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**Original Article**

# Study to explore patient views of PROm data access, use, and VISualisatION (PROVISION): the PROVISION study

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## Abstract

***Background:*** **Patient-reported outcome measures (PROMs) are standardised questionnaires completed by patients to measure health-related quality of life. It is unclear how these data are accessed by patients or clinicians and how it should be presented to optimize its use.**

***Objective:*** **The aim of this study is to explore patient perspectives on PROM data access and visualisation.**

***Design:*** **A qualitative focus group study design was used. A topic guide was utilised throughout the focus groups with participants sent exemplar graphs to review beforehand to facilitate discussion around PROM visualisation.**

***Setting:*** **Participants were recruited from a tertiary care hospital and via social media between January 2023 and May 2024. All focus groups took place via Microsoft Teams and lasted ∼1 h.**

***Participants:*** **Thirteen participants from three clinical specialties (epilepsy, heart failure, and hip arthroplasty) and an additional group with any long-term condition requiring consultant led care were recruited and took part across four focus groups.**

***Main Outcome Measure(s):*** **Patient perspectives relating to PROM data access and method of data visualisation.**

***Results:*** **Access to PROM data was seen as beneficial. Accessibility in terms of technology use and readability of results was seen as a priority by participants. Therefore, the simpler visualisations used (e.g. bar charts) were seen as the preferred option compared to more complicated spider diagrams. Most felt that it would be preferable for their data to be discussed with a member of their care team, which would be important for those who could not access their data for technology and language reasons.**

***Conclusions:*** **Access and discussion of PROM data was seen as beneficial and could potentially aid in making positive changes to health behaviour. However, it needs to be accessible to all in terms of physical access (i.e. via email or an app) but also readability of results.**

**Keywords** PROM data visualisation, data accessibility, patient perspectives

## Key Messages

- Use of patient-reported outcome measure (PROM) data, especially when presented in graphical form, was considered to be useful to patients with the potential to benefit their health outcomes.
- Patients reported that they rarely see their PROM data or discuss it with their care team.
- Participants felt that accessing data would be helpful, especially if discussed with their care team. However, how data are accessed and visualised is important in both practical / physical terms and readability.

## Background

Patient-reported outcome measures (PROMs) are standardised, validated questionnaires that are completed by patients to measure, domains such as symptoms, functional status, or their health-related quality of life (QoL) [1]. They can be generic, such as EQ-5D-5L [2] or condition-specific to capture elements of health relevant to a particular patient group or condition. Data are routinely collected in many areas of healthcare but historically, less emphasis has been placed on individual-level data being accessible to patients or their care team in clinical practice to guide decision-making. Recent evidence suggests that the use of PROMs can improve QoL and can increase beneficial patient–physician communications leading to better health outcomes for the patient [3, 4]. However, to date, little focus has been placed on how we ensure that patients remain

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engaged in systematic PROM collection and that their results do not vanish into a clinical 'black hole', but are available for them to see and understand [5].

It has been suggested that data are easier to understand when presented visually, and more effective than language or numbers alone [6]. Pictographic presentation of data is generally well understood and accepted and has been advocated for risk communication [7]. Previous studies on graphical representations of patient-reported data have shown that patients prefer bar charts and line graphs as these are easy to interpret and quick for retrieving information about PROM scores over time [8, 9].

Whilst the benefits of discussing PROM data have been demonstrated, few UK studies exist which aim to assess patient views in relation to whether and how they might wish to access, visualise, and use their PROM data as part of their care.

The results of the study will be used to inform local initiatives which aim to provide data visualisations to improve engagement with a national programme of PROM implementation [10].

# Objectives

This pilot study aims to develop understanding of how PROMs can be meaningfully integrated into use as an aid to patient–clinician communication by exploring patient perspectives on PROM data accessed, uses, and visualisations.

While PROMs are being used increasingly in standard care to assess symptoms and health-related QoL, their potential to enhance communication and improve shared decision-making is underutilised [11, 12]. Utilising qualitative data from a series of focus groups undertaken with patients from different clinical areas, this study seeks to address the following research questions:

1. What are the experiences of patients in relation to PROM collection and access to their own PROM?
2. What are the preferences of patients in relation to which PROM data should be displayed and how?
3. What are the preferences of patients in relation to how they might access their PROM data?
4. What are the views of patients relating to how having access to their own PROM data may impact on their experience of their care?
5. What are the views of patients relating to how having access to their own PROM data may impact their condition and how they manage it?

# Methods

Ethical approvals were sought and granted from Wales Research Ethics Committee on 17 January 2023 (Ref. 22/WM/0280). Several amendments were sought to aid recruitment with the final amendment approved on 23 August 2023.

## Design

This study followed a qualitative research design, with focus groups used as the method of data collection. This method was chosen as we aimed for a discussion around the topic area which has been shown to make people feel at ease and talk openly and can stimulate discussions and interactions [13].

Due to slow recruitment, the minimum number of participants was revised from 24 to 12. To achieve this, it was initially envisaged that there would be 3–6 focus groups, each aiming to recruit at least four participants. Four being an accepted minimum sample size for a single focus group [14]. As research suggests that 50%–80% of data saturation is often sufficient to meet project aims, and that 80% of all themes are discovered within the first 2–3 focus groups, 12 participants was agreed as a minimum, based on four participants across three focus groups to achieve this 80% target [15]. Figure 1 shows the study design and the flow of participants through the study.

A topic guide and exemplar graphs were developed (Appendices 1 and 2) to support data collection related to the research questions. These were developed using elements of the Capability, Opportunity and Motivation Model of Behaviour [16] with additional steering group/stakeholder input prior to study commencement.

Once a sufficient number of participants had been screened and consented, focus groups were conducted and recorded using Microsoft Teams, and facilitated by an experienced qualitative researcher (L.K.). Recordings of the focus groups were transcribed by an external transcription service.

## Participants

Patients were eligible to participate if they had a diagnosis within one of three clinical specialties hip arthroplasty, heart failure, or epilepsy. These clinical areas within Cardiff and Vale University Health Board were chosen as they encompass both finite care episodes and chronic conditions, and are also likely to include patients with varied demographics. In the event of low recruitment, a contingency group comprising anyone with a long-term condition requiring consultant-led care or was awaiting a surgical procedure would be considered. Informed consent was required for all participants. Clinicians or research nurses from each speciality would identify eligible participants within their clinics. Each potential participant was given an invitation pack either in-person, via email or in the post, containing a cover letter from their clinician, patient information sheet, expression of interest form, and screening questionnaire. If CEDAR staff received a completed expression of interest form, then the participant would be contacted with more information and to provide an opportunity to ask any questions before arranging attendance at a focus group.

## Focus groups

Once each focus group was arranged, consent would be taken over the phone by a trained researcher (L.K.) within 24 h prior to the focus group. Participants were sent an example of the EQ-5D-5L questionnaire and visualisation exemplars of this (Appendix 2) to review before participation in the focus group. An opportunity for questions was given when approached initially, when consenting, and before starting the focus groups.

A topic guide (Appendix 1) and exemplar graphs (Appendix 2) were followed during the focus groups with the exemplar graphs introduced at the end and discussed in relation to readability, accessibility, usefulness, and any other points that were deemed important.

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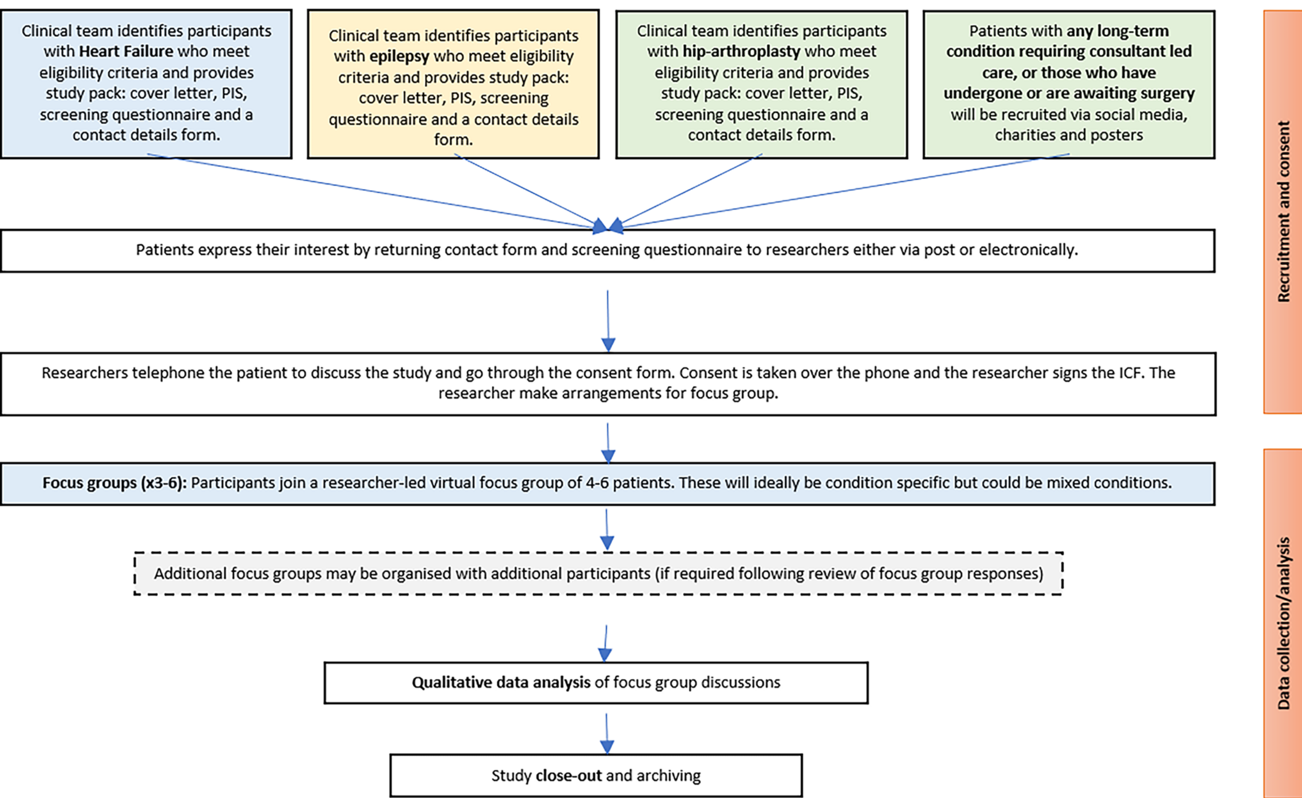


**Figure 1** Study design.

The same researcher (L.K.) was present throughout all focus groups and encouraged interactions with each participant through targeted questioning if some had not been as forthcoming as others or through a general probing question to the group. This was with the view as to not let each focus group be dominated by individual participants and to encourage the views of everyone involved.

## Analysis

Transcripts were analysed using inductive thematic analysis focusing on the research questions using NVivo 12 qualitative analysis software. Primary analysis was conducted by a trained qualitative researcher (L.K.) who developed the initial coding structure based on each research question theme. Subthemes within each research question were then further developed during a second wave of analysis. Any less dominant or opposing views were still included in the results if they were directly relevant to the research question being discussed. Given the low sample size, it was deemed inappropriate to set a minimal number of coding occurrences to be included in the result. The final coding structure was peer reviewed by an additional trained researcher (C.L.). Any disagreements were resolved via discussion and debrief.

## Sample

A total of 19 participants were recruited to the study between October 2023 and May 2024. Purposive sampling was planned for this study; however, due to lower than expected recruitment, the approach was adapted, and convenience sampling was used. 'Recruited' refers to being assessed as eligible and booked into a focus group. Six of those recruited were not consented as they either decided not to participate in the focus group or did not respond to further contact. These participants therefore did not participate in the study, with the final sample size being $n = 13$.

Due to participant availability, three of the focus groups had only three participants. This was due to a last-minute cancellation in one and the lack of overall recruitment in the second and third. Each focus group lasted 45–60 min. Figure 2 shows the participant flowchart from expression of interest to consent and participation.

Sample demographics are reported in Table 1. Recruitment of participants for the study was challenging, as such the final focus group comprised individuals with any long-term condition. The final sample consisted of four from the heart failure group, four from the hip-arthroplasty group, four from the 'other long-term condition' group, and one from the epilepsy group.

In the final sample, two focus groups were solely from one condition (heart failure and hip arthroplasty) and two were mixed conditions (hip, epilepsy, and any long-term condition).

There was a good spread of ages within the sample. However, 100% of the sample was White with the majority also married. Two-thirds of the sample felt that their health was 'Good' when recruited with the remainder reporting it as 'Fair'. Two of the focus groups were made up of 100% male participants.

# Results

Analysis aimed to examine the participants experience and opinions on the use of PROM data focusing on the original research questions. A breakdown of the subthemes within each research

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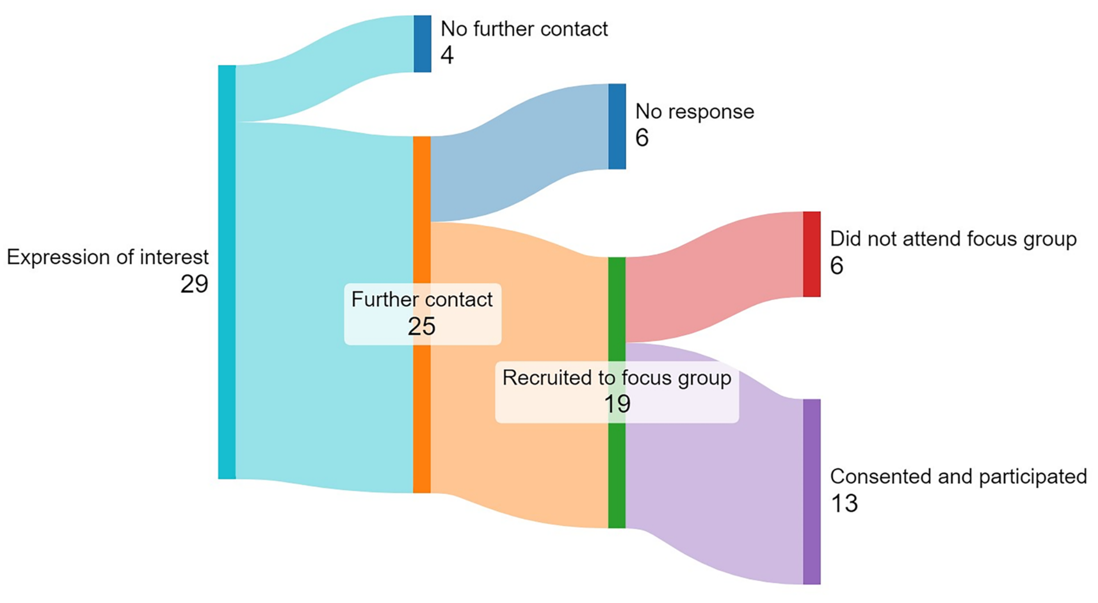


**Figure 2** Participant flowchart.

question are presented in Table 2. Results are summarised below. See Appendix 3 for a comprehensive list of quotes for each research question.

## What are the experiences of patients in relation to PROM collection and access to their own PROM?

Around half of the participants had experience of completing PROM tools, with most of these having completed them several times. However, most of these people had never seen their PROM responses since completing the questionnaire or discussed them with clinical teams. One participant who had received feedback found the discussion around the improvement from pre-procedure to post-procedure useful showing how much progress they had made, which informed the decision to discharge them.

> *P10—'they asked the questions, but they never return the answers, so to speak'.*
> *P12—'It was actually quite nice to go through it with the doctor because it was quite nice for him to say, oh you've done much better and then you feel quite pleased with yourself, you know?'*

## What are the preferences of patients in relation to which PROM data should be displayed and how?

All participants wanted to see more than their current PROM responses; however, there was no clear consensus on how much data people would like to see. Progression over time was important, even when seeing a deterioration over time due to chronic conditions.

> *P3—'Yeah, because sometimes if you've just got the most up to date ones, you don't really see how far you've come … small little goals are probably what we hold onto more than anything really'.*

Being able to compare to other people was important for some participants, particularly before they had treatment for acute conditions so that they could see the potential impact of treatment.

> *P10—'To get an understanding of the broader picture I suppose is what I'd be interested in.… so you'd have some sort of sense of, out of 100%, out of 80 patients that have gone through X'.*

When considering the display of PROM data, several visualisations were discussed as illustrated in Appendix 2. The overarching feedback was that any graph used needed to be easy to interpret and accessible to all.

The line graph (A) was liked by some as a simple representation of responses, but quite a few participants thought that it was hard to interpret the lines when they crossed. This was particularly thought to be an issue if it was printed out in black and white. Generally, it was thought as too complex to use unless there was clear labelling of lines.

> *P9—'well, you'd have to be quite mathematical to understand it'.*

The bar chart (B) also had mixed feedback but was preferred to the line graph. The colour coding was deemed helpful and made it easy to interpret. Some participants, however, did find it 'too busy'.

> *P11—'if I look at that I'm going to go right, August was not good, whereas October was not so bad. That I can see straight away'.*

The spider diagram (C) was disliked universally and was the least favourite of all the participants. Its format was unfamiliar,

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and most people struggled to interpret the large amount of data, even those with technical backgrounds.

*P6—'as an engineer I'm used to looking at things like that, but I have to say that is really unfriendly'.*

**Table 1** Sample demographics.

| | |
|---|---|
| Gender | |
| Female | 4 (31) |
| Male | 9 (69) |
| Age group (years) | |
| 18–29 | 0 (0) |
| 30–49 | 3 (23) |
| 50–59 | 3 (23) |
| 60–69 | 4 (31) |
| 70+ | 2 (15) |
| Unknown | 1 (8) |
| Ethnicity | |
| Asian or Asian British | 0 (0) |
| Black, Black British, Caribbean, or African | 0 (0) |
| Mixed or multiple ethnic groups | 0 (0) |
| White | 13 (100) |
| Other ethnic group | 0 (0) |
| Prefer not to say | 0 (0) |
| Marital status | |
| Never married or civil partnered | 1 (8) |
| Married | 8 (61) |
| Divorced | 2 (15) |
| Civil partnership | 1 (8) |
| Widowed | 0 (0) |
| Prefer not to say | 1 (8) |
| Current health | |
| Very good | 0 (0) |
| Good | 8 (61) |
| Fair | 4 (31) |
| Bad | 0 (0) |
| Very bad | 0 (0) |
| Prefer not to say | 1 (8) |
| Clinical group consented and participated in focus group | |
| Epilepsy | 1 (8) |
| Heart failure | 4 (31) |
| Hip arthroplasty | 4 (31) |
| Any long-term condition | 4 (31) |

The colour coded table (D) was well liked and found to be easy to interpret change over time and patterns of symptoms. One focus group thought that the words on the labelling were visually overwhelming and superfluous. Some concerns were raised around the colours used and the negative connotations of red. Issues for people with colour blindness or other sight issues was noted.

*P5—'I think the colours are useful. I think there's too much writing. You could just put slight or severe rather than write it up numerous time, but you can see the differentiation colour wise'.*
*P11—'And red and green, if you were colour blind it's tricky …'.*
*P13—'Yeah, I just feel if you're already not feeling okay and you're worried about what you've got or whatever, to then have it sort of red lighted … there is a sort of an emotional thing I think that you look at a particular thing and you go green is good, red is bad'.*

The multiple bar charts visualisation (E) was the most popular option throughout all the focus groups as it was easy for people to read and understand changes over time. The main criticism was that it was a 'bit bland', and the use of different colours was suggested as an additional improvement. Both the colour-coded table (D) and the multiple bar charts (E) allowed people to see detailed changes in responses over time, and this was a key benefit.

*P4—'That's the one for me'.*
*P2—I'm horribly old school and it's just a normal graph just to see how I've gone up or down or whatever'.*

## What are the preferences of patients in relation to how they might access their PROM data?

There was almost unanimous feedback that participants would like to see their own PROM responses so that they could track any progress and changes. Several people noted that having an opportunity to discuss results directly with a clinician during an appointment was also important to them. However, some were also wary of making extra work for staff by having these discussions.

**Table 2** Subthemes of research questions 1–5.

| | Research question 1 | Research question 2 | Research question 3 | Research question 4 | Research question 5 |
|---|---|---|---|---|---|
| Subthemes | • Experience of PROMs<br>• Feedback | • Timeframe<br>• Complexity/ simplicity<br>• Accessibility | • Clinician feedback<br>• Digital feedback | • Informed decision-making<br>• Communication | • Motivation<br>• Self-management |
| Subtheme refinement/ additions | • 'Feedback' refined to 'Lack of feedback' | • Addition of 'Data load' | • 'Clinician feedback' refined to 'Direct feedback'<br>• 'Digital feedback' refined to 'Indirect feedback' | | |

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Some feedback suggested that receiving an indirect approach via email or even using an App or a website containing PROM responses before a consultation would be helpful, and would also allow people to look at their data at home.

*P1—'Yeah, I think just getting an email report would be great'.*
*P9—'…but you can use the NHS website to look at all your documents and things like that. It might be worth putting it on that so you can do that if you so require, or wish or….'*
*P1—'if it's either going the right way or pretty horizontal, I suppose, I'm sorry, I'm looking at one of the graphs, but then maybe you don't want to waste anybody's time as well if it's going the right way'.*

## What are the views of patients relating to how having access to their own PROM data may impact on their experience of their care?

One benefit was for those people on a waiting list, who currently do not receive any communications from their healthcare provider. Invitations to complete PROMs were suggested as being a useful way for people to be monitored and also be reassured that they had not been forgotten.

*P6—'You think you've been forgotten about as you're making your way through the list so at least having these questionnaires does give you the, well it gave me the opinion that actually I was still being considered on the list, somewhere'.*

One issue noted, however, was that symptoms can change day-to-day, but that for some people seeing a deterioration or lack of improvement might demotivate them. The counterpoint to this was that many responders suggested that PROMs would be a useful reference point to illustrate positive changes that can be difficult to judge without evidence. This was thought to be useful both for measuring changes following a one-off intervention such as surgery, and for people who have long-term conditions to measure the impact of different treatment strategies.

*P11—'as an aide memoire in terms of if there has been an improvement and you're asked, six months down the line what was it like six months ago, you may not actually remember accurately what it was like, so if you've got something that's actually documentary evidence'.*

Most participants said that they are open with clinical teams about their health and related impact, but that the PROMs would still be useful in clinic discussions and should be used if available. This would be particularly useful for people who were concerned about their symptoms or QoL as the PROM data would provide an opening for discussions.

The potential for PROMs to impact on a patients' experience of care was acknowledged to be more than partly down to how they are used by providers. There were several discussions around how healthcare services might utilise this information which focused not only around using the data in consultations but also on using PROM data to trigger care provision.

*P7—'I think anything that shows you how you're doing is, can only be a good thing, can't it?'*
*P13—'because you could say to the doctors I used to be able to do this and now I can only do that, so I need something done, so you have got a bit of evidence built up there'.*
*P12—'there needs to be some action if it's showing a problem. You can't be just filling in all these questionnaires and be looking at your app and thinking, God I'm getting worse and worse, but nobody's listening, nobody's picking this up, nobody's doing anything'*

## What are the views of patients relating to how having access to their own PROM data may impact their condition and how they manage it?

Most participants thought that seeing their own PROM data might help people to self-manage and would motivate some people to look after themselves more, e.g. to try and make health-related improvements.

Another impact on self-management was the potential of people to see evidence of a deterioration in symptoms or QoL in their PROM data. This could act as an alert for a patient that something was wrong that they might otherwise have ignored, prompting more immediate action. Changes in PROMs were also thought to be useful to share with friends and family members who often act as a support network, and who would then use this information to provide further encouragement.

*P10—'It's up to me….to manage my progression at the moment because there is nothing in place, but if there were something in place I think that would probably motivate me more, to do more'.*
*P 1—'If it's improving then have the option to increase it or, if it's getting worse the option then to increase the frequency I guess'.*

Some of the discussions suggested that generic tools may be less able to support self-management, with condition specific PROMs considered to be more useful for this.

# Discussion

All study objectives were met successfully, with useful data gathered on participants' experiences of competing and accessing their own PROM data, their preferences in what data are useful and in what format, and how they access it. Interestingly, in relation to impacting on their experience of care, there was a perceived benefit not only for use in clinic consultations but also in providing a communication channel while people are on a waiting list. This aligns with other literature on PROMs use as a communication tool [17, 18].

However, the main finding from this study is that the provision of PROM data to patients could support self-monitoring behaviour. Several participants noted that access to the data in isolation was less useful than if it was also used in discussion with their care

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team to understand their progress over time. This would seem particularly pertinent to those who do not have access to health technologies and devices such as fit-bits, smart phones, etc., and to those who might not be able to interpret the results accurately. This again highlights the importance of having an additional discussion with a member of the care team to make sure the results are understood by the patient [4, 19].

The way data are presented was suggested as being important and that simple bar graph is the preferred choice for presentation of PROM data over time. This again related back to the idea of being accessible and interpretable to all. This supports previous research suggesting that bar charts and line graphs were preferred [9, 20, 21].

Preferences in terms of the volume of available data for people to see were highly variable, suggesting that a broad approach is required, with high level data being available as a headline, with more detailed data available to deep dive for those who want it. Similarly, a recent study found that the preferences of patients and clinicians differed in respect to data visualisation, underlining the importance of exploring different options [21, 22].

The discussions noted that access to PROM data by patients has the potential to improve healthcare in a number of ways. This included enhancing clinical discussions, improving coproduction, increasing patient empowerment by supporting people on a waiting list and helping people to monitor changes in health, and accessibility to data. These results also highlight the dual purpose of PROMs and that in addition to being an outcome measure, they can also be utilised as a powerful patient empowerment tool regarding shared decision-making and self-management.

This all aligns with participatory research approaches [23, 24], with the study findings providing actionable results to inform ongoing local initiatives in the field of data visualisation.

This study is informed by participatory research and coproduction theory, which conceptualise knowledge generation as a collaborative process, which values both experiential and professional expertise [25]. By involving patients from multiple long-term condition groups in shaping the interpretation and application of PROM data visualisations, this study extends participatory principles into the domain of digital health infrastructure, positioning patients as co-interpreters of outcome data rather than passive respondents.

International literature on PROM implementation demonstrates that successful integration depends not only on technical infrastructure but also on stakeholder engagement, contextual fit, and perceived usefulness. Drawing on insights from Normalization Process Theory, implementation requires coherence (sense-making) and cognitive participation to become embedded in routine care. These study results contribute to this, showing how patients construct meaning around visualised PROM data, and identifying conditions under which such visualisations may support self-management and relational communication. Our findings suggested that, for some individuals, PROM responses could enhance self-management and improve communication with family members and healthcare professionals, aligning with evidence that PROMs can function as dialogical tools within clinical encounters. This study advances theoretical discussions at the intersection of participatory health research, implementation science, and digital PROM infrastructure [1]. As local informatics teams develop visualisations in different clinical areas based on the findings of this and other research, future work will aim to identify any resulting benefits.

The main issue with this study was recruitment being challenging for several reasons. Firstly, the study was intended to recruit from additional sites. However, for logistical reasons this was not possible, and the study had to be moved to a single site. Secondly, the first version of the protocol limited the researchers in how they recruited participants and how they conducted the focus groups. Amendments expanded these methods of recruitment to include use of social media, and posters with a QR code linked electronic expressions of interest form. Furthermore, an additional contingency group consisting of people with any-long term condition was included (as described above) and the capacity to run mixed-condition focus groups. Thirdly, the study's concept proved difficult for participants and members of the care team to understand, which did not make it an appealing study. Fourthly, there was a lack of incentive both clinical and otherwise for participants. An addition of a monetary incentive helped but only minimally. Lastly, the clinical specialties chosen may have hindered recruitment. Feedback from the heart-failure group stated that this patient group was generally older, frailer, and much less likely to want to complete the focus group and be technically able to reliably use Microsoft Teams.

Three of the four focus groups only had three participants, where four is generally regarded as the minimum number when all coming from the same patient group [9]. This could have negatively affected the data collected due to the lack of broad and varied opinions. However, as the participants were from different clinical specialities it could be argued that this would have provided a differing range of experiences and opinions to potentially counteract the low sample sizes. Further, it has been suggested previously that two focus groups with smaller numbers provide more data than one with a larger number of participants [26].

Another concern with this study is the very small sample size and the switch from purposive sampling to convenience sampling. The low sample size was disappointing; however, data gathered from the focus groups appeared to reach saturation after three focus groups with no further themes added to the coding structure from the analysis of the fourth focus group. This is in line with previous research suggesting that 50%–80% of themes are identified from the first 2–3 focus groups [16]. Although people from different age groups and diagnoses were represented, there was a general lack of diversity within the sample. Due to the issues surrounding recruitment to this study the sampling strategy was adapted, and the result was a purely convenience sample of which 100% were White, and all in fair or good health. While the homogeneity of the groups may have led to more open discussions [13], this, together with the low numbers, may affect generalisability and representativeness. However, the results provide a useful insight and highlight opportunities for future research.

It is possible that those from other groups such as those with bad or very bad health, could have different experiences with access to technology, treatment, and the ability and desire to complete PROM data [4]. This could also be the case for people with language barriers and those who lack confidence in using technology in their day-to-day life. This digital divide could have two impacts on the results and implications of this study, firstly the recruitment to the study itself as the need for participants to be able to use and access Microsoft Teams could have deterred people from entering the study. It was reported by the

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research staff that this was the case for some potential participants. Secondly, it could be argued that those who did participate would be more confident using technology. This is a weakness, particularly as this study related to people's preferences in accessing data completed digitally. This is also likely to have created bias [27]. While these weaknesses will have shaped the data collection, and the perspectives represented, the research team remained mindful of this throughout the data analysis.

Bias may have been introduced via the qualitative researcher during the focus group sessions. Ideas and opinions reported in the earlier focus groups could have influenced the probing and follow-up questions asked in the latter focus groups. However, the use of the topic guide, whilst semi-structured, will have standardised the questioning to the focus groups.

Further, the main researcher in this study is a highly experienced qualitative researcher in relation to both semi-structured interviews and focus groups. As a result, they are familiar with the impact that the existing views and opinions that people may potentially have as a result of previous experiences can have of subsequent data collection. The researcher also has no affiliations with any of the conditions included in this study. To appropriately identify different views, divergent and minority perspectives were identified during coding. These were discussed among the research team, and incorporated into the final thematic structure through subthemes or illustrative quotes, ensuring a nuanced representation of participants' experiences.

Despite the limitations discussed above, a strength of this study is that it still provides first-hand feedback from participants in relation to their experiences of PROMs, views on the acceptability of PROM data visualisation, and accessibility of these data. The findings suggest that the adoption of PROM visualiations fit the attributes of Diffusion Innovation Theory, demonstrating a perceived advantage, can be trialled, are modifiable and compatible with current technical developments, have limited complexity, and are likely to have observable benefits [28]. A recent systematic review of PROM implementation from the USA showed that just the administration of a PROM improved patient outcomes in several clinical areas, but that also in 43% of the included studies, an improvement in clinical outcomes was demonstrated when PROM data were fed back to either the patient or healthcare provider [29]. These improvements increased when the PROMs were used to monitor the condition and inform the patients care pathway. As the use of PROM data grows in clinical practice, it is essential that we develop our understanding of the factors influencing adoption, implementation, and utilisation, including the development of effective data visualisation tools [30].

Future research would need to focus efforts on recruitment in general but also of a more diverse sample to make the findings generalisable. In addition, it would be helpful to involve staff from digital teams who would be involved in building patient data dashboards to gauge how practical the development and implementation of prom visualisation would be.

The implications of these findings are not only to guide future research but also to inform future clinical practice. This could include the introduction of protected time during appointments to review and discuss PROM data using simple visualisations and incorporate these discussions into the patient/clinician decision-making process. This has the potential to improve coproduction and self-monitoring and give patients a sense of empowerment regarding their care.

# Conclusion

Access to PROM data was seen as generally beneficial with the potential to aid in making positive changes to health behaviour. However, it was clear that it would need to be accessible to all both in terms of technology use and readability of results. Therefore, the simpler visualisations used (e.g. bar charts) were unanimously seen as the preferred option compared to something more complicated such as a spider diagram. Most also felt that it would be preferable for their data to be fed back and discussed with a member of their care team. This would be particularly important for those who could not access their data for digital or other reasons such as language barriers.

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# Author Contributions

Laura Knight (Data curation, Formal analysis, Investigation, Methodology, Project administration, Visualisation, Writing—original draft), Kathleen Withers (Conceptualisation, Funding acquisition, Methodology, Supervision, Writing—original draft), Michael Beddard (Validation, Writing—review and editing), Christina Lloydwin (Formal analysis, Validation, Writing—review and editing), Judith White (Conceptualisation, Methodology, Writing—review and editing), Sarah Puntoni (Conceptualisation, Funding acquisition, Methodology, Writing—review and editing), Sally Lewis (Conceptualisation, Methodology, Funding acquisition, Writing—review and editing)

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# Conflict of interest

No conflicts of interests were declared.

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This study was funded from an ongoing contract between CEDAR and Value Transformation (formerly the Welsh Value in Health Centre), part of NHS Wales Performance and Improvement. CEDAR was commissioned to undertake all work on this study as part of its ongoing relationship and portfolio with Value Transformation. This partnership supports PROM implementation and use as part of the wider drive towards value-based healthcare in Wales.

## Data availability

The participants of this study did not give consent for their full dataset to be shared publicly. Due to this and the possibility of participants being identified from their data, supporting data are not available.

## Copyright

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## Appendix 1 Topic guide

### PROVISION focus group topic guide

#### Welcome and introduction

- Thank you very much for agreeing to take part in this focus group today
- I'm ____ and this is _____. We work as NHS researchers at Cedar Healthcare Technology Research Centre, which is based within Cardiff and Vale University Health Board.
- This focus group is for the PROVISION study which aims to understand your views on accessing your patient reported outcomes assessments. I'll explain more about these assessments in a minute. We want to listen to your opinions on this, so please be as honest as possible.
- This session is for patients with ______.

Confirm receipt and understanding of Patient Information Sheet.

Brief explanation of how to use Microsoft Teams, encourage the use of hands up, refer to focus group instructions.

This focus group will be video recorded, the recordings will be transcribed but you will not be identified by name in these transcripts. ____ will also take notes during the session. You don't have to keep your video on during the session but it often helps conversations between one another.

Confirm receipt of assessment diagrams and EQ5D example. Does anyone have any questions on this before we start?

### Is everyone happy if I start recording now? Start recording

#### Description of assessments

The PROM assessments aim to understand how a patient is feeling, and can help to show whether their treatment is working. There are a number of different types of these assessments that can be used. Doctors will often look at the results of these assessments to understand whether a treatment or procedure has improved a patient's life or wellbeing. We are interested in whether patients might like to see the information from their assessments for themselves.

#### Examples of assessments

We've sent an example of one of these assessments, which is called the EQ5D. Here's a short story about how this might be used from a patient perspective. *(only read for the appropriate condition)*

- Lou filled in a PROMs assessment after their hip replacement surgery. The assessment asked about pain and how easy or difficult it was to go about their day, such as washing and dressing. Lou was quite young when they had their hip replacement, so they knew they might need to have it redone after around 15 years. Lou filled assessments in every year and liked knowing that they'd be able to see this data and speak to their health care team about it so they would know when they might need the operation to be redone.
- Sam started to fill in PROMs assessments after their diagnosis with epilepsy. The assessment asked about pain and how easy or difficult it was to go about their day, such as washing and dressing. Sam found it useful to fill in the assessments as they helped to show when treatment was working or when changes might need to be made.
- Jo started to fill in a PROMs assessment after their heart failure. The assessment asked about pain and how easy or difficult it was to go about their day, such as washing and dressing. Jo found it useful to track their recovery and see improvements in their assessment results.

#### Questions

- What is your experience of using technology to manage your health? (prompt: smartwatches, apps)
- What is your understanding of patient-reported outcome measure assessments? (prompt: are you familiar with the tools shared?)
- Can you tell me about your experience of filling in these assessments?
    - Prompt:
        - Is this something you've discussed with your health care team?
        - Have you ever had feedback on your assessment results?
- What do you see as the potential benefits and disadvantages of having access to your assessment results? (motivation to improve personal health, emotional impacts)
- How would you like to access your assessment results if they were available (if at all)?
    - Prompt (benefits and disadvantages of different options):
        - When? (just before or after an appointment?)
        - How often?
        - Where? (from home, while in health services)
        - What medium (app/website/paper copy via post or in waiting room)?

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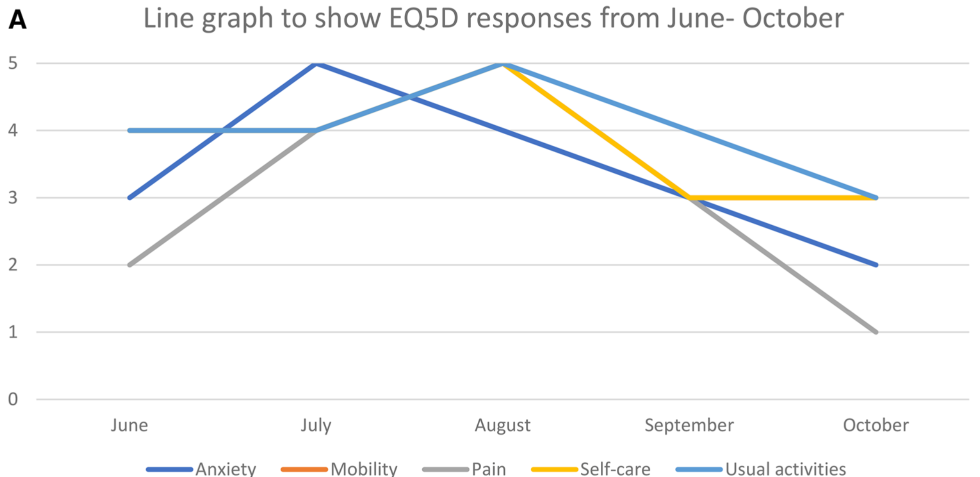
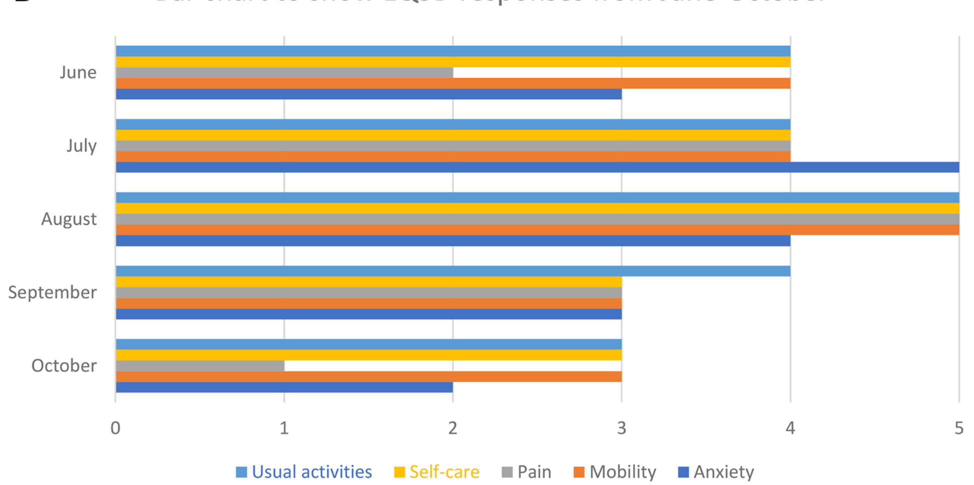
- How (if at all) do you think this information would impact on how you manage your own health condition? (prompt: discussions with clinicians, symptom recognition, motivation?)
- How would you feel about discussing your assessment results with your health care team? (prompt: who, how would you describe your relationship, when)
- Can you tell me about how confident you think you would feel to ask any questions or share concerns about your assessment results with your health care team?
- How would you feel about discussing your assessment results with people close to you, such as a family member, friend or carer? Prompt: would it be helpful?
- Some patients fill in a number of assessment results, would you prefer to access to all of this data, or would it be useful to limit the data to one or two of these? (possible contradictions in tools.)
- We've provided a number of display options, what are your preferences for how the assessment results would look?
  - Prompt:
    - Words/numbers
    - Colour coding
    - Explanation of numbers/terms
    - Types of graph
- Ask participants to rate the displays from best to worst as a group or individually

**Does anyone have anything to add to what we've talked about today?**

**Thank you very much for taking part in our focus group.**

# Appendix 2 Exemplar graphs

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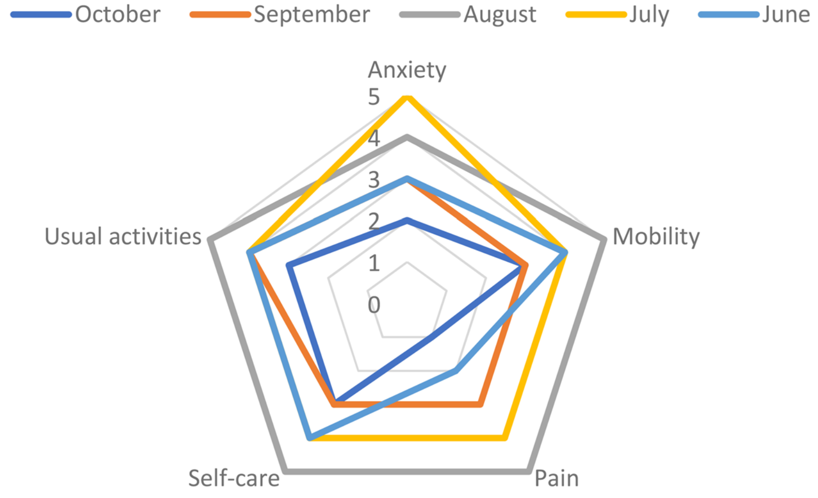
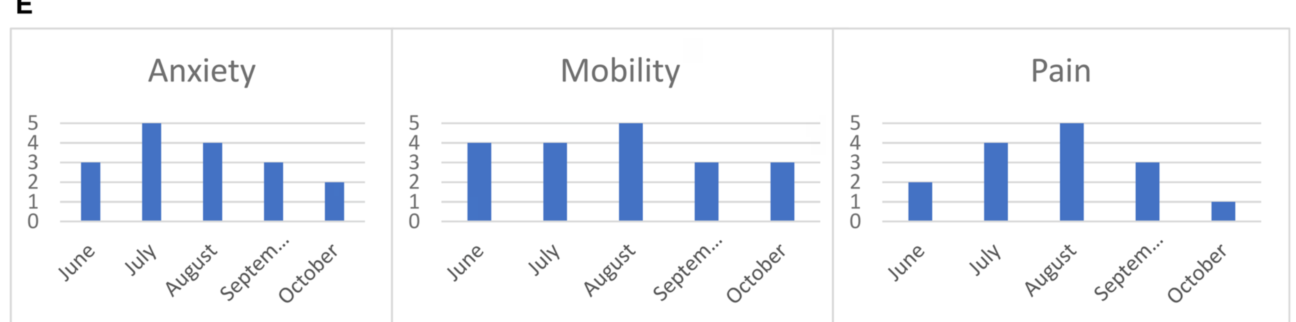
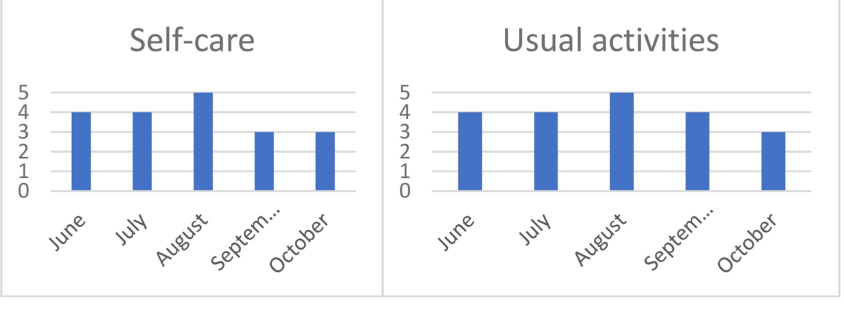



**D**

| | June | July | August | September | October |
|---|---|---|---|---|---|
| Anxiety | I am moderately anxious or depressed | I am extremely anxious or depressed | I am severely anxious or depressed | I am moderately anxious or depressed | I am slightly anxious or depressed |
| Mobility | I have severe problems in walking about | I have severe problems in walking about | I am unable to walk about | I have moderate problems in walking about | I have moderate problems in walking about |
| Pain | I have slight pain or discomfort | I have severe pain or discomfort | I have extreme pain or discomfort | I have severe pain or discomfort | I have no pain or discomfort |
| Self-care | I have severe problems washing or dressing myself | I have severe problems washing or dressing myself | I am unable to wash or dress myself | I have moderate problems washing or dressing myself | I have moderate problems washing or dressing myself |
| Usual activities | I have severe problems doing my usual activities | I have severe problems doing my usual activities | I am unable to do my usual activities | I have severe problems doing my usual activities | I have moderate problems doing my usual activities |

**E**

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# Appendix 3 Full quotes table

| Research question | Exemplar quotes |
|---|---|
| **Question 1.** What are the experiences of patients in relation to PROM collection and access to their own PROM? | *P9—'Yeah, I would agree with …, that they asked the questions, but they never return the answers, so to speak'.*<br>*P4—'I suppose sometimes it's the not knowing that's the worst. At least if you know what the avenues are, yeah, I suppose looking at some kind of graph or having a report every now and then instead of just sitting there thinking, okay, well what's next basically. That's quite hard, I think, for me anyway'.*<br>*P6—'Yeah, I think one of the weaknesses of the system is that every time I get the questionnaire to fill in, I don't get any results from the previous questionnaire that I filled and therefore I can't see where I was and where I'm going…'.*<br>*P7—'I was told certain figures and then on another visit then, which was probably six months after, the figures have gone down but I was kept in the dark for a further three months after that. I didn't know for about nine months that the figures reference heart and stuff like that, although I was told that I was doing everything right, the figures had gone down'.* |
| **Question 2.** What are the preferences of patients in relation to which PROM data should be displayed and how? | *P1—In relation to the line graph example 'I think just a normal bar chart that goes up and down a little bit like the weather over the year of where you are, it's very simple to see whether you're going up or whether you're going down is probably what the majority of people are used to in that way. I think it's a little bit more complicated, especially for people who don't really look at graphs at all'*<br>*P2—'the spider one completely confused me….I'm horribly old school and it's just a normal graph just to see how I've gone up or down or whatever. It, it's fine, but the rest of it, I got a U for o-level statistics so I'm really not very good with that'.*<br>*P9—In relation to the spider diagram example –'you'd have to be quite mathematical to even look at it without going, oh my gosh'.*<br>*P11—'And red and green, if you were colour blind it's tricky…'.*<br>*P13—'Yeah, I just feel if you're already not feeling okay and you're worried about what you've got or whatever, to then have it sort of red lighted……. there is a sort of an emotional thing I think that you look at a particular thing and you go green is good, red is bad'.* |
| **Question 3.** What are the preferences of patients in relation to how they might access their PROM data? | *P1—'Yeah, I think just getting an email report would be great'.*<br>*P9—'…but you can use the NHS website to look at all your documents and things like that. It might be worth putting it on that so you can do that if you so require, or wish or…'.*<br>*P1—'if it's either going the right way or pretty horizontal, I suppose, I'm sorry, I'm looking at one of the graphs, but then maybe you don't want to waste anybody's time as well if it's going the right way'.* |

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| Research question | Exemplar quotes |
|---|---|
| **Question 4.** What are the views of patients relating to how having access to their own PROM data may impact on their experience of their care? | *P1—'…if there's anything on there that's concerning then the team will obviously give you a call with that. I suppose then just at time where you can ask questions about it I suppose, if you've got any concerns or questions that there's someone there to pick up the phone to or to email I guess. I'd be happy with that'.* <br> *P9—'…so somebody's going to have to sit there and go through those and get them so they're to you, rather than a general answer. It would have to be to you'.* <br> *P10—'I wouldn't say no if I were to have some sort of, if I were to have some sort of dialogue with the consultant for an update, but I wouldn't expect it. I know the NHS is under pressure so there's far more people in need than myself, I suppose'.* <br> *P13—'I suppose what I'm saying is that a lot of it comes from the consultant, the people that you trust, and if they say you're doing well you believe them, and it boosts you'.* |
| **Question 5.** What are the views of patients relating to how having access to their own PROM data may impact their condition and how they manage it? | *P1—'If it is an easy sort of, if it's easy for me to get that info then it would certainly drive me forward and keep me positive'.* <br> *P11—'six months down the line what was it like six months ago, you may not actually remember accurately what it was like, so if you've got something that's actually documentary evidence to say, right this is what it was, because you did this, at the time, now it's this, and we can compare that with this to demonstrate improvement or not, depending on how it's gone'.* <br> *P3—'Yeah, because sometimes if you've just got the most up to date ones, you don't really see how far you've come because it is a long journey really but at least you can see where you started and where you are, whether it's over a year or two years. With what we've had, small little goals are probably what we hold onto more than anything really'.* <br> *P13—'Well, it might be like people who weigh themselves twice a day or whatever and it just becomes something that is your fixation particularly if it's health related because you want it to get better'.* <br> *P12—'You can imagine some people the other extreme and every five minutes, I've gone up one, I've gone up one'.* <br> *P13—'when you're going through different treatments to see if things work. It's also quite useful there as well because you're actually able to, and as you say it is subjective but you are able to look at things and go, okay, at that point I was on this medication and things were kind of okay, and then at this point I was on this medication and it wasn't as good. It's quite a useful barometer in that way'.* |

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