact and challenges*)	Enabler	Interviewees revealed that YAs' needs for effectively managing their CKD are often not being met by their employers and teachers. Many YAs have expressed frustration at the lack of understanding regarding their needs, such as employers not recognising the need for frequent	*"It would be nice if employers understood that chronic illnesses like CKD affect similarly as it would affect other serious illnesses like cancer or heart problems"* YA. *"Sometimes their peers can't understand if they're really tired and trying to explain to their work that although they look well, they're actually not feeling that well"* ST.	YAs with CKD need employers, educational institutions, and social groups to be understanding and offer flexibility in scheduling and accommodations. This may include adjusted work or study hours, access to rest areas, or modified participation requirements to enable them to participate in social activities while managing their health needs.	**Environmental context and resources** (Opportunity / physical environment)

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
		bathroom breaks due to increased fluid intake or needing time off due to illness. They voiced the need for understanding and support at work and school to enable YAs to engage in social activities while managing their health needs.			
Virtual platforms and online communities *(Improving activation)*	Enabler	Virtual platforms, such as mobile phone apps were emphasised throughout interviews, mainly by professionals who	"*My daughter has her phone in her hand constantly so an app.. getting across that knowledge about, depends on what stage and how you can prevent and maintain your health now so like the exercise.. Even if the exercise can be done on the app, like a fit fitness*" ST. "*I think the biggest thing for me is when I found out, I was diagnosed, I went*	YAs can benefit from virtual platforms and online communities, which provide opportunities to connect, share experiences, and participate in social activities from the	**Social influences** (*Opportunity / social environment*)

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
		acknowledged that the YA population would positively respond to such virtual platforms. YAs talked about engaging in online forums and blogs which provides a good opportunity for social interaction. They expressed a desire to share their experiences on YA blogs and forums, and wished for more opportunities to do so, and recognised that online	*online and I found blogs, and I found forums, and I just read what some people were going through. I wrote my own blog about chronic illnesses and I shared it. And I got a lot of people reading it, and a lot of praise and actually, it helped other people.*" YA.	comfort of their homes. They can overcome physical limitations and foster a sense of belonging through virtual support groups, webinars, and online events.	

Barriers/ enablers identified from qualitative synthesis (*Theme*)	**Barrier / enabler**	**Brief description**	**Data extract (YAs/ST)**	**Determinants**	**Potential TDF domains** (and *COM-B component/ sub-component*)
		communities can help them foster a sense of belonging.			

CKD Chronic kidney disease; *COM-B* Capability, Opportunity, Motivation-Behaviour; *HCPs* Health Care Professionals; *PCC* Person-Centred Care; *ST* staff; *TDF* Theoretical Domains Framework; *YAs* Young Adults.

Table BBB2

Definitions of TDF (V2) Domains and Constructs, and Corresponding COM-B Components and Sub-Components

COM-B components (brief *definition*)	**COM-B sub-components**	**TDF domain** (*definition*)	**TDF construct**
Capability (*Psychological or physical ability to engage in a specific activity*)	Psychological capability	**Knowledge** (*An awareness of the existence of something*)	Knowledge (including knowledge of condition/scientific rationale) Procedural knowledge Knowledge of task environment
		Skills (cognitive and interpersonal) (*An ability or proficiency acquired through practice*)	Skills Skills development Competence Ability Interpersonal skills Practice Skill assessment
		Memory, attention, and decision process (*The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives)*	Memory Attention Attention control Decision making Cognitive overload/tiredness
		Behavioural regulation (*Anything aimed at managing or changing objectively observed or measured actions*)	Self-monitoring Breaking habit Action planning
	Physical capability	**Skills** (physical) (*An ability or proficiency acquired through practice*)	Skills Skills development Competence Ability Interpersonal skills Practice Skill assessment

COM-B components (brief *definition*)	**COM-B sub-components**	**TDF domain** (*definition*)	**TDF construct**
Motivation (*Mental processes that energise and direct specific behaviour*)	Reflective motivation	**Social/professional role and identity** (*A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting*)	Professional identity Professional role Social identity Identity Professional boundaries Professional confidence Group identity Leadership Organisational commitment
		Beliefs about capabilities (*Acceptance of the truth, reality or validity about an ability, talent, or facility that a person can put to constructive use*)	Self-confidence Perceived competence Self-efficacy Perceived behavioural control Beliefs Self-esteem Empowerment Professional confidence
		Optimism (*The confidence that things will happen for the best or that desired goals will be attained*)	Optimism Pessimism Unrealistic optimism Identity
		Beliefs about consequences (*Acceptance of the truth, reality, or validity about outcomes of behaviour in a given situation*)	Beliefs Outcome expectancies Characteristics of outcome expectancies Anticipated regret Consequents
		Goals (*Mental representations of outcomes or end states that an individual wants to achieve*)	Goals (distal/proximal) Goal priority Goal/target setting Goals (autonomous/controlled) Action planning Implementation intention
		Intentions (*A conscious decision to perform a behaviour or a resolve to act in a certain way*)	Stability of intentions Stages of change model Transtheoretical model and stages of change

COM-B components (brief *definition*)	**COM-B sub-components**	**TDF domain** (*definition*)	**TDF construct**
	Automatic motivation	**Reinforcement** (*Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus*)	Rewards (proximal/distal, valued/not valued, probable/improbable) Incentives Punishment Consequents Reinforcement Contingencies Sanctions
		Emotion (*A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event*)	Fear Anxiety Affect Stress Depression Positive/negative affect Burn-out
Opportunity (*External factors that either facilitate behaviour or make it less likely to happen*)	Social environment	**Social influences** (*Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours*)	Social pressure Social norms Group conformity Social comparisons Group norms Social support Power Intergroup conflict Alienation Group identity Modelling
	Physical environment	**Environmental context and resources** (*Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour*)	Environmental stressors Resources/material resources Organisational culture/climate Salient events/critical incidents Person × environment interaction Barriers and facilitators

Adapted from Cane et al. (2012) and Michie et al. (2014a). *COM-B* Capability, Opportunity, Motivation-Behaviour; *TDF* Theoretical Domains Framework.

Appendix CCC

Formation of the Possible Solutions to the Problem and Resulting COM-B Logic Model

Matrix of Links Among the COM-B Model, TDF Domains, Intervention Functions, and BCTs for YAs with CKD

Behavioural diagnosis using COM-B barriers/ enablers	**TDF v.2 domains linking to COM-B components**	**Intervention functions: What needs to be done to change behaviour**	**Suggested BCTs (using the 93 BCT taxonomy v.1)**
Psychological Capability			
Enabler			
Effective communication and self-advocacy skills	**Skills** (cognitive and interpersonal)	**Education** -About CKD risk factors and positive and negative health consequences associated with effectively communicating individual preferences, needs, and concerns, dealing with social perception and influence, and seeking emotional support. **Training** -Provision of skill training and practice to improve YAs' communication and self-advocating skills to empower them to navigate their social environments. **Enablement** -Provision of practical tools and techniques for effective communication in social settings.	5.1 Information about health consequences; 5.3 Information about social and environmental consequences; 1.1 Goal-setting (behaviour); 1.3 Goal-setting (outcome); 1.2 Problem-solving; 1.4 Action Planning; 1.8 behavioural contract; 1.9 Commitment; 4.1 Instruction on how to perform the behaviour; 6.1 Demonstration of the behaviour; 8.1 Behavioural practice/ rehearsal; 8.6 Generalisation of target behaviour; 8.7 Graded tasks; 10.9 Self-reward; 2.3 Self-monitoring of behaviour; 2.4 Self-monitoring of outcome(s) of behaviour. [9.1 Credible source - Intervention Facilitators]
Physical Capability			

Behavioural diagnosis using COM-B barriers/ enablers	**TDF v.2 domains linking to COM-B components**	**Intervention functions: What needs to be done to change behaviour**	**Suggested BCTs (using the 93 BCT taxonomy v.1)**
(none)			
Physical Opportunity (physical environment)			
(none)			
Social Opportunity (social environment)			
Barrier			
Social judgment, stigma, discrimination, and peer pressure	**Social influences**	**Environmental Restructuring** -Shaping physical and social environments to promote CKD awareness and dismiss misconceptions. **Enablement** -Provision of support to help YAs to deal with social challenges to effectively navigate their social environments. -Provision of social support and resources to help YAs to deal with social pressure (e.g., resisting negative peer influences) and make choices aligned with their values and goals.	2.2 Feedback on behaviour; 2.7 Feedback on the outcome(s) of behaviour; 5.1 Information about health consequences; 5.3 Information about social and environmental consequences; 1.5 Review behaviour goal(s); 1.7 Review outcome goal(s); 1.2 Problem-solving; 1.4 Action Planning; 1.8 behavioural contract; 1.9 Commitment; 4.1 Instruction on how to perform the behaviour; 6.1 Demonstration of the behaviour; 6.2 Social comparison; 6.3 Information about others' approval; 8.1 Behavioural practice/ rehearsal; 8.6 Generalisation of target behaviour; 8.7 Graded tasks; 10.9 Self-reward; 2.3 Self-monitoring of behaviour; 2.4 Self-monitoring of outcome(s) of behaviour;12.2 Restructuring the social environment. [9.1 Credible source - Intervention Facilitators]
Enabler			

Behavioural diagnosis using COM-B barriers/ enablers	**TDF v.2 domains linking to COM-B components**	**Intervention functions: What needs to be done to change behaviour**	**Suggested BCTs (using the 93 BCT taxonomy v.1)**
Family and peer support	**Social influences**	**Environmental restructuring** -Promoting participation in social activities by offering family and peer support programs. **Enablement** -Provision of social support and resources to facilitate connections, provide opportunities to learn coping strategies, receive emotional support, and exchange advice from others who share similar experiences.	2.2 Feedback on behaviour; 2.7 Feedback on the outcome(s) of behaviour; 5.1 Information about health consequences; 5.3 Information about social and environmental consequences; 1.5 Review behaviour goal(s); 1.7 Review outcome goal(s); 1.2 Problem-solving; 1.4 Action Planning; 1.8 behavioural contract; 1.9 Commitment; 4.1 Instruction on how to perform the behaviour; 6.1 Demonstration of the behaviour; 8.1 Behavioural practice/ rehearsal; 3.1 Social support (unspecified); 8.6 Generalisation of target behaviour; 8.7 Graded tasks; 10.9 Self-reward; 2.3 Self-monitoring of behaviour; 2.4 Self-monitoring of outcome(s) of behaviour. [9.1 Credible source - Intervention Facilitators]
Reflective Motivation			
(none)			
Automatic Motivation			
Barrier			
Negative emotions	**Emotion**	**Persuasion** -Supporting YAs to change the way they feel about future uncertainty. **Modelling**	2.2 Feedback on behaviour; 2.7 Feedback on the outcome(s) of behaviour; 5.1 Information about health consequences; 5.3 Information about social and environmental consequences; 5.6 Information

Behavioural diagnosis using COM-B barriers/ enablers	TDF v.2 domains linking to COM-B components	Intervention functions: What needs to be done to change behaviour	Suggested BCTs (using the 93 BCT taxonomy v.1)
(anxiety / worry)		-Demonstration of effective strategies to express feelings and seek assistance. **Enablement** -Provision of a supportive and safe environment for YAs to talk about their anxiety and worries about the future and supportive strategies to enable YAs to seek emotional support.	about emotional consequences; 1.5 Review behaviour goal(s); 1.7 Review outcome goal(s); 1.2 Problem-solving; 1.4 Action Planning; 1.8 behavioural contract; 1.9 Commitment; 4.1 Instruction on how to perform the behaviour; 6.1 Demonstration of the behaviour; 8.1 Behavioural practice/ rehearsal; 3.3 Social support (emotional); 8.6 Generalisation of target behaviour; 8.7 Graded tasks; 10.9 Self-reward; 2.3 Self-monitoring of behaviour; 2.4 Self-monitoring of outcome(s) of behaviour; 11.2 Reduce negative emotions. [9.1 Credible source - Intervention Facilitators]

CKD Chronic kidney disease; *BCT* Behaviour Change Techniques; *COM-B* Capability, Opportunity, Motivation-Behaviour; *TDF* Theoretical Domains Framework; *YAs* Young Adults.

Appendix DDD

Intervention Resource for YAs

Table DDD1

PCC Plan Development - Workshop 1

“Think back to the month before this workshop. Did you talk to someone about your needs, preferences, and worries associated with CKD? Please choose the statement that best describes you.				
1.“No, and I do not intend to start”	2.“No, but I am considering it”	3.“No, but I seriously intend to start”	4.“Yes, but only for a brief period”	5.“Yes, and for a long period”
☐	☐	☐	☐	☐

Workshop 1:

Behavioural determinant(s): **Communication and self-advocacy skills to 1) communicate individual needs, preferences, and worries associated with CKD**/ 2. Manage social perception and influence 3. Seek emotional support.

Positive health outcomes of effectively communicating individual needs, preferences, and worries associated with CKD:

Potential consequences of not being able to effectively communicate needs and express concerns:

Goal-setting: SMART goals (Specific, Measurable, Achievable, Realistic, and Timely)

Goals related to behaviour:

Goals related to the outcome of desired behaviour:

Problem-solving

Barriers to behaviour change:

Personalised strategies to overcome barriers:

Action-planning

What?

When?

Where?

How often/ long/
much?
Realistic?
Appropriate?
Start/ end
On a scale of 0 to 10, how confident do you feel about carrying out this plan?
1 2 3 4 5 6 7 8 9 10

Is there anything that can increase your confidence?
No (*continue to the next step*) Yes (*restate plan and rating*)

Behavioural contract and commitment

I will start practising effective communication and self-advocacy skills to communicate my personal needs, preferences, and concerns, in the next week.

YA’s signature: Facilitator's signature:

Brainstorming exercise:

Exercise 1: Types of communication:

Exercise 2: Strategies that may help in communicating individual needs, preferences, and concerns with:

Professionals: *Employers*: *Teachers*:

Other types of communication and effective strategies for communicating needs, preferences, and worries associated with CKD:

Role-plays:

Professionals:	*Employers*:	*Teachers*:
-In groups of three, decide who will play the YA patient and professional, and who will act as an observer. -Spend 5 minutes reading the context of the scene -*If acting as a patient*: reflect on your experience living with CKD, your current needs, preferences, and worries that you may want to communicate with professionals, and note them down. -*If acting as a professional*: practice	-In the same groups, switch roles and decide who will play the employee and employer, and who will act as an observer. -Spend 5 minutes reading the context of the scene -*If acting as an employee*: reflect on your experience living with CKD, your current needs, preferences, and worries that you may want to communicate with employers, and note them down.	- In the same groups, again switch roles and decide who will play the student and teacher, and who will act as an observer. -Spend 5 minutes reading the context of the scene -*If acting as a student*: reflect on your experience living with CKD, your current needs, preferences, and worries that you may want to communicate with teachers, and note them down.

active listening and empathy -*If acting as an observer*: silently observe the role-play and note down your feedback by listing things that went well in the discussion and things that could be improved. -<u>Context of the scene:</u> YA patient has a scheduled appointment with their professional to discuss their condition and its management. The patient participant is to share their experiences related to CKD, focusing on the following aspects: personal needs (e.g., medication management, dietary restrictions, and/or lifestyle adjustments), preferences (e.g., for treatment plans, and/or involvement in decision-making), and concerns (e.g., about potential complications, future uncertainties, and/or impact on social life).	-*If acting as an employer*: practice active listening and empathy -*If acting as an observer*: silently observe the role-play and note down your feedback by listing things that went well in the discussion and things that could be improved. -<u>Context of the scene:</u> YA employee has a meeting with their employer to discuss their condition, its consequences, and management. YA participant is to voice their personal needs, preferences, and concerns to request suitable accommodations that will allow them to work effectively in their roles.	-*If acting as a teacher*: practice active listening and empathy -*If acting as an observer*: silently observe the role-play and note down your feedback by listing things that went well in the discussion and things that could be improved. -<u>Context of the scene:</u> YA student meets with a teacher to discuss relevant adaptations related to their personal needs, preferences, and any concerns they may have, to allow them to effectively study and achieve their learning goals.

Group discussion: reflecting on role-plays:

-What went well in discussions:

-What could be improved:

-Additional strategies for effective communication of needs, preferences, and concerns not discussed earlier:

Homework (practice, self-monitoring, and self-reflection):

Task 1**:** Practice communicating better with your friends and family through role-playing real-life scenarios, like making plans with friends or family, while voicing your needs and preferences, and addressing concerns regarding these plans. Reflect on each exercise and identify areas for improvement. Practise until you feel confident in your communication skills, and then move on to Task 2.

***Task 2*:** Participate in a group discussion, whether formal or informal, such as a casual gathering. Share your ideas, preferences, needs, and concerns actively, and listen carefully to others. Be clear and concise in expressing your thoughts, and be open to hearing other viewpoints. Afterwards, take time to reflect and evaluate how the discussion went, including your own performance, what worked well, and what could have been improved. Note these reflections daily.

Homework self-reflection:

***Task 1*:**

What worked (why):

What did not work (why):

***Task 2*:**

What worked (why):

What did not work (why):

Next workshop:

Date:
Time:
Place:

Thank you and see you next week!

Table DDD2

PCC Plan Development - Workshop 2

"Think back to the month before this workshop. Did you try to handle how people see you and the pressure from others? Please choose the statement that best describes you.

1."No, and I do not intend to start"	2."No, but I am considering it"	3."No, but I seriously intend to start"	4."Yes, but only for a brief period"	5."Yes, and for a long period"
☐	☐	☐	☐	☐

Workshop 2:

Behavioural determinant(s): **Communication and self-advocacy skills to** 1) communicate individual needs, preferences, and worries associated with CKD/ **2. Deal with social perception and influence** 3. Seek emotional support.

Positive health outcomes of dealing with social perception and influences (social judgment, stigma, discrimination, and peer pressure):

Potential consequences of not being able to deal with social perception and influences:

Review and set new goals: SMART goals (Specific, Measurable, Achievable, Realistic, and Timely)

Goals related to behaviour:

Goals related to the outcome of desired behaviour:

Problem-solving

Barriers to behaviour change:

Personalised strategies to overcome barriers:

Action-planning

What?

When?

Where?

How often/ long/ much?

Realistic?

Appropriate?

Start/ end

On a scale of 0 to 10, how confident do you feel about carrying out this plan?

1 2 3 4 5 6 7 8 9 10

Is there anything that can increase your confidence?
No (*continue to the next step*) Yes (*restate plan and rating*)

Behavioural contract and commitment

I will start practising effective communication and self-advocacy skills to deal with social perception and influence, in the next week.

YA's signature: Facilitator's signature:

Brainstorming exercise: Challenging stigma and stereotypes

Exercise 1: In the last workshop, we learned about communicating assertively. This means expressing needs, preferences, and concerns respectfully and confidently while also considering the rights and feelings of others. To practice assertiveness, we will brainstorm and discuss assertiveness skills in small groups. Please write down as many skills as you can think of.

Exercise 2: In the same groups, familiarise yourself with two brief scenarios below, and discuss and note down potential communication strategies to challenge or address the stigma and stereotypes presented in the scenario:

Scenario 1: Someone overhears you talking about your CKD and says: "Oh, that's the old's person disease, right?" - How would you respond?

Scenario 2: You are hanging out with your friend who knows about your condition. During a conversation, they make a joke about your kidney problem that makes you uncomfortable - How would you address it and respond?

Group discussion: Reflect on your own performance by comparing the ideal responses to the scenarios provided by facilitators:

Role-plays: Assertive responses to peer pressure

Scenario 1:	*Scenario 2*:	*Scenario 3*:
-Familiarise yourself with the scenario below. -In pairs, decide who will act as a person facing peer pressure (participant 1), and who will play a person applying pressure (participant 2). *Scenario 1*:	-Familiarise yourself with scenario 2. -In the same pairs, switch roles to practice the scenario below. *Scenario 2*: Your friends pressure you to drink alcohol at the party, despite knowing	-Familiarise yourself with scenario 3 below. -In the same pairs, switch roles again. *Scenario 3*: Your friend is making fun of someone based on their appearance. Practise standing up against

A friend wants you to skip a class with them. Practice asserting that you prefer to attend the class and explain your reasons.	that you should watch your alcohol intake. Practise expressing your concerns about drinking and explaining how it may affect your health, and asserting your choice not to drink.	bullying, expressing your concerns and discomfort with this behaviour, and advocating for respect.

Group discussion: reflecting on role-plays:
-What went well in discussions:

-What could be improved:

-Additional strategies for effective communication and self-advocacy skills when dealing with social perception and influence:

Social support:
Spend some time thinking about whom you could contact for support when required, and who would encourage you in continuing behaviour change, including friends, family, or professionals.
Have you made any connections at the previous workshop and perhaps you and your peer can motivate and support each other outside workshops?

Homework (practice, self-monitoring, and self-reflection):
Task 1**:** Think of a situation where you may feel like others are judging you negatively. Write down how you feel when this happens. Then, make a list of three people you can talk to for support in these situations. Also, think about ways to avoid such situations. Write in your daily diary how reaching out to people for support and avoiding these situations could help you overcome negative social influences. Remember, it is important to seek support when you need it.
Task 2**:** Once you feel confident with the strategies identified in Task 1, choose a situation to apply them. Practice with a new person or someone you know. Afterwards, ask the responder how well you did. Note down their positive affirmations, and if identified, any areas of improvement. Then, engage in a self-reflection by writing how you think the exercise went, what you did well, and how you think you could improve.
Homework self-reflection:
Task 1**:** notes:

What worked (why):

What did not work (why):

Task 2**:** notes:
Responder:
What worked (why):

What did not work (why):

You:
What worked (why):

What did not work (why):

Next workshop:
Date:
Time:
Place:

Thank you and see you next week!

Table DDD3

PCC Plan Development - Workshop 3

"Think back to the month before this workshop. Did you reach out to friends or family when you needed someone to talk to or comfort you? Please choose the statement that best describes you.

1."No, and I do not intend to start"	2."No, but I am considering it"	3."No, but I seriously intend to start"	4."Yes, but only for a brief period"	5."Yes, and for a long period"
☐	☐	☐	☐	☐

Workshop 3:

Behavioural determinant(s): **Communication and self-advocacy skills to** 1) communicate individual needs, preferences, and worries associated with CKD/ 2. Deal with social perception and influence **3. Seek emotional support.**

Positive health outcomes of seeking emotional support, from peers and/or family. (Consider how it may impact your emotional well-being):

Potential consequences of not being able to seek emotional support, from peers and/or family. (Consider how it may impact your emotional well-being):

Review and set new goals: SMART goals (Specific, Measurable, Achievable, Realistic, and Timely)

Goals related to behaviour:

Goals related to the outcome of desired behaviour:

Problem-solving

Barriers to behaviour change:

Personalised strategies to overcome barriers:

Action-planning

What?

When?

Where?

How often/ long/ much?

Realistic?
Appropriate?
Start/ end
On a scale of 0 to 10, how confident do you feel about carrying out this plan?

1 2 3 4 5 6 7 8 9 10

Is there anything that can increase your confidence?
No (*continue to the next step*) Yes (*restate plan and rating*)

Behavioural contract and commitment

I will start practising effective communication and self-advocacy skills to seek emotional support when required, in the next week.

YA’s signature: Facilitator's signature:

Brainstorming exercise:

In groups, practice the following exercises:

Exercise 1: Think of, and note down, situations when you may require to seek emotional support from your peers or family members. Consider, for example, situations that made you anxious or uncertain and worried.

Exercise 1: In the same groups, select one of the situations (e.g., the most common one) considered in the first exercise and list as many strategies you can think of to reduce negative emotions caused by the chosen situation.

-**Group discussion**: additional stress management strategies provided by the facilitator:

Role-plays:

In pairs, familiarise yourself with the scenarios below. Decide and agree on who will act as a person seeking emotional support for a specific situation (participant 1), and who will play a person providing support (participant 2). Note that: the role of “Participant 1” is to seek emotional support based on a given scenario, and the role of “Participant 2” is to utilise the information learnt from the previous task to provide advice.

Scenario 1:	*Scenario 2*:	*Scenario 3*:
-Familiarise yourself with the scenario below.	-Familiarise yourself with the scenario below, and practice in the same pairs, but switch roles	-Familiarise yourself with scenario 3 below and switch roles again.
Scenario 1: You (participant 1) have been feeling increasingly anxious about joining the	*Scenario 2*:	*Scenario 3*: You (participant 1) have been feeling increasingly

peer support group for the first time. Express your concerns and seek help from your buddy on how to reduce your anxiety and any negative thoughts.	You (participant 1) have been feeling anxious and uncertain about your career path after completing your studies, not knowing what opportunities await. Express your concerns and pursue advice from your buddy.	overwhelmed by juggling between medical appointments and study deadlines. Express your concerns and pursue advice from your buddy.

Group discussion: reflecting on role-plays:
-What went well in discussions:

-What could be improved:

-Additional strategies for effective communication and self-advocacy skills when seeking emotional support:

Social support:
Whom I could contact for emotional support when required:

Homework (practice, self-monitoring, and self-reflection):
***Task 1*:** In a situation where you feel anxious or uncertain about something, practice different strategies discussed at the workshop and reflect on how effective these were in reducing your negative emotions. List them down starting with the most effective strategy that works for you, followed by less effective strategies, and include a brief note about why a particular strategy works for you and in what situation(s).
***Task 2*:** Choose a friend or a family member and share with them a recent challenge that you faced and express your interest in seeking their advice. Then, engage in a self-reflection by writing how you think the exercise went, what you did well, and how you think you could improve.
Homework self-reflection:
***Task 1*:**
List of strategies that work for me when dealing with negative emotions (why and when):

***Task 2*:**

What worked (why):

What did not work (why):

Next workshop:
Date: *1-month post-Workshop 3*
Time:
Place:

Thank you and see you next **month**!

Table DDD4

PCC Plan Development - Workshop 4

"Think about the time since the first workshop a few weeks ago. Have you been practising how to effectively communicate and stand up for yourself? Have you been sharing your own needs, preferences, and worries associated with CKD? Have you been trying to get support when you need it emotionally? Please choose the statement that best describes you.

1."No, and I do not intend to start"	2."No, but I am considering it"	3."No, but I seriously intend to start"	4."Yes, but only for a brief period"	5."Yes, and for a long period"
☐	☐	☐	☐	☐

The final Workshop:

Behavioural determinant(s): **Communication and self-advocacy skills to 1) communicate individual needs, preferences, and worries associated with CKD/ 2. Manage social perception and influence 3. Seek emotional support.**

Discussion on relapse and prevention strategies:

Exercise 1: Potential triggers to participating in social activities as that may lead to relapse:

Exercise 2**:** Potential relapse prevention strategies for each selected trigger from Task 1.

Potential triggers (copy from flipchart)	*Potential relapse prevention strategies*

Discussion on overcoming setbacks and regaining commitment:

Group discussion: Potential strategies to overcome setbacks, particularly to regain commitment to participation in social activities.

Social support: 3 people whom I could contact for support when I experience setbacks.

1)
2)
3)

Final homework:

Task 1: Continue with your PCC development, and use what you learned in the workshops on goal-setting, coping, and action planning. Start by setting goals and planning social activities that involve interacting with others. You can choose any activity you like, but consider what might prevent you from participating and come up with personal strategies to overcome those barriers. Remember different strategies work for different people, so find what works for you. When you are confident in your plan, sign the behavioural contract to make it official. Finally, seek support from someone you listed in the previous task.

***Task 2*:** Put your plan into action. Afterwards, reflect on how well you did and if any triggers could have caused you to relapse. Pre-plan and implement, when required, personalised strategies (specifically those that work for you) to prevent relapse, overcome setbacks and regain commitment. Use your support buddy for encouragement, emotional support, or to help you regain commitment. Remember to praise yourself for your successes and reward your good performance!

Ongoing PCC plan development for participating in social activities

Goal-setting: SMART goals (Specific, Measurable, Achievable, Realistic, and Timely)

Goals related to behaviour:

Goals related to the outcome of desired behaviour:

Problem-solving

Barriers to behaviour change:

Personalised strategies to overcome barriers:

Action-planning

What?

When?

Where?

How often/ long/ much?

Realistic?

Appropriate?

Start/ end

On a scale of 0 to 10, how confident do you feel about carrying out this plan?

1 2 3 4 5 6 7 8 9 10

Is there anything that can increase your confidence?

No (*continue to the next step*) Yes (*restate plan and rating*)

Behavioural contract and commitment

I will start participating in social activities in the next weeks/ months.

Your signature:

Support buddy to contact for encouragement, emotional support, or to help you regain commitment following the setback:

Homework self-reflection:

The social activity(ies) I participated in:

What went well:

What could be improved:

Any potential triggers leading to relapse?
If yes, potential relapse prevention strategies for selected triggers that work for me:

Did you experience setback(s)?
If yes, potential strategies to overcome setbacks and regain commitment that works for me:

Did you contact support buddy for:
-Encouragement?
-Emotional support?
-and/or support to regain your commitment?
If yes to any of the above, was their support beneficial?

Additional notes:

This was the final workshop, however, remember that it is not the end of your journey, but the beginning of a path to progress beyond these workshops. Do not go through this journey on your own, remember the importance of support, especially when experiencing challenges, and do not be discouraged when you experience setbacks. Remember that setbacks are normal and relapse prevention is an ongoing process, thus implement strategies that work best for you and move forward. Finally, stay in touch and keep an eye on opportunities to connect with fellow participants, and expand your social network. Once again thank you for your participation and engagement, your commitment to personal growth and positive change is truly inspiring. Best wishes on your continued journey!

Appendix EEE

Intervention Resource for Facilitator

Guide sheet for Facilitator - **Workshop 1**:

Pre-Workshop Preparations:

-Define objectives and plan the agenda:

Ensure that you have a clear understanding of what participants should gain from the workshop, clarifying the workshop's purpose, goals, and desired outcomes. Follow a comprehensive agenda for the workshop, detailing the order of activities. Ensure that you allow an appropriate amount of time for each activity and maintain a balance between discussions and interactive exercises. You can utilise the provided estimated time for activities to guide time management.

-Gather materials and check venue:

Ensure that you have all necessary materials needed for activities, including flipcharts, markers, pens, and resources for YAs (see Appendix DDD). Safeguard the workshop venue by visiting ahead of time to make sure that it is set up suitably for groups of YAs, ensuring appropriate lighting, seating, and any equipment if needed.

-Select icebreaker activities:

Select icebreaker activities that will make participants feel at ease, help attendees get to know each other, and create a positive atmosphere right from the beginning. Here are some examples:

-Two truths and a lie: prompt each participant to share two true statements and one false statement about themselves, while asking the rest of the group to guess which statement is the lie.

-Name and fun facts: prompt participants to introduce themselves and share a unique or surprising fact about themselves.

-Introduce the person next to you: divide participants into pairs and set a time (e.g., 3-5 minutes) for participants to find an interesting fact about each other. Once the time is up, encourage them to introduce their colleague to the rest of the group.

During Workshop 1:

Step 1:

Welcome, introduction, icebreaker activity, and ground rules:

Begin by welcoming participants, introducing yourself, and providing participants with a brief overview of the workshop's objectives and agenda, information on facilities, and check if they have any questions. Get to know participants and build rapport by utilising icebreaker activities (see examples above). Together with YAs, establish ground rules for maintaining a productive, respectful, and inclusive environment during group workshops, and note them down on the flipchart to be visible throughout the workshops and review them when required. A few ground rules to consider: turn off devices, active participation, respectful communication, one conversation at a time, confidentiality, no judgment or criticism, respect diverse perspectives and opinions, and have fun! Finally, remind participants that their participation is voluntary and that they can withdraw at any time without providing any reason. Remember that participants' well-being is a priority. During discussions, be mindful of time management, and group dynamics (create an inclusive environment where everyone can feel comfortable engaging in discussions, but be mindful of those quieter YAs and encourage them to share their ideas and opinions and manage those with dominating personalities), and use simple language and encourage participants to expand on their responses by using open-ended questions. Be prepared to adapt the workshops to individual needs and preferences. Spend approximately 30-45 minutes on this activity.

Step 2:
Stage assessment:
Utilise the questions below to assess YAs' stage of readiness for behaviour change. Prompt YAs to consider communication with professionals, employers and/or teachers. Note that, YAs indicating 1 and 2 are categorised as pre-intenders, those indicating 3 as intenders, and 4 and 5 as actors. Note down a stage for each YA and utilise this information throughout the workshop to emphasise the most appropriate stage-specific strategies when possible. Spend approximately 10-15 minutes on this activity.

"Think back to the month before this workshop. Did you talk to someone about your needs, preferences, and worries associated with CKD? Please choose the statement that best describes you.				
1."No, and I do not intend to start"	2."No, but I am considering it"	3."No, but I seriously intend to start"	4."Yes, but only for a brief period"	5."Yes, and for a long period"
☐	☐	☐	☐	☐

Adapted from Lippke et al. (2012).

Step 3:
Provide participants with intervention resources in the form of PCC plan development and encourage its use throughout whole interventions during workshops and as a diary outside the workshops. Together with YAs, start PCC plans development, guided by the resource for YAs below:

Workshop 1: Behavioural determinant(s): **Communication and self-advocacy skills to 1) communicate individual needs, preferences, and worries associated with CKD**/ 2. Manage social perception and influence 3. Seek emotional support.	**Estimated time for activity (minutes)**
Outcome expectancies: Prompt YAs to individually list positive health outcomes of effectively communicating individual needs, preferences, and worries associated with CKD. Advise them to consider communication with professionals, employers, and teachers.	10-15

Risk perception: Prompt YAs to individually list potential consequences of not being able to effectively communicate needs and express concerns. Advise them to consider communication with professionals, employers, and teachers.	10-15
In the group, briefly discuss with YAs the identified outcome expectancies and risk perception, and highlight others not listed. Then prompt a general discussion on "What is the problem."	10-15
Goal-setting: Prompt YAs to set personalised goals guided by SMART (Specific, Measurable, Achievable, Realistic, and Timely) goals, related to behaviour, as well as to the outcome of desired behaviour. Once completed, review these personalised goals, ensuring that they follow SMART goals, in brief group discussions. In situations where participants struggle to set personalised goals, ask them permission to share ideas based on their own experience or examples from previous group sessions, and share 2-3 ideas.	15-20
Break	20-30
Problem-solving: Prompt YAs to identify, analyse, and note down barriers preventing them from effectively communicating and self-advocating their needs, preferences, and concerns in social interactions and discuss personalised strategies that include overcoming these barriers. Briefly discuss in a group.	15-20
Action-planning: Encourage YAs to plan to practice effective communication and self-advocating in different social scenarios to communicate their needs, preferences, and worries. Prompt the action plan with the following questions: What? when? where? how often/ long/ much? realistic? appropriate? start/ end? Assess YAs' confidence to carry out this personalised plan by asking them to rate their confidence on a 0-10 scale. Ask them if there is anything that can increase their confidence (if >7 on the scale). If yes, prompt YAs to restate the plan and rating, and potentially suggest ideas. If not, continue to the next step.	20-30
Behavioural contract and commitment: Agree with YAs about the written commitment statement in their PCC plan, ensure that they understand it, and together with YA sign the contract.	5
Brainstorming exercise: Split YAs into smaller groups (e.g., two groups with 5 or 6 participants each) and ask them to brainstorm and note down: ***Exercise 1:*** All types of communication they can think of. ***Exercise 2:*** Strategies that they think may help them to communicate their needs, preferences, and concerns with professionals, employers, and teachers. Allow about 5-10 minutes for each exercise, then encourage participants to share their ideas with everyone. Following this, discuss with YAs additional strategies not mentioned by them. Use the below information to ensure all relevant topics are covered. **Types of communication:**	50-60

-Verbal communication: comprises the use of spoken words to convey information, ideas, and thoughts, in face-to-face conversations, presentations, meetings, phone calls, and so on.
-Non-verbal communication: non-verbal cues accompany verbal communication and comprise body language, posture, gestures, eye contact, facial expressions, and tone of voice. Advise YAs that non-verbal cues play an important role in communication, and they should be able to recognise these.
-Other types of communication: written (e.g., written words, such as letters, emails, etc.), visual (e.g., visuals, such as images, graphs, videos, etc.), digital (e.g., digital platforms, such as social media, video conferencing, etc.), as well as formal and informal communications.

Strategies for effective communication of needs, preferences, and concerns with professionals, employers, and teachers

Professionals:	*Employers*:	*Teachers*:
-Prepare ahead: write down any questions, concerns, and topics you want to discuss before appointments and bring a notebook with you to ensure that you address and note down all important information during discussions. -Be honest and open: openly share your symptoms and worries. -Actively participate: share your treatment goals and preferences to work on suitable plans, communicate any challenges related to lifestyle adjustments and seek guidance on how to manage them effectively, and discuss your emotional well-being or any mental	-Know your rights: understand your rights and protections under disability laws. -Request accommodations: communicate your requirements, for example, request workplace accommodations (such as flexible scheduling, work hours, remote work, or modified tasks) and explain how these would enable you to perform your job effectively. When requesting accommodations, provide employers with medical documentation outlining your condition and recommended adjustments and emphasise your skills,	-Notify early: inform teachers or educators about your condition, including potential symptoms and side effects, and any potential impact on your studies at the beginning of the term. -Discuss accommodations: if required, arrange accommodations with disability service in your school/college/university, such as extended deadlines. -Develop a study plan: together with teachers create a plan for staying up-to-date with coursework in case of situations when you miss classes due to medical appointments or treatment. -Advocate yourself: when faced with difficulties, calmly communicate your challenges with teachers and seek their

health challenges that you may be experiencing. -Ask for clarification: do not hesitate to ask a professional to explain when something is unclear. Summarise what you have understood and confirm if your interpretation is correct. Ask for written resources to review at home.	contributions, willingness to work, and commitment to maintain productivity. -Open dialogue: keep an open line of communication with your employer about your condition, treatment schedule, and any changes that may affect your work.	understanding and support. -Stay organised: use planners, digital tools, or apps to manage your schedules and assignments effectively.	
Other skills/ topics to discuss: active listening (emphatic listening, asking clarifying questions, and providing feedback), open-ended questions, assertiveness versus passive and aggressive communication, setting boundaries, use of "I" statements (constructive expression of needs and worries), positive body language, and strategies for overcoming self-doubts and building self-confidence.			
Break			20-30
Role-plays: effective communication of needs, preferences, and concerns with professionals, employers, and teachers. Split YAs into small groups of three (one to act as patient, employee, or student, one as either professional, employer, or teacher, and one as an observer) and encourage them to practice the above-discussed skills in three role-play scenarios. During the role-plays, ensure a respectful and supportive environment and emphasise the focus on practising effective communication and self-advocacy skills, rather than perfect performance.			80-90
Professionals: Scenario 1: *Self-reflection and self-advocating exercise.* -Appoint one participant to act as a patient, one to act as a professional, and one to act as an observer. -Preparation: Prompt participants to spend 5 minutes reading the context	*Employers*: Scenario 2: *Self-reflection and self-advocating exercise.* -Appoint one participant to act as an employee, one as an employer, and one as an observer. (Ensure that the participants switched roles).	*Teachers*: Scenario 3: *Self-reflection and self-advocating exercise.* -Appoint one participant to act as a student, one as a teacher, and one as an observer. (Ensure that the participants switched roles). -Preparation: Prompt participants to spend 5 minutes reading the context of the scene,	

of the scene, and encourage those acting as a patient to reflect on their experience living with CKD, current needs, preferences, and worries that they may want to communicate with professionals, and advise them to note them down. -Context of the scene: YA patient has a scheduled appointment with their professional to discuss their condition and its management. The patient participant is to share their experiences related to CKD, focusing on the following aspects: personal needs (e.g., medication management, dietary restrictions, and/or lifestyle adjustments), preferences (e.g., for treatment plans, and/or involvement in decision-making), and concerns (e.g., about potential complications, future uncertainties, and/or impact on social life). The professional participant is to actively listen and respond empathetically to the	-Preparation: Prompt participants to spend 5 minutes reading the context of the scene, and encourage those acting as an employee to reflect on their experience living with CKD, current needs, preferences, and worries that they may want to communicate with employers, and advise them to note them down. Prompt them to think of relevant adaptations they may have to request to allow them to fulfil their roles as employees. -Context of the scene: YA employee has a meeting with their employer to discuss their condition, its consequences, and management. YA participant is to voice their personal needs, preferences, and concerns to request suitable accommodations that will allow them to work effectively in their	and encourage those acting as a student to reflect on their experience living with CKD, current needs, preferences, and worries that they may want to communicate with teachers, and advise them to note them down. Prompt them to think of relevant adaptations they may have to request to allow them to fulfil their roles as students. -Context of the scene: YA student meets with a teacher to discuss relevant adaptations related to their personal needs, preferences, and any concerns they may have, to allow them to effectively study and achieve their learning goals. The role of the participant acting as the teacher is the same as the role of the professional in scenario 1, and the role of the observer is also the same as in scenario 1. -At the end of the role-play, encourage reflection on the discussion between the acting student and teacher (see below). *Allow approximately 20 minutes for practising each scenario, including preparation time.*

concerns conveyed by the YA patient. Whereas, the role of the observer participant is to observe the role-play and note down constructive feedback (what went well in the discussion and what could be improved). -At the end of the role-play, encourage reflection on the discussion between the acting patient and professional (see below).	roles. The role of the participant acting as the employer is the same as the role of the professional in scenario 1, and similarly, the role of the observer is the same as in scenario 1. -At the end of the role-play, encourage reflection on the discussion between the acting employee and employer (see below).	
Group discussion: At the end of the role-plays, encourage reflection and facilitate a group discussion to allow participants to share their key learnings from the role-play. Prompt the observing participant to report on what went well and what could be improved in the discussions in all three scenarios. Encourage all participants to discuss any additional strategies that they think may improve effective communication and self-advocacy skills when expressing individual needs and preferences, and dealing with CKD-related concerns.		
Homework (practice, self-reflection, and self-monitoring): Encourage YAs to continue practising tasks performed at the workshop, in the next week as homework. Advise them to begin with easy-to-perform tasks (task 1 in their PCC plan), and gradually increase task difficulty by moving to the second task of their homework. Encourage self-reflection and self-praise whenever progress in performing behaviour is made, as well as self-monitoring by directing YAs to fill in their plans daily. Discuss the information about homework below and ensure that participants understand what is being asked of them. ***Task 1*****:** Practice communicating better with your friends and family through role-playing real-life scenarios, like making plans with friends or family, while voicing your needs and preferences, and addressing concerns regarding these plans. Reflect on each exercise and identify areas for improvement. Practise until you feel confident in your communication skills, and then move on to Task 2. ***Task 2*****:** Participate in a group discussion, whether formal or informal, such as a casual gathering. Share your ideas, preferences, needs, and concerns actively, and listen carefully to others. Be clear and concise		10-15

in expressing your thoughts, and be open to hearing other viewpoints. Afterwards, take time to reflect and evaluate how the discussion went, including your own performance, what worked well, and what could have been improved. Note these reflections daily.

Next workshop: (date, time, and place)

Step 4:

Post-Workshop Wrap-Up:

-Summary of key points:

Provide YAs with a brief summary of the workshop, including the most important concepts and lessons that were learned.

-Questions and answers:

Prompt YAs to ask questions or share their final thoughts, and ensure to address any remaining doubts or concerns they may have.

-Feedback:

Ask participants to provide verbal feedback on the session and indicate any areas to improve for future workshops.

-Resources and network opportunities:

Remind YAs to take home the provided resource to enable homework and daily recording. Additionally, to use network opportunities and foster ongoing learning and collaboration, encourage participants to exchange contact information and continue discussions beyond the workshops. Finally, set up/agree on a date, time, and place for the next workshop. Spend approximately 20-30 minutes on this activity.

[*Estimated workshop time: between 6-7 hours*]

Guide sheet for Facilitator - **Workshop 2**:

Pre-Workshop Preparations:

-Revise the pre-preparation plan from Workshop 1:

Revise steps from pre-workshop 1 preparation (including, defining objectives, planning the agenda, gathering materials, and checking the venue), as well as review and adapt to YAs' feedback on the previous workshop when required.

During Workshop 2:

Step 1:

Welcome, re-establish rapport, recap ground rules, and provide feedback:

Begin by welcoming participants, re-establishing rapport, and providing them with a brief overview of the workshop's objectives and agenda. Remind YAs of the previously set ground rules to sustain a respectful and inclusive environment, and that their participation is voluntary. Then, encourage a group discussion by asking participants to share how they have been doing since the last workshop, how their homework went, and whether they have any concerns they would like to discuss before commencing a new workshop, including any obstacles they may have faced when practising the learnt skills. Following participants' responses, provide them with constructive verbal feedback, highlighting any areas of improvement and reinforcing successful performance. Use positive messages when providing feedback (e.g., for a successful performance: “Well done! You’re making progress towards achieving your goal(s)”; for a less successful performance: “Don’t worry, you’re on the right track, stay positive and let’s try again”) to reinforce positive behaviours. If any of the YAs indicated facing obstacles, ensure addressing these by discussing potential relapse prevention strategies to avoid lapses. Finally, during the workshop, remember to be mindful of time management and group dynamics, and the use of simple language, and open-ended questions by participants. Be prepared to adapt the workshops to individual needs and preferences. Spend approximately 20-30 minutes on this activity.

Step 2:

Stage assessment:

Utilise the questions below to assess YAs’ stage of readiness for behaviour change. Note that, YAs indicating 1 and 2 are categorised as pre-intenders, those indicating 3 as intenders, and 4 and 5 as actors. Note down a stage for each YA and utilise this information throughout the workshop to employ the most appropriate stage-specific strategies. Spend approximately 10-15 minutes on this activity.

“Think back to the month before this workshop. Did you try to handle how people see you and the pressure from others? Please choose the statement that best describes you.

1.“No, and I do not intend to start”	2.“No, but I am considering it”	3.“No, but I seriously intend to start”	4.“Yes, but only for a brief period”	5.“Yes, and for a long period”
☐	☐	☐	☐	☐

Adapted from Lippke et al. (2012).

Step 3:

Encourage the continuous use of PCC plans by prompting YAs to carry on developing their plans in workshop 2 (see below).

Workshop 2: Behavioural determinant(s): **Communication and self-advocacy skills to** 1) communicate individual needs, preferences, and worries associated with CKD/ **2. Deal with social perception and influence** 3. Seek emotional support.	**Estimated time for activity (minutes)**
Outcome expectancies: Prompt YAs to individually list positive health outcomes of effective communication and self-advocacy skills to deal with social perception and influences. Advise them to consider social judgment, stigma, discrimination, and peer pressure.	10-15
Risk perception: Prompt YAs to individually list potential consequences of not being able to deal with social perception and influences. Advise them to consider social judgment, stigma, discrimination, and peer pressure.	10-15

In the group, briefly discuss with YAs the identified outcome expectancies and risk perception, and highlight others not listed.	10-15
Reviewing and setting new goals: Prompt YAs to review their goals and set new personalised goals guided by SMART (Specific, Measurable, Achievable, Realistic, and Timely) goals, related to a new behavioural determinant, as well as to the outcome of desired behaviour. Once completed, review these personalised goals, ensuring that they follow SMART goals, in brief group discussions. In situations where participants struggle to set personalised goals, ask them permission to share ideas based on their own experience or examples from previous group sessions, and share 2-3 ideas.	15-20
Break	20-30
Problem-solving: Prompt YAs to identify, analyse, and note down barriers preventing them from effectively communicating and self-advocating to deal with social perception and influences. Briefly discuss in a group.	15-20
Action-planning: Encourage YAs to plan to practice effective communication and self-advocating in different social scenarios to manage social perception and influences. Prompt the action plan with the following questions: what? when? where? how often/ long/ much? realistic? appropriate? start/ end? Assess YAs' confidence to carry out this personalised plan by asking them to rate their confidence on a 0-10 scale. Ask them if there is anything that can increase their confidence (if >7 on the scale). If yes, prompt YAs to restate the plan and rating, and potentially suggest ideas. If not, continue to the next step.	20-30
Behavioural contract and commitment: Agree with YAs about the new written commitment statement in their PCC plan, ensure that they understand it, and together with YA sign the contract.	5
Brainstorming exercise: challenging stigma and stereotypes. Split YAs into smaller groups (e.g., two groups with 5 or 6 participants each) and remind them of brief discussion and practice from the previous workshop about assertiveness as a communication style which involves expressing one's needs, preferences, and worries respectfully and confidently, while considering the rights and feelings of others. Then ask them to brainstorm and note down: ***Exercise 1*****:** As many assertiveness skills as they can think of. ***Exercise 2*****:** Then for the second exercise, in the same groups, ask them to familiarise themselves with two of the brief scenarios below, and discuss and note down potential communication strategies to challenge or address the stigma and stereotypes presented in the scenario: *Scenario 1*: Someone overhears you talking about your CKD and says: "Oh, that's the old's person disease, right?" - How would you respond? *Scenario 2*: You are hanging out with your friend who knows about your condition. During a conversation, they make a joke about your	50-60

kidney problem that makes you uncomfortable - How would you address it and respond?

Allow about 10 minutes for the first exercise and about 20 minutes for the second exercise. Then encourage participants to share their ideas with everyone. Following this, provide YAs with examples (use examples below) and demonstrate how to ideally respond to each scenario and encourage comparison with their own performance in group discussion.

-Exercise 1) Assertiveness skills: clear communication, the use of "I" statements, active listening, empathy, expressing needs and setting boundaries, saying "no", offering alternatives, dealing with criticism, handling disagreements, and acknowledging own feelings. Other aspects to be mindful of: body language, tone of voice, and staying calm.

-Exercise 2): <u>Scenario 1</u>: Encourage the practice of dismissing myths and stereotypes. Example of the response: *"Actually, CKD can affect people of all ages, not just older people. The notion that it's an old person's disease is a myth. It's important to be aware that kidney health matters at any age and stage of life as it can allow for an early diagnosis".*

<u>Scenario 2:</u> Encourage the practice of addressing the situation assertively. Example of the response: "*I know that you didn't mean anything by this joke, but I want to let you know that living with CKD can be challenging, and jokes like these sometimes make me feel uncomfortable. So, I'd appreciate it if we can avoid making fun of kidney problems".*

Break	20-30
Role-plays: assertively responding to peer pressure. Per up YAs and encourage them to practice effective communication and self-advocacy to deal with social influence in three role-play scenarios. During the role-plays, ensure a respectful and supportive environment and emphasise the focus on practising skills, rather than perfect performance.	60-90

-<u>Preparation:</u> Prompt participants to spend time reading the context of the scene, and then appoint one participant to act as a person facing peer pressure (participant 1), and one to act as a person applying pressure (participant 2).	-<u>Preparation:</u> Prompt participants to familiarise themselves with scenario 2, and ensure that they switched roles. *<u>Scenario 2</u>*: Your friends pressure you to drink alcohol at the party, despite knowing that you	-<u>Preparation:</u> Prompt participants to familiarise themselves with scenario 3, and ensure that they switched roles again. *<u>Scenario 3</u>*: Your friend is making fun of someone based on their appearance. Practise standing up against bullying, expressing your

<u>*Scenario 1*:</u> A friend wants you to skip a class with them. Practice asserting that you prefer to attend the class and explain your reasons.	should watch your alcohol intake. Practise expressing your concerns about drinking, explaining how it may affect your health, and asserting your choice not to drink.	concerns and discomfort with this behaviour, and advocating for respect. *Allow approximately 15 minutes for practising each scenario, including preparation time.*	
Group discussion: At the end of the role-plays, encourage reflection and facilitate a group discussion to allow participants to share their key learnings from the role-plays. Prompt participants to report on what went well and what could be improved in the discussions in all three scenarios. Encourage them to discuss any additional strategies that they think may improve effective communication and self-advocacy skills when dealing with social perception and influence.			
Social Support: Encourage YAs to spend some time thinking about whom they could contact for support when required, particularly those who would encourage them in continuing behaviour change, including friends, family, or professionals. Ask if YAs made any connections at the previous workshop and perhaps can motivate and support each other outside workshops. Additionally, provide relevant resources if possible (e.g., peer groups that offer support - locally dependent).			10-15
Homework (practice, self-monitoring, and self-reflection): Encourage YAs to continue practising skills and filling in the diary in the next week as homework. Advise them to begin with easy-to-perform tasks and gradually increase task difficulty by moving to the next task of their homework. Encourage self-reflection and self-praise whenever progress in performing behaviour is made, as well as self-monitoring by directing YAs to fill in their plans daily. Discuss the information about homework below and ensure that participants understand what is being asked of them. ***Task 1*****:** Think of a situation where you may feel like others are judging you negatively. Write down how you feel when this happens. Then, make a list of three people you can talk to for support in these situations. Also, think about ways to avoid such situations. Write in your daily diary how reaching out to people for support and avoiding these situations could help you overcome negative social influences. Remember, it is important to seek support when you need it. ***Task 2*****:** Once you feel confident with the strategies identified in Task 1, choose a situation to apply them. Practice with a new person or someone you know. Afterwards, ask the responder how well you did. Note down their positive affirmations, and if identified, any areas of improvement. Then, engage in a self-reflection by writing how you think the exercise went, what you did well, and how you think you could improve.			10-15

Next workshop: (date, time, and place)

Step 4:

Post-Workshop Wrap-Up:

-Summary of key points, questions and answers, and next workshop:

Provide YAs with a brief summary of the workshop, including the most important concepts and lessons that were learned. Prompt YAs to ask questions or share their final thoughts, and ensure to address any remaining doubts or concerns they may have. Finally, set up/agree on a date, time, and place for the next workshop. Spend approximately 20-30 minutes on this activity.

[*Estimated workshop time: between 5-7 hours*]

Guide sheet for Facilitator - **Workshop 3**:

Pre-Workshop Preparations:

-Revise the pre-preparation plan from Workshop 1:

Revise steps from pre-workshop 1 preparation, including, defining objectives, planning the agenda, gathering materials, and checking the venue.

During Workshop 3:

Step 1:

Welcome, re-establish rapport, provide feedback, and remind ground rules:

Follow the same steps as in Workshop 2 step 1. Spend approximately 20-30 minutes on this activity.

Step 2:

Stage assessment:

Utilise the questions below to assess YAs' stage of readiness for behaviour change. Note that, YAs indicating 1 and 2 are categorised as pre-intenders, those indicating 3 as intenders, and 4 and 5 as actors. Note down a stage for each YA and utilise this information throughout the workshop to employ the most appropriate stage-specific strategies. Spend approximately 10-15 minutes on this activity.

"Think back to the month before this workshop. Did you reach out to friends or family when you needed someone to talk to or comfort you? Please choose the statement that best describes you.

1."No, and I do not intend to start"	2."No, but I am considering it"	3."No, but I seriously intend to start"	4."Yes, but only for a brief period"	5."Yes, and for a long period"
☐	☐	☐	☐	☐

Adapted from Lippke et al. (2012).

Step 3:

Encourage the continuous use of PCC plans by prompting YAs to carry on developing their plans in workshop 3 (see below).

Workshop 3: Behavioural determinant(s): **Communication and self-advocacy skills to** 1) communicate individual needs, preferences, and worries associated with CKD/ 2. Deal with social perception and influence **3. Seek emotional support.**	**Estimated time for activity (minutes)**
Outcome expectancies: Prompt YAs to individually list positive health outcomes of effective communication and self-advocacy skills to seek emotional support, from peers and/or family, while considering the impact on their emotional well-being.	10-15
Risk perception: Prompt YAs to individually list potential consequences of not being able to seek emotional support, from peers and/or family, while considering the impact on their emotional well-being.	10-15
In the group, briefly discuss with YAs the identified outcome expectancies and risk perception, and highlight others not listed.	10-15
Reviewing and setting new goals: Prompt YAs to review their goals and set new personalised goals guided by SMART (Specific, Measurable, Achievable, Realistic, and Timely) goals, related to a new behavioural determinant, as well as to the outcome of desired behaviour. Once completed, review these personalised goals, ensuring that they follow SMART goals, in brief group discussions. In situations where participants struggle to set personalised goals, ask them permission to share ideas based on own experience or examples from previous group sessions, and share 2-3 ideas.	15-20
Break	20-30
Problem-solving: Prompt YAs to identify, analyse, and note down barriers preventing them from effectively communicating and self-advocating to seek emotional support when needed. Briefly discuss in a group.	15-20
Action-planning: Encourage YAs to plan to practice effective communication and self-advocating in different social scenarios to seek emotional support. Prompt the action plan with the following questions: what? when? where? how often/ long/ much? realistic? appropriate? start/ end? Assess YAs' confidence to carry out this personalised plan by asking them to rate their confidence on a 0-10 scale. Ask them if there is anything that can increase their confidence (if >7 on the scale). If yes, prompt YAs to restate the plan and rating, and potentially suggest ideas. If not, continue to the next step.	20-30
Behavioural contract and commitment: Agree with YAs about the new written commitment statement in their PCC plan, ensure that they understand it, and together with YA sign the contract.	5
Brainstorming exercise: Split YAs into smaller groups and prompt them to do the following exercises:	30-45

<table>
<tr><td colspan="3">***Exercise 1***: Think of, and note down, situations when you may require to seek emotional support from your peers or family members. Consider, for example, situations that made you anxious or uncertain and worried.
In the same groups, ask YAs to select one of the situations (e.g., the most common one) considered in the first exercise and:
Exercise 2: In the same groups, select one of the situations (e.g., the most common one) considered in the first exercise and list as many strategies you can think of to reduce negative emotions caused by the chosen situation.
Allow about 10-15 minutes for each exercise and then encourage participants to share their ideas with everyone. Following this, provide YAs with additional examples of stress management strategies (use examples below).
-**Exercise 2**): Examples of stress management strategies:
Deep breathing exercises (deeply inhaling through the nose, holding for a few seconds, and slowly exhaling through the mouth); muscle relaxation (tensing and then relaxing muscle group in the body, starting with the toes and working way up); mindfulness and meditation (engaging in mindfulness and meditation practices, while staying present and reducing anxious thoughts and focusing on breathing, calming phrases, and bodily sensations); challenging negative thoughts with positive affirmations; engaging in activities that one enjoys (e.g., hobbies); other personalised relaxation techniques that help one relax, as well as ensuring regular exercises, healthy diet, adequate sleep, and limited screen time.
Remind participants that different strategies work for different people, thus it is important to find strategies that resonate with them.</td><td></td></tr>
<tr><td colspan="3">*Break*</td><td>20-30</td></tr>
<tr><td colspan="3">**Role-plays:**
Per up YAs and encourage them to utilise the information learnt from the brainstorming exercises in three different scenarios below. Explain to participants that the role of “Participant 1” is to seek emotional support based on a given scenario, and the role of “Participant 2” is to utilise the information learnt from the previous task to provide their buddy with advice. During the role-plays, ensure a respectful and supportive environment and emphasise the focus on practising skills, rather than perfect performance.</td><td>60-90</td></tr>
<tr><td>-Preparation:
Prompt participants to spend time reading the context of the scene, and then appoint one participant to act as a person seeking emotional support for a specific situation (participant 1), and one</td><td>-Preparation:
Prompt participants to familiarise themselves with scenario 2, and ensure that they switched roles.

Scenario 2:</td><td>-Preparation:
Prompt participants to familiarise themselves with scenario 3, and ensure that they switched roles again.

Scenario 3:
You (participant 1) have been feeling</td><td></td></tr>
</table>

to act as a person providing support (participant 2). *Scenario 1:* You (participant 1) have been feeling increasingly anxious about joining the peer support group for the first time. Express your concerns and seek help from your buddy on how to reduce your anxiety and any negative thoughts.	You (participant 1) have been feeling anxious and uncertain about your career path after completing your studies, not knowing what opportunities await. Express your concerns and pursue advice from your buddy.	increasingly overwhelmed by juggling between medical appointments and study deadlines. Express your concerns and pursue advice from your buddy. *Allow approximately 15 minutes for practising each scenario, including preparation time.*	
Group discussion: At the end of the role-plays, encourage reflection and facilitate a group discussion to allow participants to share their key learnings from the role-plays. Prompt participants to report on what went well and what could be improved in the discussions in all three scenarios. Encourage them to discuss any additional strategies that they think may improve effective communication and self-advocacy skills when seeking emotional support.			
Social Support: Encourage YAs to spend some time thinking about whom they could contact for emotional support when required, including friends, family, or professionals. Additionally, provide relevant resources if available.			10-15
Homework (practice, self-monitoring, and self-reflection): Encourage YAs to continue practising skills and filling in the diary in the next week as homework. Advise them to begin with easy-to-perform tasks and gradually increase task difficulty by moving to the next task of their homework. Encourage self-reflection and self-praise whenever progress in performing behaviour is made, as well as self-monitoring by directing YAs to fill in their plans daily. Discuss the information about homework below and ensure that participants understand what is being asked of them. ***Task 1*:** In a situation where you feel anxious or uncertain about something, practice different strategies discussed at the workshop and reflect on how effective these were in reducing your negative emotions. List them down starting with the most effective strategy that works for you, followed by less effective strategies, and include a brief note about why a particular strategy works for you and in what situation(s). ***Task 2*:** Choose a friend or a family member and share with them a recent challenge that you faced and express your interest in seeking their advice. Then, engage in a self-reflection by writing how you think the exercise went, what you did well, and how you think you could improve.			10-15

Next workshop: (date - *1-month post-Workshop 3,* time, and place)

Step 4:

Post-Workshop Wrap-Up:

-Summary of key points, questions and answers, and next workshop:

Provide YAs with a brief summary of the workshop, including the most important concepts and lessons that were learned. Prompt YAs to ask questions or share their final thoughts, and ensure to address any remaining doubts or concerns they may have. Finally, remind participants that the next, last workshop will take place after one month and it will involve reviewing workshops and skills they learnt. Set up/agree on a date, time, and place for the next workshop accordingly. Spend approximately 20-30 minutes on this activity.

[*Estimated workshop time: between 5-7 hours*]

Guide sheet for Facilitator - **Workshop 4**:

Pre-Workshop Preparations:

-Revise the pre-preparation plan from Workshop 1:

Revise steps from pre-workshop 1 preparation, including, defining objectives, planning the agenda, gathering materials, and checking the venue.

During Workshop 4:

Step 1:

Welcome, re-establish rapport, provide feedback, and remind ground rules:

Follow the same steps as in Workshop 2 step 1, and remind the participants that this is the final workshop. Spend approximately 20-30 minutes on this activity.

Step 2:

Stage assessment:

Utilise the questions below again to assess YAs' stage of readiness for behaviour change, this time for all three behavioural determinants. Note that, YAs indicating 1 and 2 are categorised as pre-intenders, those indicating 3 as intenders, and 4 and 5 as actors. Review with YAs their stage progress from the first workshop and provide feedback. Acknowledge any progress made by reinforcing successful performance. Spend approximately 20-30 minutes on this activity.

"Think about the time since the first workshop a few weeks ago. Have you been practising how to effectively communicate and stand up for yourself? Have you been sharing your own needs, preferences, and worries associated with CKD? Have you been trying to get support when you need it emotionally? Please choose the statement that best describes you.				
1."No, and I do not intend to start"	2."No, but I am considering it"	3."No, but I seriously intend to start"	4."Yes, but only for a brief period"	5."Yes, and for a long period"
☐	☐	☐	☐	☐

Adapted from Lippke et al. (2012).

Note that, if any of the participants are categorised as pre-intenders at this stage, review their behaviour and outcome goals and set new SMART goals, and if required, prompt them to revisit outcome expectancies and risk perception to each behavioural determinant from previous workshops.

Step 3:
Refer YAs to their PCC plans for this final workshop 4 (see below).

Workshop 4: Behavioural determinant(s): **Communication and self-advocacy skills to 1) communicate individual needs, preferences, and worries associated with CKD/ 2. Deal with social perception and influence 3. Seek emotional support.**	**Estimated time for activity (minutes)**
Maintenance phase: **Discussion on relapse and prevention strategies:** Begin the workshop by explaining the concept of relapse and its part in behaviour change, making participants aware that setbacks are a normal part of the process and that relapse prevention is a continuing process. Following this, prompt YAs to the tasks below, and advise them to consider participation in social activities behaviour.	10-15
Exercise 1: Encourage YAs to individually list potential personal triggers that they think may lead to relapse (e.g., stress or unexpected life events). Once completed, facilitate a group discussion by asking participants to share their ideas. Note each potential trigger visibly on the flipchart to refer to it when discussing relapse prevention strategies.	30-40
***Exercise 2*:** Split participants into smaller groups, and encourage them to brainstorm all potential prevention relapse strategies they can think of for each selected trigger from Task 1. Once completed, facilitate group discussion to debate the recognised potential strategies for each trigger. Provide YAs with additional not-mentioned strategies, and remind them that different strategies work for different people, thus it is important to find strategies that resonate with them.	40-50
Break	20-30
Recovery phase:	10-15

Discussion on overcoming setbacks and regaining commitment: Begin by explaining the recovery phase where individuals learn to overcome setbacks and regain commitment. Re-emphasise the importance of ongoing improvement and support, particularly in challenging situations.	
Group discussion: Prompt YAs to think of strategies to overcome setbacks, particularly to regain commitment, and discuss in a group discussion. Again, advise them to consider participation in social activities.	30-40
Social support: Following the group exercise, re-emphasise the importance of ongoing support, and suggest establishing a means for participants to stay connected to continue sharing progress, challenges, and success beyond workshops. Further, task YAs to identify 3 people whom they could contact for support when they experience setbacks. Then when discussing homework, prompt participants to utilise social support in real life (see below).	10-15
Homework: Encourage continuous self-reflection and self-monitoring by prompting YAs to practise skills beyond workshops by engaging in final homework to continue with their PCC plan development. Ensure participants that during workshops they learnt how to plan set goals and plan action, and prompt them to the tasks below. ***Task 1:*** Continue with your PCC development, and use what you learned in the workshops on goal-setting, coping, and action planning. Start by setting goals and planning social activities that involve interacting with others. You can choose any activity you like, but consider what might prevent you from participating and come up with personal strategies to overcome those barriers. Remember different strategies work for different people, so find what works for you. When you are confident in your plan, sign the behavioural contract to make it official. Finally, seek support from someone you listed in the previous task. ***Task 2:*** Put your plan into action. Afterwards, reflect on how well you did and if any triggers could have caused you to relapse. Pre-plan and implement, when required, personalised strategies (specifically those that work for you) to prevent relapse, overcome setbacks and regain commitment. Use your support buddy for encouragement, emotional support, or to help you regain commitment. Remember to praise yourself for your successes and reward your good performance!	15-20

Encourage the ongoing PCC plan development for participating in social activities.

Step 4:

Post-Workshop Wrap-Up:

-Summary of key points, questions, and answers:

Provide YAs with a summary of the most important concepts and lessons learnt during workshops. Prompt YAs to ask questions or share their final thoughts, and ensure to address any remaining doubts or concerns they may have. Finally, remind

participants that this was the final workshop, express your gratitude and thank everyone for their active participation and engagement. Reflect on the journey and one more time encourage YAs to carry forward the key takeaways from workshops and wish them success in their continued journey. Spend approximately 30-40 minutes on this activity.
[*Estimated workshop time: between 4-5 hours*]

Appendix FFF

Intervention Content

Table FFF1

Workshop 1 - Communicating Individual Needs, Preferences, and Worries Associated with CKD

Stage assessment[c]					
HAPA stage (*Groups of YAs*)					
Motivational stage (*Pre-intenders*)		Volitional stage 1 (*Intenders*)		Volitional stage 2 (*Actors*)	
Potential stage-specific variables/ mediators to address[c]					
-Self-efficacy (motivational) -Risk perception -Outcome expectancies -Goal setting		-Action planning -Coping planning -Social support -Self-efficacy (maintenance)		-Action planning -Coping planning -Social support -Self-efficacy (recovery) -Action control	
Workshop content: (intervention functions: *Education, Training, and Enablement*)					
BCTs (*Potential mediators*)	Intervention strategies	BCTs (*Potential mediators*)	Intervention strategies	BCTs (*Potential mediators*)	Intervention strategies

Pre-workshop preparations and stage assessment	-Prepare for the workshop.[b] -Start the workshop by introducing yourself, getting to know YAs and building rapport.[b] -Conduct stage assessment.[a&b]	1.2 Problem-solving (*Coping planning*)	-Prompt YAs to identify, analyse, and note down barriers preventing them from effectively communicating and self-advocating their needs, preferences, and concerns in social interactions and briefly discuss in group personalised strategies that include overcoming these barriers. [a&b]	8.6 Generalisation of target behaviour; 8.7 Graded tasks; 10.9 Self-reward	*Homework:*[a&b] -Prompt YAs to continue practising tasks performed at the workshop, in the next week as homework. -Advice starting with easy-to-perform tasks (e.g., practising with close friends and/or family; see Task 1). Increase task difficulty by prompting YAs to practice tasks in various social situations (e.g., group discussion; see Task 2). -Prompt YA to self-praise and reward themselves if, and only if, they have made an effort and/or progress in performing the behaviour.

5.1 Information about health consequences; 5.3 Information about social and environmental consequences (*Outcome expectancies; risk perception*)	-Provide participants with intervention resources for YAs (PCC plans development)[a] and encourage their use throughout the whole intervention during workshops and as a daily diary outside the workshops. -Prompt YAs to think of the positive health outcomes of effectively communicating and self-advocating individual needs, preferences, and worries associated with CKD (e.g., increased confidence and improved social relationships).[a&b] -Prompt YAs to think of, and help them understand, the potential consequences of not being able to effectively communicate their needs and express their concerns. Discuss the above in a group discussion and highlight	1.4 Action Planning (*Action Planning*)	-Encourage YA to plan to practice effective communication and self-advocating in different social scenarios to communicate their needs, preferences, and worries (utilise questions from skill 2 in the BAP tool).[a&b] -Assess how confident YAs are to carry out this personalised plan and confirm whether anything could increase their confidence (question 2 and skill 4 from the BAP tool). If YAs indicate that their confidence could be improved, encourage them to restate the plan and rating, otherwise prompt them to the next step[a&b]	2.3 Self-monitoring of behaviour; 2.4 Self-monitoring of outcome(s) of behaviour (*Action control*)	-Encourage self-reflection by asking YAs to monitor and record daily (in the PCC plans) their tasks performed at home and in social situations.[a&b] -Encourage YAs to record how well they think they performed the tasks.[a&b]

	other examples if not listed.[a&b] Followed by the broad question: “What is the problem”				
1.1 Goal-setting (behaviour); 1.3 Goal-setting (outcome) (*Goal-setting/ Intention formation*)	-Prompt YAs to set personalised SMART goals (defined in relation to the behaviour to be achieved and a positive outcome of wanted behaviour) using a behavioural plan (skill 2 in BAP tool) and encourage YAs to note them down in the provided PCC plan.[a&b] Then in group, briefly discuss with YAs their personalised goals ensuring that they follow SMART goals.[b] Share ideas if required.	1.8 Behavioural contract; 1.9 Commitment	-Agree with YAs about the written commitment statement in the behavioural contract in the PCC plan and together with YAs sign the contract.[a]	Post-workshop wrap-up	-Conclude and agree upon the date and timing of the next workshop.[a&b]

	4.1 Instruction on how to perform the behaviour; 6.1 Demonstration of the behaviour	-*Brainstorming exercise*:[a&b] *Exercise 1:* -Split YAs into smaller groups and encourage them to think of, and not down, all types of communication they can think of. *Exercise 2:* -In the same groups, ask YAs to brainstorm and note down ideas on how to effectively communicate needs, preferences, and worries associated with CKD, with professionals, employers, and teachers. -Allow time for both exercises and prompt YAs to share their ideas with everyone once completed. Then provide YAs with additional examples which were not mentioned by participants. Use the examples of types of communication and strategies for effective communication of needs,

		preferences, and worries in various personal and professional contexts, included in the intervention resource.[b]	
	8.1 Behavioural practice/ rehearsal	-*Role-playing exercise:*[a&b] -Prompt YAs to practice effective communication and self-advocacy skills by utilising 3 scenarios provided in the intervention resources. -*Group discussion:* Following the role-plays, encourage reflection by facilitating group discussion. Discuss what went well in discussions, what could be improved, and additional effective strategies that arose during the practice.	

[a] Refer to the intervention resource for YAs in Appendix DDD; [b] Refer to the intervention resource for facilitators in Appendix EEE; [c] Potential stage-specific variables (mediators) were adapted from the intervention matrix for HAPA-based stage-specific treatments in Schwarzer et al. (2011)' study. *BAP* Brief Action Planning; *BCT* Behaviour Change Techniques; *CKD* Chronic Kidney Disease; *HAPA* Health Action Process Approach; *PCC* Person-centred Care; *SMART* Specific, Measurable, Achievable, Realistic, and Timely; *YA* Young Adults.

Table FFF2

Workshop 2 - Dealing with Social Perception and Influence

Stage assessment[c]					
HAPA stage (*Groups of YAs*)					
Motivational stage (*Pre-intenders*)		Volitional stage 1 (*Intenders*)		Volitional stage 2 (*Actors*)	
Potential stage-specific variables/ mediators to address[c]					
-Task self-efficacy (motivational) -Risk perception -Outcome expectancies -Goal setting		-Action planning -Coping planning -Social support -Maintenance Self-efficacy		-Action planning -Coping planning -Social support -Recovery self-efficacy -Action control	
Workshop content: (intervention functions: *Environmental Restructuring and Enablement*)					
BCTs (*Potential mediators*)	Intervention strategies	BCTs (*Potential mediators*)	Intervention strategies	BCTs (*Potential mediators*)	Intervention strategies
Pre-workshop preparations, welcome, and feedback: 2.2 Feedback on behaviour; 2.7 feedback on the outcome(s) of behaviour; And stage assessment and	-Revise the pre-preparation plan from workshop 1, and adapt to YAs' feedback on the previous workshop when required.[b] -Start with re-establishing rapport, providing a brief workshop overview, and reminding participants about ground rules.[b] -Ask YAs how they have been doing since the last workshop. Discuss how their homework went -	1.2 Problem-solving (*Coping planning)*	-Prompt YAs to identify, analyse, and note down barriers preventing them from effectively dealing with social perception and influence, and briefly discuss in group personalised strategies that include overcoming these barriers. [a&b]	8.6 Generalisation of target behaviour; 8.7 Graded tasks; 10.9 Self-reward; 12.2 Restructuring the social environment; 6.3 Information	*Homework:*[a&b] -Prompt YAs to continue practising skills in the next week as homework. -Advice starting with easy-to-perform tasks, increasing task difficulty by moving to the next task once confident with task 1. -Prompt YA to self-praise and reward themselves if, and only

	what worked/ did not, and why. Ask YAs whether they would like to discuss any particular issues today, and if yes, spend time discussing these.[a&b] -Provide YAs with feedback on their learnt skills and outcome(s) of performing desired behaviours, address any areas of improvement and reinforce successful performance.[a&b] -Conduct stage assessment.[a&b]			about others' approval	if, they have made an effort and/or progress in performing the behaviour.
5.1 Information about health consequences; 5.3 Information about social and environmental consequences (*Outcome expectancies; risk perception*)	-Prompt YAs to restate their outcome expectancies (positive health outcomes of effective communication and self-advocacy to deal with social perception and influence) and risk perception (potential consequences of not being able to deal with social perception and influence). Discuss the above in a group discussion and highlight other examples if	1.4 Action Planning (*Action Planning*)	-Encourage YA to set new plans for the coming week to practice effective communication and self-advocating skills in different social scenarios to deal with social perception and influence.[a&b] -Assess how confident YAs are to carry out this new plan and confirm whether anything could increase their confidence.	2.3 Self-monitoring of behaviour; 2.4 Self-monitoring of outcome(s) of behaviour (*Action control*)	-Encourage self-reflection by reminding YAs to monitor and record daily (in the PCC plans) their tasks performed at home and in social situations.[a&b]

	not listed.[a&b]		If yes, encourage them to restate the plan and rating, otherwise prompt them to the next step.[a&b]		
1.5 Review behaviour goal(s); 1.7 Review outcome goal(s) (*Goal-setting/ Intention formation*)	-Review behaviours and outcome(s) goals to add skills (set new SMART goals) to effective communication and self-advocacy, specifically to deal with social perception and influence.[a&b] Share ideas if required.	1.8 behavioural contract; 1.9 Commitment	-Agree with YA about a new written commitment statement in the behavioural contract in the PCC plan and together with YA sign the new contract.[a]	Post-workshop wrap-up	-Conclude and agree upon the date and timing of the next workshop.[a&b]

	4.1 Instruction on how to perform the behaviour; 6.1 Demonstration of the behaviour; 6.2 Social comparison	-*Brainstorming exercise:*[a&b] *Exercise 1:* -Split YAs into smaller groups and encourage them to think of, and note down, as many assertiveness skills as they can think of. *Exercise 2:* -In the same groups, ask YAs to familiarise themselves with 2 provided scenarios and ask them to brainstorm and note down ideas on how to effectively address or challenge the stigma and stereotypes presented in scenarios. -Once completed, prompt YAs to share their ideas with everyone. Then provide YAs with examples (utilise those in intervention resources), demonstrate how to ideally respond to each scenario, and encourage comparison with their	

own performance in group discussion.

	8.1 Behavioural practice/ rehearsal	-*Role-playing exercise:*[a&b] -Prompt YAs to practice assertive responses to peer pressure by utilising 3 scenarios provided in the intervention resource. -*Group discussion:* Following the role-plays, encourage reflection by facilitating group discussion. Discuss what went well in discussions, what could be improved, and additional effective strategies that arose during the practice.	
	3.1 Social support (unspecified) (*Social support*)	Prompt YAs to spend time thinking about whom they could contact for support when required, particularly those who would encourage them in continuing behaviour change.[a&b]	

[a] Refer to the intervention resource for YAs in Appendix DDD; [b] Refer to the intervention resource for facilitators in Appendix EEE; [c] Potential stage-specific variables (mediators) were adapted from the intervention matrix for HAPA-based stage-specific treatments in Schwarzer et al. (2011)' study. *BCT* Behaviour Change Techniques; *HAPA* Health Action Process Approach; *PCC* Person-centred Care; *SMART* Specific, Measurable, Achievable, Realistic, and Timely; *YA* Young Adults.

Table FFF3

Workshop 3 - Seeking Emotional Support

Stage assessment[c]					
HAPA stage (*Groups of YAs*)					
Motivational stage (*Pre-intenders*)		Volitional stage 1 (*Intenders*)		Volitional stage 2 (*Actors*)	
Potential stage-specific variables/ mediators to address[c]					
-Task self-efficacy (motivational) -Risk perception -Outcome expectancies -Goal setting		-Action planning -Coping planning -Social support -Maintenance Self-efficacy		-Action planning -Coping planning -Social support -Recovery self-efficacy -Action control	
Workshop content: (intervention functions: *Persuasion, Modelling, and Enablement*)					
BCTs (*Potential mediators*)	Intervention strategies	BCTs (*Potential mediators*)	Intervention strategies	BCTs (*Potential mediators*)	Intervention strategies
Pre-workshop preparations, welcome, and feedback: 2.2 Feedback on behaviour; 2.7 feedback on the outcome(s) of behaviour; And stage assessment and	-Repeat steps from the previous workshop in terms of pre-preparation, re-establishing rapport, providing a brief workshop overview, and reminding participants about ground rules.[b] -Ask YAs how they have been doing since the last workshop. Discuss how their homework went, what worked/ did not, and why. Ask YAs whether they	1.2 Problem-solving (*Coping planning)*	-Prompt YAs to identify, analyse, and note down barriers preventing them from effectively seeking emotional support from peers and family, and briefly discuss in group personalised strategies that include overcoming these barriers.[a&b]	8.6 Generalisation of target behaviour; 8.7 Graded tasks; 10.9 Self-reward	*Homework:*[a&b] -Prompt YAs to continue practising skills in the next month as homework. -Advice starting with easy-to-perform tasks, increasing task difficulty by moving to the next task once confident with task 1. -Prompt YA to self-praise and reward themselves if, and only

	would like to discuss any issues today, and if yes, spend time discussing these.[a&b] -Repeat provision of feedback on homework performance and learnt skills, address any areas of improvement, and reinforce successful performance.[a&b] -Repeat stage assessment.[a&b]				if, they have tried and/or progressed in performing the behaviour.
5.1 Information about health consequences; 5.3 Information about social and environmental consequences; 5.6 Information about emotional consequences (*Outcome expectancies; risk*	-Prompt YAs to restate their outcome expectancies (positive health outcomes of effectively seeking emotional support from peers and family) and risk perception (potential consequences of not being able to seek emotional support), while also considering the impact on their emotional well-being. Discuss the above in a group discussion and highlight other examples if not listed.[a&b]	1.4 Action Planning (*Action Planning*)	-Encourage YA to set new plans for the coming week to practice effective communication and self-advocating skills in different social scenarios to seek emotional support.[a&b] -Assess how confident YAs are to carry out this new plan and confirm whether anything could increase their confidence. If yes, encourage them to restate the plan and rating, otherwise prompt them to the next step.[a&b]	2.3 Self-monitoring of behaviour; 2.4 Self-monitoring of outcome(s) of behaviour (*Action control*)	-Encourage self-reflection by reminding YAs to monitor and record daily (in the PCC plans) their tasks performed at home and in social situations.[a&b]

perception)					
1.5 Review behaviour goal(s); 1.7 Review outcome goal(s) (*Goal-setting/ Intention formation*)	-Review behaviours and outcome(s) goals to add skills (set new SMART goals) to effective communication and self-advocacy, specifically to seek emotional support.[a&b] Share ideas if required.	1.8 behavioural contract; 1.9 Commitment	-Agree with YAs about a new written commitment statement in the behavioural contract in the PCC plan and together with YAs sign the new contract.[a]	Post-workshop wrap-up	-Conclude and remind YAs that the last workshop will take place one month after this workshop, and thus set up the date and timing of the next workshop accordingly.[a&b]
		4.1 Instruction on how to perform the behaviour 6.1 Demonstration of the behaviour; 11.2 Reduce negative emotions	-*Brainstorming exercise:*[a&b] *Exercise 1:* -Split YAs into smaller groups and encourage them to think of and note down situations when they may require emotional support from their peers or family members. *Exercise 2:* -In the same groups, ask YAs to select one of the situations considered in the first exercise and list as many strategies they can think of to reduce negative emotions caused by the chosen situation.		

	-Once completed, prompt YAs to share their ideas with everyone. Then provide YAs with additional stress management strategies not mentioned by participants (utilise examples in intervention resources).
8.1 Behavioural practice/ rehearsal	-*Role-playing exercise:*[a&b] -Pair up participants and prompt them to utilise the information learnt from the brainstorming exercises in three role-plays -*Group discussion:* Following the role-plays, encourage reflection by facilitating group discussion. Discuss what went well in discussions, what could be improved, and additional effective strategies that arose during the practice.

	3.3 Social Support (emotional) (*Social support*)	Prompt YAs to spend time thinking about whom they could contact for support when required, with emphasis on emotional support.[a&b]

[a] Refer to the intervention resource for YAs in Appendix DDD; [b] Refer to the intervention resource for facilitators in Appendix EEE; [c] Potential stage-specific variables (mediators) were adapted from the intervention matrix for HAPA-based stage-specific treatments in Schwarzer et al. (2011)' study. *BCT* Behaviour Change Techniques; *HAPA* Health Action Process Approach; *PCC* Person-centred Care; *SMART* Specific, Measurable, Achievable, Realistic, and Timely; *YA* Young Adults.

Table FFF4

Workshop 4 - Reviewing Behaviour Change

Stage assessment[c]					
HAPA stage (*Groups of YAs*)					
Motivational stage (*Pre-intenders*)		Volitional stage 1 (*Intenders*)		Volitional stage 2 (*Actors*)	
Potential stage-specific variables/ mediators to address[c]					
-Task self-efficacy (motivational) -Risk perception -Outcome expectancies -Goal setting		-Action planning -Coping planning -Social support -Maintenance Self-efficacy		-Action planning -Coping planning -Social support -Recovery self-efficacy -Action control	
Workshop focus: a *review of behaviour(s) and maintenance and recovery phases*					
BCTs (*Potential mediators*)	Intervention strategies	BCTs (*Potential mediators*)	Intervention strategies	BCTs (*Potential mediators*)	Intervention strategies
Pre-workshop preparations, welcome, and feedback: 2.2 Feedback on behaviour; 2.7 feedback on the outcome(s) of behaviour; And stage assessment and	-Repeat steps from the previous workshop in terms of pre-preparation, re-establishing rapport, providing a brief workshop overview, and reminding participants about ground rules.[b] -Ask YAs how they have been doing since the last month. Discuss how their homework went, what worked/ did not, and why. Ask whether they would	1.2 Problem-solving (*Coping planning);* 4.1 Instruction on how to perform the behaviour	*Relapse and prevention strategies* -Facilitate a group discussion on relapse prevention, beginning with explaining the concept of relapse, and advise YAs to consider participation in social activities while implementing the exercises below. -*Brainstorming exercise:*[a&b]	8.6 Generalisation of target behaviour; 8.7 Graded tasks; 10.9 Self-reward; 2.3 Self-monitoring of behaviour; 2.4 Self-monitoring of outcome(s) of	-Encourage continuous self-reflection and self-monitoring by prompting YAs to continue with their PCC plan development by engaging in final “homework”. *Homework:*[a&b] -*Task 1*: Prompt YAs to continue practising skills beyond workshops, particularly goal-setting, action and coping

	like to discuss any issues today, and if yes, spend time discussing these.[a&b] -Repeat provision of feedback on homework performance and learnt skills, address any areas of improvement, and reinforce successful performance.[a&b] -Repeat stage assessment for all 3 behavioural determinants, review and provide feedback on YAs' stage progress.[a&b]		*Exercise 1:* Encourage YAs to think about and share their personal triggers that may lead to relapse and note them down on a flip chart for the next task. *Exercise 2:* Split participants into smaller groups, and prompt them to brainstorm all potential prevention relapse strategies they can think of for each selected trigger. -*Group discussion:* Facilitate group discussion to debate all recognised potential strategies for each trigger and provide participants with additional not-mentioned strategies.	behaviour (*Action control*) [Homework also includes: 1.4 Action Planning (*Action Planning*); 1.8 behavioural contract; 1.9 Commitment; 8.1 Behavioural practice/ rehearsal]	planning for participating in social activities, while considering barriers to behaviour and strategies to overcome them. Encourage seeking support from one support buddy that they selected in the previous task. -*Task 2*: Encourage putting plans into action and self-reflecting on performance utilising PCC plans. Prompt identification and implementation of personalised strategies to prevent relapse, overcome setbacks and regain commitment that works them. Prompt to utilise social support. -Remind YA to self-praise and reward themselves if, and only if, they have tried and/or progressed in performing the

					behaviour.
		BCTs: 1.2 and 4.1 continue; 3.1 Social support (unspecified) (*Social support*)	*Overcoming setbacks and regaining commitment* -*Group discussion:*[a&b] Start by explaining the recovery phase where individuals learn to overcome setbacks and regain commitment. Encourage group discussion on potential strategies for these. -Re-emphasise the importance of ongoing support, especially in challenging situations, and suggest establishing a means for participants to stay connected to continue sharing progress, challenges, and success beyond workshops. -Prompt YAs to identify 3 people whom they could contact for support when they experience setbacks.[a&b]	Final post-workshop wrap-up	-Conclude this final workshop by summarising and emphasising key takeaways from all workshops, addressing any remaining doubts or concerns, and encouraging ongoing support.[a&b]

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[a] Refer to the intervention resource for YAs in Appendix DDD; [b] Refer to the intervention resource for facilitators in Appendix EEE; [c] Potential stage-specific variables (mediators) were adapted from the intervention matrix for HAPA-based stage-specific treatments in Schwarzer et al. (2011)' study. *BCT* Behaviour Change Techniques; *HAPA* Health Action

Process Approach; *PCC* Person-centred Care; *YA* Young Adult.

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