An introduction to the potential for the mobile ehealth revolution to impact on hard to reach, marginalised and excluded groups.

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This collection draws together contemporary research and thinking from leading scholars in the field of mobile ehealth. Here eHealth in this book is defined by the World Health Organisation (WHO, 2005) as the "the cost-effective and secure use of information communication technologies (ICT) in support of health and health related fields, including health-care services, health surveillance, health literature, and health education, knowledge and research" (page 109). eHealth is a broad term, which in the health care sector includes a broad scope of purposes ranging from purely administrative services across the spectrum of health care service delivery (Health Canada, 2010). Put simply, eHealth is the use of computing and associated technologies serving and promoting health and wellbeing needs. Mobile health is the use of mobile, wireless technologies to connect, communicate and promote this computing with the aim of supporting individual's health and wellbeing. The growing emphasis on mHealth programs is reflected in the WHO's 2016 report of the third global survey on eHealth noting that over 90% of member states countries reported at least one mHealth initiative (WHO, 2016).

Since the early 2000's, there has been unprecedented growth in the eHealth sector as the use of information and communication technology expands across both developed and developing countries (WHO, 2016). Traditional eHealth has been hugely advanced through improvements in mobile technologies and increased availability of applications. Continued growth of cellular networks across the globe fuel the rapid takeup of mHealth (WHO, 2016). Seven billion people, 95% of the global population, now live in an area covered by a mobile-cellular network (International Telecommunication Union, 2016). (); comprising of mobile-broadband networks of 3G or above each connecting 84% of the global population. However, there are large differences found between different countries and states. In developed countries around 90% of people have a mobile broadband contract and in Singapore and Japan the rate is over 100% (with people have over one subscription). In developing countries, the rate averages around 39%, but with great fluctuations – Africa remains the lowest continent of mobile subscriptions at around 20% network (International Telecommunication Union, 2016).

People are beginning to engage with digital technologies such as Fitbits, and mHealth apps to assist with self-monitoring and tracking one's health, physical activity and nutrition, in addition to managing chronic health conditions, such as diabetes or fall prevention (i.e. iStoppFalls). While research in this field is still in its infancy, digital care platforms available on the internet or through download to a digital device are growing in popularity. The notion of the quantified self may be increasingly realized through digital resources such as www.medhelp.org, a digital platform that partners with healthcare partners such as Merck and Fitbit to support patient engagement and deliver health solutions and drive changes in clinical outcomes to millions of users (See for example www.medhelp.com/) .

The use of digital games utilized for cognitive or physical rehabilitation in conjunction with the usability and accessibility issues is also relatively new. Hence, little is still unknown about the utility, use and best-design practices of these technologies for certain demographics. Although since 2008, research in the area of use and best-design practices has grown enabling researchers to explore and understand the needs and requirements of older adults in the domain of games for health and digital game playing (Marston & Graner Ray, 2015; Marston, 2013b; 2012; De Schutter, 2010; Nap et al., 2009; IJsselsteijn, et al., 2007;). In addition, research and thinking in this area stems from a variety of disciplines including public health, computer science, human-computer interaction (HCI), psychology, sociology and gerontology, resulting in very different questions being addressed and different research frameworks being utilized.

The intention of this proposed edited book is to collectively bring together a series of works primarily associated with life logging activities, mHealth apps and digital gaming across the lifespan. Since the turn of the 21st Century, researchers have been exploring the possibilities of utilizing commercial and purpose built digital game hardware and software for primary use within health rehabilitation aimed at adults approximately 60-70 years. There remains a gap in understanding of the barriers and facilitators of eHealth technology use by older compared to younger cohorts. There has been little emphasis on expanding understanding of how older adults engage in life logging activities via technology devices such as Fitbit or access online health resources to support self-care. Since the introduction of smartphones (e.g. iPhone), the popularity of mHealth apps amongst younger populations has grown exponentially, resulting in a variety of apps to enable users to self-monitor their health, and integrate their day-to-day

habits easier for example, online purchasing (e.g. Amazon), women's health (e.g. monitor menstrual cycle, pregnancy), order and pay for transport (e.g. coach companies, taxi firms), online dating, social media, utilities (e.g. flashlight, calculator), download and read documents (e.g. Adobe, Microsoft Word) and access up-to-date current affairs (e.g. BBC News). These are just some of the apps available and there are many more which have been specifically developed for towns and cities worldwide. Although the development and phenomenal take-up of smartphones has enabled the utility of mHealth apps to users across the lifespan, there is little published work associated to theoretical concepts, research methods and in-depth studies (e.g. feasibility, prospective, randomised control trials) focusing on the usability and accessibility of using apps, in addition to the accuracy and reliability of data collected over a period of time. Therefore, bringing together mHealth apps and ascertaining where in society these apps sit and whether users are gaining their full potential warrants further exploration and study.

The World Health Organisation (WHO) corporate strategy establishes the goals of building healthy populations and communities and combating ill-health through the adoption of four strategic approaches:

- Reducing excess mortality, morbidity and disability, especially in poor and marginalized populations.
- Promoting healthy lifestyles and reducing factors of risk to human health that arise from environmental, economic, social and behavioural causes.
- Developing health systems that equitably improve health outcomes, respond to peoples' legitimate demands, and are financially fair.
- Developing an enabling policy and institutional environment in the health sector, and promoting an effective health dimension to social, economic, environmental and development policy.

It is important to stress that health and wellbeing must be viewed beyond simply as services delivered by the health sector alone. The contribution of other sectors are vitally for improving the health and well-being of the population.

The United Nation's (UN) global partnership for sustainable development, Agenda 21 emphasised many elements which are necessary for the integration of local and national health concerns into environment and development planning. These are: (1) identification and assessment of health hazards associated with environment and development, (2) development of environmental health policy incorporating principles and strategies for all sectors responsible for development, (3) communication and advocacy of this policy to all levels of society and, (4) a participatory approach to implementing health-and-environment programmes. The potential for ehealth and mhealth to help meet these priorities across the globe is exciting. Increased data collection and sharing of such data at a macro and micro-level (for example life logging) can lead to better understanding and therefore early detection of or avoidance of hazards and can help develop and maintain evidence-based environmental health policy. Such technology advances communication between different sectors and different users across society and helps foster more of a participatory approach to health and wellbeing, giving individuals more responsibility for their own health and wellbeing, supported by a variety of experts.

Mobile eHealth technologies have the potential to support the health and wellbeing of vulnerable and marginalised populations who traditionally have been more difficult to reach groups on the margins of the greater population. This edited collection will highlight how mobile eHealth technologies can support such groups who traditionally might be excluded or find it difficult to reach mainstream services. The main group concentrated upon is the older population. Ageing is a global phenomenon, society is ageing at a faster rate than ever. People are living longer and at the same time birth rates and infant mortality is at an all-time low in many countries. Across the globe we live in an ageing society.

Western countries especially are seeing a rapidly ageing society due to a combination of people living longer due to better health and social care and lower birth rates. This results in both a higher number and a higher percentage of people in their later years. There are now 840 million people over 60 across the World, representing 11.7 per cent of the population. In 1950, there were only 384.7 million people aged over 60, representing only 8.6 per cent of the global population (UN, 2015).

Projections suggest there will be 2 billion people aged over 60, representing 21.2 per cent of the global population by 2050 (UN, 2015). The rate of increase in older people is faster in wealthier countries. For example, the United Kingdom (UK) will reach 25% of the population being over 60 by around 2030 (ONS, 2015). The health of an ageing society is naturally of utmost importance as the prevalence of chronic disease is increased among . It is imperative that older people not only live longer but live well for longer, that they are healthy and have good quality of life, that they are not excluded from activity and stay connected to the things that matter to them.

On the face of it, it seems telehealth and telecare systems should be able to support individuals to remain independent and able to live at home longer without recourse to using services. But not only does the right technology need to be available and accessible to the right person at the right time in their preferred location of care but that it must also be provided in a safe and secure manner which meets legal standards and policies. As one may see from chapter six which comprises of three contributions by Lynch and Fisk, Mantovani and Cristobal Bocos and Wiersinga) this may not be as straightforward as is hoped. We need to understand the specific detail of the in-person interaction between individual and health professional. When compared to traditional provision of face to face care, important questions arise including can telehealth provide the same or better level of care; does provision of care through telehealth supports identify the same detail as in person consultation does? Can eHealth web platforms and apps identify the nuances that in person consultation can do? Above all, the question remains, how and when should it supplement or replace in person consultation? The answer is, yet, we just do not have a strong enough evidence base to reliably know and more research is needed to identify how eHealth may fit into practice within and across countries.

An example of where we now, in terms of how mobile eHealth, can be seen in the prolific availability of apps available to support someone living with long-term chronic pain. Rosser and Eccleston noted in 2011 that in this case a person may have access to at least 111 different apps to support living with their pain. These range from passive systems that provide information (54% of them), to monitoring and tracking (24%) and interventions (17%), some provide linking with healthcare, some are individual, some provide peer to peer support (Rosse and Eccleston, 2011). Since 2011, one can only imagine the vast number of apps which would now be available given the vast expansion in digital app and eHealth

technology. Faced with the plethora of apps, it can be overwhelming for a patient or even a health professional make the correct choice of which eHealth resource best fits the needs of the person.

Despite the abundance of available applications, the scientific evaluation of apps is scarce. Moreover, there are barriers to the use of mHealth for chronic pain management, which are similar for other conditions. Vardeh et al. (2013) identify (1) security and privacy concerns, (2) the burden of too much information (especially via sound and text), (3) an overwhelming amount of information, (4) an overemphasis on pain rather than exploring diversionary tactics, (5) poor compatibility with other records (for example medical records), (6) physical or cognitive restriction in using the device and (7) that costs may be increased rather than reduced. In this book, the chapter by Ruzic and Sanford (Chapter 2) examines this in more detail.

More research is not only needed on the efficacy of such systems, but on the acceptability as well. Developing evidence based standards, co-designing of apps with people who would use them and having systematic design strategies, start to order such a milieu of technology. This collection of papers deals with this, see Fisk and Lynch (Chapter 6), for example, on setting standards and Ruzic and Sanford on design strategies (Chapter 2), especially relating their new set of standards to people living with Multiple Sclerosis as they age.

Digital technology is often seen as a panacea for global health issues, not least in developing countries with dispersed communities and limited resources. Indeed, there are more mobile apps per head in Africa than any other developing country outside of India. Successful examples include speeding up of early infant HIV diagnosis by turning around test results quicker in the SMART project Nigeria, and improving access to health information and services among rural women and children in The Mobile Technology for Community Health (MOTECH) initiative with the Ghana Health Service. Access to healthcare varies considerably across different developing countries and regions.

As a result, inequalities exist in provision healthcare across developing countries. Generally, people living in urban locations have better access to healthcare than the rural areas. The dispersed nature of populations and healthcare in developing countries have resulted in the World Health Organisation promoting eHealth projects aimed at crossing the physical

accessibility to healthcare. As an example in Africa where inequalities are high, these include the Telemedicine Network for Francophone African Countries (RAFT), Access to Research in Health Programme, ePortuguese Network and Pan-African e-Network Project.

This collection of chapters can help to demystify the mobile eHealth revolution. It offers up a mirror which helps researchers, developers and society look at technological advances and identifies technology, as the primary means of leading the mobile eHealth revolution. We need to pause and slow down the technocratic approach to allow for an evidence base to be developed to show whether the plethora of eHealth technology is assisting to improve the health and wellbeing of individuals in contrast to simply be a means of generating revenue for its creators. Chapters in this book will assist to support better understanding of how eHealth technology fits within society and within individual lives. It is paramount to reflect on whether technology enables its users to improve their daily lives, to function better collectively and individually.

We start this collection with Ruzic and Stanford (Chapter 2) who look at four different design strategies for involving older people in developing usability of technologies – Universal Design, design for Ageing, Universal Usability and handheld Mobile Device Interface Design. All four have merits, but not one approach does everything. It is a case of choosing the right approach for the questions being asked or utilising the best parts of all four approaches. In bringing the best parts of each together the integrative guidelines Universal Design Mobile Interface Guidelines (UDMIG) are proposed and their refinement and applicability are discussed in the chapter.

The nature of mobile eHealth that allows personalisation and connectivity with other people, fosters a perfect platform for developing support for people in the form of challenges or games. Across Europe the Interactive Software Federation of Europe (ISFE) has reported digital game play across Europe to decrease as people age, with most gamers being in the youth categories (ISFE, 2012). But there has been an increase in looking at older digital gamers (Musselwhite et al., 2016). Marston (2013; 2012) identified a series of rationales, pleasures, in-game perspectives as to why older adults would engage with games: a purpose, educational elements, goals, addressing real problems, gain knowledge, enjoyment, satisfaction, and obstacles. For the game to be successful the implementation of objectives,

challenges, goals, and rewards, should be introduced over the duration of play. Malone (1980; 1982) and IJsselsteijn et al. (2007) suggest implementing varying and increasing levels of difficulty to facilitate this goal. Allowing users to build upon their skill and mastery is an important element of gaming. Offering users, the opportunity to complete different levels will enable users to build upon one's self-confidence and the skills needed (Malone, 1981; 1982; Melenhorst, 2002; IJsselsteijn et al., 2007).

Implementing specific content into a game has the potential to build upon ones' knowledge; therefore, learning enables users to enhance their skills, knowledge, and personal achievement. Understanding the design requirements of older adults is one of the fundamental areas that need to be addressed and supported by the games industry, and research and development projects for future development. Van Bronswijk (2006), states ''active engagement of older adults in the design process is imperative to successful take-up of the technologies, bridging the generation-gap of young creative and older users'' (p. 184). Integrating older adults from the initial concept stage, continuing throughout the development and marketing processes, could enable industry and projects to learn and understand end-user concerns. Integrating learning and educational elements could provide end-users of all generations the ability to learn while playing and provide a purpose to game playing.

Combining a purpose within play will aid users to understand the end goal and objectives of the game.. Whilst combining a variety of levels of difficulty, challenges has the potential to aid the learning process, build upon self-confidence, and keep the end-users focused and engaged. Subsequently, providing a clear and positive feedback during play would enable users to build up their self-confidence and knowledge. There are four chapters addressing how far games can improve the health and wellbeing of older adults. Duplaa et al. (Chapter 3) note how most research on games and health have centred on the benefits of digital gameplay on computers and game consoles. They take the discussion a step further looking at the potential for mobile digital games in the health and wellbeing of older adults, specifically in terms of physical, mental and social interactions. There are two chapters giving further examples of gamification and health. Marston et al. (Chapter 3) introduce knowledge gleaned from the iStoppFalls programme on what type of games older people enjoy playing and how and why they play such games – what is their motivation to interact? What do they enjoy doing? What do they themselves get out of it? It's an important reminder not just to look at

objective outcomes in relation to games but to look at interaction with games from the perspective of the older person themselves.

A further example is shown by Paczynski et al. (Chapter 3) examining how an interactive and immersive art programme called Splashboard can aid health and wellbeing of participants living with one or more medical conditions including dementia, depression or recovering from stroke. The simplicity of the technology is key, the art is created on a video screen of the real world, simply by moving the body in different ways to create a "painting". Naturally, the nature of such technology improves physical activity but also important is the improvements in immersion and enjoyment when creating with technology such as this. Sometimes, immersion, flow and enjoyment of creating art are the motivation for physical activity, thus improving health and wellbeing without it feeling like a chore. Again, seems common sense but amazing how many times enjoyment is overlooked as being important in relation to motivating people to improve their health and wellbeing.

Big data is often championed and heralded as helping to improve society. Data is collected and now shared in many different health and care situations. This data can be highly personalised and used at individual and collective levels. One growing trend associated with this is the quantified self where mobile devices can collect data about our daily lives. Simple and relatively cheap devices can now include collection of all sorts of data from steps taken, distance travelled, sleep patterns to heart rate and calorie intake. A little more complex and with some direct user input can see people add their own thoughts or feelings to the data, creating to the second life logging e-diary technologies. How might these systems be used to improve health and wellbeing of people? Again, especially people on the margins or those for whom technology is not always seen as second nature. These elements are covered in terms of philosophies of the self in Sacremento and Wanick's Chapter 2 and then applicability of this to keeping older people independent and at home viewed in DeMaeyer's contribution (Chapter 2). How this changes the behaviour through changes in understanding of the body are described.

Technologies are increasingly being viewed as a means to keeping people independent and keeping people from accessing services unnecessarily. Technology can reduce the geographical distance required to travel to healthcare providers, surgeries, hospitals and out-patient clinics, for example. Technology can compile health monitoring of individuals and

send them to healthcare professionals without the need for the individual or the healthacer professional to travel. Consultations can happen in the home with doctors and other healthcare practitioners through live video links. Reduction in unnecessary visits and keeping people from having to access healthcare is seen as the positive outcome. The reality is not as simple as it might seem, as Di Fiore and Ceschel (chapter n) remind us in their chapter of technologies supporting home care. Home care is a complex task, often supporting someone with co-morbidities and a variety of needs. The chapter reminds us to start with the person and their needs and requirements first and foremost, stressing how much of the research in the field is on the technological innovation itself rather than its interaction with people. The co-ordination of care is vital in this context but again is typically seen as secondary to the technology itself, so again there is a need to involve users of the technology, the support workers, in the development of such technology.

Mobile ehealth has the potential for revolutionising how people understand and interact with their own health and their own bodies. They are both enablers and disrupters as pointed out by Lynch and Fisk (Chapter 6). There is the decentralisation of medicine, a reduction in top-down nature of medical provision and a wider potential for sharing data. Ultimately it has potential to change individual's own health behaviour. Naturally, this has very strong ethical and governance implications. Who owns such data when it is ultimately the person's own behaviour, yet it is only interpreted through interaction with the device and sometimes additional interaction with health professionals? What are the security issues; what if there are breaches of data? What are the privacy issues? These are again covered by Lynch and Fisk (Chapter 6). Given that much mobile eHealth appears as apps, Mantovani and Critsobal Bocos (Chapter 6) and Wiersinga (Chapter 6) cover the legal issues surrounding such mobile apps.

Medical devices are clearly covered by law that enables them to be fit for purpose and have undergone rigorous testing, but apps fit a grey area just outside of this and can be developed and sold as a non-medical device meaning they are not subject to such stringent checks and laws. There is much debate about top-down regulation vs bottom-up innovation, with new laws perhaps being needed to fit such technologies.

This is an exciting time for health and technology. Potential issues with individual ownership of and individual responsibility for health can be resolved with mobile eHealth. They can be

of benefit to groups who are marginalised or excluded from regular health and complement existing health services and support. But, it is also a dangerous time. Technology continues to advance quickly while the research evidence to support its use and philosophical debate surrounding the value of its use have not yet caught up to highlight the relative merits and dangers of such apps and how individuals and society can gain best outcomes from them and maximize their use to facilitate understanding and improvement in health behaviours. This book aims to provide evidence to begin to plug this gap, drawing on expertise in the field to pause and reflect on the social, philosophical and human issues surrounding the accelerated development of mobile eHealth, telehealth and abundance of health and wellbeing apps.

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