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Asesu Dyfeisiau ac Ymchwil Gofal Iechyd

CEDAR

Centre for Healthcare **E**valuation,
Device **A**ssessment and **R**esearch

National PREM Refresh

Interim Report

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Abbreviations

Abbreviation	Definition
ABUHB	Aneurin Bevan University Health Board
BCUHB	Betsi Cadwaladr University Health Board
CAVUHB	Cardiff and Vale University Health Board
CTM	Cwm Taf Morgannwg
CTMUHB	Cwm Taf Morgannwg University Health Board
HDUHB	Hywel Dda University Health Board
LD	Learning Disability
PHW	Public Health Wales
PREM	Patient Reported Experience Measure
PROM	Patient Reported Outcome Measure
PTHB	Powys Teaching Health Board
RCT	Rhondda Cynon Taf
SBUHB	Swansea Bay University Health Board
WAST	Welsh Ambulance Service NHS Trust
WHSSC	Welsh Health Specialised Services Commissioning
WG	Welsh Government

About CEDAR

CEDAR is an NHS-academic research and evaluation centre which is part of Cardiff and Vale University Local Health Board and Cardiff University. As a healthcare



technology research centre, CEDAR focuses on research and evaluation involving medical devices and diagnostics. We work with the NHS, academic institutions, commercial sector, publicly funded organisations, and charities. Our areas of expertise include systematic reviewing, health economics, clinical trial facilitation, qualitative research, analysis of routinely-collected and linked health data, and medical device regulations.

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Executive summary

Patient Reported Experience Measures or PREMs measure a person's experience of healthcare, and are seen as a way of understanding patient satisfaction. They are also a key tool in supporting service improvement projects. To support and align data collection across Wales, a set of core PREMs was developed in 2013 as part of a national approach. This was subsequently updated in 2017 resulting in a set of 11 questions. In order to make sure that it remains relevant to current service provision, Welsh Government have commissioned a 'refresh' of the core PREM.

This will consist of two phases: phase one, to evaluate and adapt the existing PREM with key stakeholders; phase two, to collect data with the updated PREM to carry out statistical validation. This interim report details phase one.

Phase one aims to;

- o Identify any redundant questions
- o Identify any improvements in wording / phrasing
- o Identify any additional areas / questions for inclusion

Key stakeholders from across Wales were identified by Welsh Government, and invited to participate. Focus groups and interviews were offered with a range of dates, both in Welsh or English, and with in-person and remote options.

Thirty three people participated, including service users, representatives from advocacy groups and patient experience team members from across Wales. The existing questions were discussed in detail with feedback also received on the related introduction and free text questions. Some of the existing questions were thought to be suitable, with others requiring some changes in wording. The length of the PREM was thought to be appropriate and there was agreement that it should not be longer than necessary. There were several suggestions for additions to the PREM, with consensus that 'Were you treated with dignity and respect' was a key question suitable for any interaction, which should be included. Two existing questions: 'Did you feel you understood what was happening in your care?', and 'Were things explained to you in a way that you could understand?' were thought to be too similar for both to be essential, and it was generally agreed that the first of these should be removed. The order of some questions has been changed to reflect feedback. There was a great deal of discussion about the question 'Were you able to speak in Welsh to staff if you needed to?'. Participants wanted this to be more inclusive to include any communications, and other languages, including British Sign Language. This question has been extended to reflect this feedback.

The current 'overall experience' question uses a scale of 0-10 and this was thought to be too complex for both those completing the question, and those analysing the data. Fewer answer options, with labels was preferred, with this also fitting in better with the format of the PREM overall.

The two free text boxes were seen as essential in giving context to responses. However, there was strong feedback that these should allow people to provide details on what was good about their experience, and what was bad about their experience, and not put the onus on service users to suggest improvements.

The updated PREM is available in Appendix 6.

NHS Wales National PREM refresh - interim report

1 Introduction

Traditional outcomes measures such as mortality and readmissions are often used to measure clinical success, however, patients and service user feedback is essential to measure successful healthcare provision. They are best placed to assess which aspects of healthcare are most important to them, and provide feedback on the quality and experiences of care they receive. A 2008 report (Darzi) highlighted the importance of understanding patient satisfaction, and advised the use of patient reported outcome measures (PROMs) and patient reported experience measures (PREMs). While PROMs ask health-related quality of life questions that provide information on health status, PREMs measure a patient's perception of the experience of healthcare, and can be useful tools in measuring patient satisfaction.

PREMs are often developed for use in a particular department or service so that experience questions specific to that area can be included. For example one clinic may have limited parking while another has plenty of car parking but a small, crowded waiting room. However, some important experiences of healthcare are universal, with aspects such as effective communications being relevant in any setting. Due to this, in an aim to improve and support data collection, a national set of core PREM questions was launched in 2013 (NHS Wales Shared Service Partnership, 2023). This was part of national approach to gaining service user feedback to facilitate service improvement initiatives. The national core set was updated in 2017, resulting in 11 recommended questions (Withers et al, 2018).

The core set was not intended to cover an exhaustive list of things that may impact on a services user's experience of care. It is designed to include the most relevant questions related to a person's experience of care that would apply in any healthcare setting. This can support data collect while still allowing services to add additional questions specific to their area if required.

The impact of COVID-19 led to a change in the way some healthcare services are provided across Wales, and Welsh Government and health boards acknowledge that this is likely to impact on the way that people access and use services. This in return may affect their experiences, and therefore it is important to ensure that the national core PREM reflects the questions that are most important to all service users across the current range of healthcare settings.

In order to confirm that the core set includes the most relevant and appropriately worded questions, Welsh Government commissioned CEDAR to carry out a 'refresh' of the national core PREM to coincide with the ongoing Welsh Government Framework for Assuring Service User Experience programme.

CEDAR staff were part of the team involved in the previous PREM update in 2018 and have experience in PROMs and PREMs development and validation. CEDAR was supported in this project by Welsh Government colleagues and the head of Person Centred Care at the Welsh Value in Health Centre.

The 2018 Core PREM (Appendix 1), consists of nine categorical questions, preceded by an introduction and a single question related to the recency of the experience. The nine questions are currently followed by two free text questions which give service users an opportunity provide context around their responses. While the introductory section and free text questions are not a formal part of the Core PREM it was agreed that they would be discussed in this refresh exercise as they provide context and are integral to the set as a whole.

2 Project aim

To update the existing national core PREM set with service users across Wales, and validate the set to ensure it is suitable for use across NHS Wales. Translate and validate the tool into Welsh.

2.1 Project plan

The project plan consists of two distinct phases as detailed below.

2.1.1 Phase One planned activities

Create a range of scenarios for use in focus groups to facilitate discussions around the use of the applicability of PREM in different care settings. These scenarios to include primary care, secondary care, and urgent care settings.

Liaise with stakeholder groups across Wales to enrol patients to take part in focus groups and / or interviews. These will aim to invite representatives from a range of diverse groups including those identified by Welsh Government. Stakeholder input will be gathered online or in person, dependent on preference and will consist of a minimum of four focus groups. These will include representatives from diverse groups, with some facilitated in English and at least one held in Welsh dependent on participant preference.

The focus groups will encourage attendees to use their own experience and also utilise the scenarios to envisage how core questions would work in different healthcare settings. This phase aims to;

- o Identify any redundant questions
- o Identify any improvements in wording / phrasing
- o Identify any additional areas / questions for inclusion

Where a need for a new questions is identified, the wording of these will be developed and tested with stakeholders.

2.1.2 Phase Two planned activities

Deploy the PREM in a broad group of stakeholders to carry out validity testing. Some stakeholders will be invited to complete the PREM on two occasions to assess test-retest validity (to measure internal validity), and measure the content validity of the PREM. The Welsh language and English language versions of the PREM will be validated in parallel.

This report details the progress on Phase One. A later report, due by the end of March 2024 will provide feedback on the project as a whole.

3 Phase One progress

3.1 Preparation

Prior to the start of the project, relevant permissions were sought, and approval to undertake the project was confirmed by relevant parties including the information governance team at the UHB leading the work. Written support was also provided from the Chief Executive of the lead UHB.

The previous PREMs updates had included the use of fictitious scenarios to help the stakeholders involved imagine what the experiences of other people might be in different care settings. The project team were keen to expand on these to ensure that area such as maternity services and spiritual care were included. Some adaptations were made to the original scenarios and a number of additional scenarios were developed. These were reviewed by the project team and by the Lead Chaplain at CTMUHB to ensure they were representative and inclusive. The scenarios are available in Appendix 2.

A Participant Information Sheet was developed for the interviews and focus groups to provide additional background information to participants, and request informed written consent to participate. This is available in Appendix 3.

3.2 Engagement

A list of stakeholder groups was provided to CEDAR by Welsh Government colleagues, with a subset of these pre-identified by WG to invite to take part in

Phase One (Appendix 4). The identified individuals within these groups were initially contacted via email and invited to express interest in participating. They could choose to take part in the Phase One engagement via focus groups and interviews, and/or the Phase Two engagement to test the draft PREM online. As a large number of stakeholders were invited, demographic information and details on the groups they represented was collected via a Microsoft Forms survey. If the focus groups were oversubscribed, this information would support the selection of as representative and inclusive a range of stakeholders as possible. Responders were offered a choice of taking part in interviews or focus groups and could choose whether to participate in English or in Welsh, and could also choose to take part in person or online.

Thirty-three individuals responded to the survey, with 24 responders indicating they would be willing to take part in a focus group and 23 willing to take part in an interview; one of these only wanted to take part in an interview and not a focus group. Two people did not want to participate in Phase One but expressed interest in taking part in Phase One while one person did not want to take part in either phase. Of all of the responders, five people wanted to take part in-person (one only as an interview, four in a focus group) with only one respondent asking to take part in Welsh.

Based on the number of responders, places were still available in the focus groups, and subsequently two additional invites were sent out to the contact group with a number of expressions of interest received via email.

Focus groups were the preferred method of gaining service user feedback, to facilitate discussion around proposed changes, therefore these were the emphasis for data collection. Interested parties were offered a choice of 22 different dates / times to attend focus groups, with these including, morning, afternoon and evening sessions. People were asked to indicate as many options as they were able to attend and advised they would be held on the most popular dates.

In addition to contacting people identified via the stakeholder list, the project lead joined meetings held by the Service User Feedback Safety & Learning Network. This was primarily to update the group on progress, but was also used as an opportunity to gather feedback from the team into their experiences of using the PREM and their needs. This provided an opportunity to gather previous learning and identify the needs of the experience teams as ultimate users of the National Core PREM.

3.3 Attendance and Representation

Ultimately five main focus groups were held, with between four and eight attendees at each. An additional smaller focus group discussion was held with two

representatives from the Service User Feedback Safety & Learning Network who wanted to provide feedback but were unable to attend the arranged focus groups. At the in-person focus group, one person joined remotely; all others were held via Teams. Thirty-four people enrolled in the focus groups, however four were subsequently unable to attend due to illness, technical issues or for reasons unknown. Ultimately, 29 individuals joined the focus groups while a further four people took part in one to one interviews (one in person, three remotely), leading to a total of 33 people involved overall. The individual who had requested their involvement take place in Welsh subsequently withdrew, therefore all feedback was received in English. The focus groups and remote interviews were all recorded and used Teams transcriptions. The in-person interview was audio recorded and supported with field notes, and the interview transcribed in an intelligent verbatim format.

The attendees included service users, advocacy group representatives (i.e. from support groups), and patient experience team representatives. The youngest attendee was aged between 18-25, the oldest were aged over 70; two thirds (n=22 were female). Groups represented included Llais, Tenovus Cancer Care, Cwm Taf People First, C3SC, Service User Involvement Group for Substance Support Services, British Deaf Association Wales, and Cardiff Lupus Group. Self-reported health conditions included hearing impairment, sight impairment, mobility problems, issues with memory, stamina, dexterity, and mental health.

3.4 Process

Once the dates of the focus groups and interviews had been agreed, all participants were sent an email invitation for the agreed time. The invitation included several attachments: the participant information sheet which they were asked to read, sign and return; the 2018 version of the Core PREM; and the written scenarios. Participants were advised of the purpose of the scenarios, acknowledging that they did not need to read them all, but were welcome to look at as many as they wished prior to the session. Attendees were offered the opportunity to join the focus group up to 30 minutes ahead of schedule in order to test out any technical issues.

The focus groups all included two CEDAR staff members, one leading the discussions, and another acting as facilitator. At the start of each group, everyone was advised of the purpose of the exercise as per the topic guide (see Appendix 5). Verbal consent to participate was also taken in case anyone had not returned a completed consent form. Participants were encouraged to consider their own experiences as well as those of friends and family members and the people represented in the written scenarios. The etiquette of a focus group was explained and people were advised how to raise a hand (virtually or physically) in order to be

brought into the discussion. The facilitators also gave quieter members of the groups an opportunity to speak where relevant.

Each question in the 2018 Core PREM was discussed in turn and its relevance and wording challenged. The order of the questions was also discussed. After this, the groups were asked whether there were any additional questions that they thought should be included. For any potential additions, subsequent focus groups were asked their opinions of the potential relevance and wording of these. Where feasible within the time constraints, participants were asked to reconsider the questions discussed thinking of the written scenarios, and whether any additional considerations might be needed to reflect the needs of the service users included in these.

Interviews followed a similar format, although only one CEDAR staff member was present.

3.5 Feedback results

Feedback for each of the questions in the 2018 core PREM is provided below, together with details around the rearranging of questions and suggestions for new questions. Where appropriate, anonymised quotes have been used to illustrate key points. The discussions led to a final 'draft' PREM set which will be tested in Phase Two and is available in Appendix 6.

3.5.1 Introduction

Although the introduction was only considered briefly, the feedback was that this section was generally acceptable. Attendees noted that it is important that the introduction is clear so that people can understand why they are being asked to provide feedback and what it will be used for. Some noted that unless the introduction to an experience survey clearly explains why the information is being requested and what it will be used for they would not fill it in.

"I mean, I'm one of those people. I don't fill out a questionnaire unless you tell me what you're going to do with the data and how you're going to improve things".
Service user. Focus Group 1 .

Some participants observed that the number of health-related questionnaires within NHS Wales is increasing, and that efforts should be made to keep them short and concise using simple language wherever possible. Demographic data was acknowledged to be important provided this was used, and some of the patient experience leads suggested advice on using and report demographic data would be useful. Allowing assistance when completing the PREM was also seen as

important and the ability to record whether this was by a friend / family member or healthcare professional.

One specific change was suggested in relation to the use of the digit '4' in the sentence 'The questions mostly have 4 options', and it was noted that it is standard convention that numbers of nine or lower should be spelled out in full unless they are referring to a digit. This would mean the sentence should read 'The questions mostly have four options'.

The question related to 'how recent was the experience you are thinking of?' was considered to be appropriate and well worded in itself, but the answer categories were felt to be too wide. While it was acknowledged that it is important that people are able to feed back on experiences that were some time ago, the developments in service user feedback means that it is often provided in near real time. Patient Experience representatives pointed out that while more historic experience feedback is still valuable, it is harder to act upon data when staff and services are likely to have changed over an extended time period. It was suggested that some service users might struggle to remember details of experiences that occurred more than a few weeks ago so historic data may be less accurate. The use of a 'date picker' on a calendar was suggested but it was noted that a healthcare experience can often span a period of time so this may not be appropriate. Ultimately, participants suggested that these time categories should be updated, allowing very recent experiences to be identified whilst still providing an opportunity to feedback on older ones.

"So the challenge with this question for me is if someone is leaving a negative experience, but it's six months in the past there's very little that I can do because in six months' time that service has moved on. Staff have moved on; a lot of things happen. So we try to use patient experience data to a) let staff know that they're doing a fantastic job which they are, but b) to pick up any issues. It's like an early warning sign....having data from two years ago isn't very helpful". Patient Experience lead, Focus Group 2.

Conclusion: This section is out of scope of the Core PREM refresh, and the feedback has been included for information purposes only. However, for the purpose of providing context to the PREM it will be included in the validation phase with modified time categories.

3.5.2 Section header: 'Thinking about your overall first impressions of the care you received'

The first section header was thought to be wordier and more complex than needed, and short simple sentences were preferred in general. Participants noted that many healthcare interactions do not include care in the traditional sense, but may be related to getting advice or results. The need to be applicable across different care settings including emergency and primary care also influences this wording. The word 'overall' was also thought to be superfluous, particularly when the last few questions related to overall experience. 'First impressions' was seen as not being particularly relevant to most of the questions, as it should be about the general experience, and was also thought that the language may be more complex than needed.

Conclusion: simplify and remove any referral to care.

3.5.3 Question 1: 'Did you feel that you were listened to?'

This question was thought to be "absolutely crucial" and integral to a person's experience of care in any situation, and all of the focus groups were keen for this to be included. In one focus group feedback was received that a service involvement group had recently reviewed this question and thought that four answer options was a little confusing. Their preferred alternative was a simple 'yes' or 'no' choice with the logic that either you feel listened to or you don't. Others within the group felt this lacked granularity and this was echoed in other discussions, and on the whole, the current use of four answer options was considered to be appropriate. The experience leads also pointed out that Yes/No answer options would make it difficult to target improvement initiatives such as focused staff training. The use of 'heat maps' was explained, which allow patient experience teams to identify wards which get a number of poor responses. Other than this, the question was wholeheartedly supported.

*"...to be listened to is key because lots of our members feel that they are not listened to by certain healthcare professionals and that people just see the learning disabilities so therefore they don't listen to what else is going on for that individual".
Patient Advocate, Focus Group 3.*

Conclusion: No change

3.5.4 Question 2: 'Were you able to speak in Welsh to staff if you needed to?'

This question was considered to be important but in need of updating to improved inclusivity and to reflect the wide range in needs and backgrounds of people living across Wales. Universally the focus groups and interviews raised the preference to increase the scope of the question to ask if people were able to use their language of choice. One patient advocacy representative noted that British Sign Language is an official language in Wales. Additionally, *speaking* in a preferred language was thought to be limited and a wider arching term to encompass general communication was suggested. The current wording was also criticised in relation to the word 'needed' where some participants thought it should be about preference not need.

Discussion with the Service User Feedback Safety & Learning Network found that this was an area that had been considered within a number of organisations, with one group using a two part question, asking what was a persons preferred language with a list of the most common languages in Wales, and whether they were able to communicate using their preferred language. This was widely supported by the network and was proposed at subsequent focus groups as a potential option where it was fully supported. An 'other' option would cover alternative options such as additional needs and easy read materials.

The placing of the question was discussed in some of the groups, and participants generally thought that as this question is about communication, it would be better placed later in the PREM set with the questions related to understanding and decision making.

Due to the proposed changes to the question related to the use of preferred method of communication, advice was sought from both the Equalities team and the Welsh Language team at Welsh Government. These confirmed that changes to include additional languages were acceptable provided that the Welsh language is not treated less favourably than the English language.

Conclusion: move to later in the set. Extend the question to two parts to encompasses a wider range of communications and language options. Language options taken from the Language, England and Wales Census 2021 (Office for National Statistics, 2021).

3.5.5 Question 3: 'From the time you needed to use this service, was the time you waited':

This question caused significant debate, as while most attendees thought the concept was very important, there were many considerations which people thought made it challenging to answer, and the wording was thought to be too complex. Some noted that while all experience questions are subjective, this one felt even more subjective than most. This led on to discussions around the data that might be readily available on waiting times and whether this question was useful. There were also debates about how it is a more appropriate question for some services than others. It was suggested that in its current format it was probably inappropriate for emergency care or use with the Welsh Ambulance Service (WAST). However, several users noted that waiting lists are currently an important focus in the NHS, and that to not ask a question related to this would be an omission.

"I just ... had to read that three times to understand what it meant". Service user, Focus Group 5.

One interviewee pointed out that he had been told there would be a very long wait for treatment on the NHS so he chose to pay for private healthcare, subsequently having follow up appointments via the NHS. He noted that although the time he waited for the NHS follow up was short, there had initially been an unacceptable wait which is what led him to seek treatment elsewhere. This was seen as an example of when it would be hard to answer.

However, the main concerns were:

- 1 It is not unusual for people not to realise that they *need* to use a service, but to be referred on from elsewhere (e.g. a GP referring someone to secondary care for tests when they have visited anticipating they would receive antibiotics)
- 2 People may suspect they need to use a service but then wait for a period of time before they try to access it (for example in scenario seven [Appendix 2], where 'Tony' puts off requesting a GP appointment). This was thought to be a particular issue for people with chronic conditions who may try to self-care.
- 3 Reference to a 'service' in the question is too specific, particularly when trying to encompass different healthcare settings.
- 4 The current wording is too complex

While attendees at one focus group thought this question should be removed, the other groups and interviewees liked it as a general concept, and thought it should

be simplified, adapted and remain. The suggested changes were focused around simplified wording and the preference for it to relate to when people contacted a service or were referred to a service and not related to need. However, it was appreciated that even after rewording, this is a question which may not be applicable everywhere.

There were no issues raised with the answer option.

Conclusion: Adapt and simplify the wording of the question.

3.5.6 Section header: 'Thinking about the place where you received your care'

This header was thought to be very outdated and potentially inappropriate, as people may receive care in their own homes, or in some cases even out in a public place. Again, it was acknowledged that people may not receive hands-on care, but may receive online or telephone advice or healthcare screening for example. The use of the word 'care' was considered to have an association with treatment which is often not the case. Almost all of the focus groups thought this section header should simply remind people to think of their experience.

Conclusion: Change wording to be more general.

3.5.7 Question 4: 'Did you feel well cared for?'

This question was popular almost universally, and was thought to bridge all sectors of the NHS. The discussions made it clear that people felt being cared for encompassed general facilities (e.g. disabled facilities), good communications and empathy. Despite the concerns around the previous question, being cared for was seen to be different to receiving care and was thought to be less strongly associated with physical care.

*"If you're going to be waiting for seven 8-9 hours and you have to change your child on the floor of the disabled toilet in A&E, can you possibly feel well cared for".
Service user, Focus Group 1.*

“ For example, this week I have been using different services and I can say I felt well cared for because they all called me back. They answered my questions. They were very kind. The thing is, there's a limitation about the knowledge of this condition, so I know with those limitations they try their best. That way I felt well cared for”.
Service user, Focus Group 3

Conclusion: No change.

3.5.8 Question 5: 'If you asked for assistance did you get it when you needed it?'

There was feedback from one group that without context this question has limited use for patient experience teams. If people were not provided with the assistance they needed, it is essential to know what that assistance was so that the problem can be addressed. However, other groups thought it was important, but had some concerns about the wording. These were primarily focused on the use of the word 'assistance' as many attendees thought this was vague and unlikely to be understood universally. Some participants initially thought it was about medical assistance while on reflection seeing it as encompassing things like being given directions to a ward or being offered a wheelchair or interpreter. Others immediately thought this was related to accessibility such as walking aids. 'Support' was offered as an alternative in several groups but inevitably the discussions found that this also had connotations of being related to something physical like help with walking to the toilet. The fact that it could cover such a wide range of things was generally thought to be quite helpful and inclusive so was not seen as an issue from a service users view point. The concerns of the patient experience teams around using this data to identify issues and improve services was seen as valid. One proposal that the question could also include a free text box for people to add details but there were concerns that this would lead to a free text box after each question, making the PREM too unwieldy. Generally it was assumed that if people could provide detail about this in the general free text boxes after the end of the main PREM.

Another issue with the wording was related to the consideration that people should not have to ask for assistance in all circumstances. For example where a person was disabled or had additional needs it would often be recorded in their notes. In these cases, appropriate assistance should be offered as a matter of course.

“[should] not necessarily have to ask for it, because if someone has it recorded in their records that should be provided as a matter of course... If someone has a vision impairment then you would hope that people would realize that before someone came in, and make sure that whatever reasonable adjustments needed to be in place were in place for them to attend”. Patient Advocate, Focus Group 4.

While there was some dissatisfaction with the wording, the general consensus was that the question should include both of the terms: ‘assistance’ and ‘support’ as a catch all.

Conclusion: Simplify and adapt wording to cover required not requested help / support.

3.5.9 Section header: ‘Thinking about your understanding and involvement in care?’

There was mixed feedback about this heading with the first two groups feeling ambivalent about it, while the other groups all thought that it was superfluous and that the PREM generally had too many sub-headings as it is relatively short. The use of the word ‘care’ raised the same concerns as previously noted. The proposed changes to the previous sub-heading to ‘Thinking about this experience’ meant that all of the questions were encompassed, and no subheading was needed here. As simplicity was considered to be a key aim, removing any unnecessary text was seen as positive.

Conclusion: remove subheading

3.5.10 Question 6: ‘Did you feel you understood what was happening in your care?’; Question 7: ‘Were things explained to you in a way that you could understand?’; and Question 8: ‘Were you involved as much as you wanted to be in decisions about your care?’

Questions six, seven and eight were seen very much as a group, which were almost always debated together. The wording of all of the three question was considered to be appropriate with no rewording required, but there were extensive discussions around their order. While the general concept of understanding was thought to be very important, there were numerous discussions related to whether questions six and seven were too similar for both to be needed.

“six is very similar to seven, so from a patient experience perspective I have no idea what I would do if someone answered yes to seven and no to six because they're just the same thing..... there's a risk of contradiction yourself within [them]”.
Patient experience lead, Focus Group 3 .

“if you know or knew what was happening in your care, is your understanding not implicit.....And then I think particularly if you feel as a patient you're reading, I'm going well, you know they just asked me that. That's the same question”. Patient Experience staff, Focus Group 6

“I was just gonna say whether that is very similar to the question before and therefore is that, you know, could you almost move to those two questions into one?”. Service user, Focus Group 2.

While a proportion of attendees thought they should all be kept, many opinions were that if things were ‘explained to you in a way you could understand’ (i.e. question seven), then there was a strong likelihood that ‘you understood what was happening in your care’ (i.e. question six). This would make question six superfluous. As users in many groups were keen to consider other topics for inclusion, and understanding the need to keep the PREM set to a limited number, almost all participants thought one could be removed and overall, question six was thought to be less relevant.

Question eight was thought to be related to shared decision making and patient empowerment, and it most of the focus groups and interviews suggested that it should be asked before question seven.

Conclusion: Remove question six. Retain questions seven and eight but reorder.

3.5.11 Section header: ‘Overall experience’

Feedback on this section header was positive, and it was thought to be helpful to re-focus people on their experience overall as they were being asked to provide a general rating which was different to previous questions. It was suggested that it would be potentially helpful to encourage people to think about their experience.

Conclusion: extend to ‘Thinking of your overall experiences’

3.5.12 Question 9: 'Using a scale of 0 - 10 where 0 is very bad and 10 is excellent, how would you rate your overall experience'

This final formal PREM question has an 11 option rating scale. There are currently labels at each end of the scale (Very bad at 0, and 10 at Excellent, with an 'Average' label centrally at number 5. While several participants raised no concerns with this question and were happy with the current wording and answer options, there were also a number of people who felt it is a very difficult question to answer. These people noted that an overall rating is challenging when you are thinking of a complex experience that has had both good and bad aspects. For example if you waited a very long time for an appointment but then had good service and good news (which you could have had earlier) was that good or bad? However, generally people thought that this type of overarching question is now common and similar to those seen in hospitality and other settings as well as healthcare. Overall it was thought to be wordier than necessary and with too many answer options. Eleven answer options was almost universally thought to be too many and was also noted to be very different from the flow of the rest of the PREM where there are four answer options. Service users found a large number of answer options confusing and some suggested they did not actually add any granularity to their responses. There was also feedback that it can be challenging for people to quantify their experiences into a single number, whereas labels are easier to interpret.

*"...you know you lump sort of 8, 9, 10 together. If it's not average or excellent then I'll just stick a tick in a box because I'm not actually really sure whether it's 6 to 9".
Service user, Focus Group 4 .*

People working in the experience teams acknowledged that sometimes answer options (i.e. options 2, 3 and 4, or 6, 7 and 8) are pooled together anyway. Additionally, one experience lead observed that when people complete the PREM on a mobile device such as a telephone, the large number of answer options is challenging as not all of them can be seen at the same time. The use of traffic light systems, or emojis / smiley faces was also suggested as potential options.

The general consensus was that five answer option would be optimum, removing the scoring and using labels instead. This would allow two extremes, a mid-point and two intermediate options.

Several people did not like the word 'Average' as a label as they considered this to be inappropriate for healthcare delivery. Alternative suggestions were 'OK', 'Fair', or 'Satisfactory' with satisfactory being suggested in a number of groups.

"...average is a bit awkward because what on Earth is average? If you don't know what everybody else is experiencing, whereas if you say it was OK then it becomes much, much clearer what it is that you are assuming. That's what you want: how did people feel about it? ... if you felt it's 'OK', you know, could have been better, could have been worse". Service user, Focus Group 1

The positioning of this question was also discussed at length with a number of different opinions, however several services users thought it should be near the end of the set so that people had considered different aspects of their care when they answered it.

Conclusion: shorten the question and reduce to five labelled answer options.

3.5.13 Final Section header 'Thinking of your responses'

As noted, there were generally thought to be too many section headers in the PREM. This section header was considered redundant as the participants felt that free text boxes naturally fit with the Overall Experience section.

Conclusion: Remove section heading

3.5.14 Questions 10 and 11 (free text boxes)

The two free text boxes are currently worded:

'Was there anything particularly good about your experience that you would like to tell us about?', and 'Was there anything that we could change to improve your experience?'

There was universal agreement that the use of free text boxes is essential to provide an opportunity to add detail and context related to a person's experience. However, it was agreed that while people should be able to feedback specifically on good experiences they should also be able to provide feedback specifically on bad experiences, and that questions should not shy away from using the appropriate terms (i.e. bad or poor service). The current wording 'Was there anything that we could change to improve your experience?' was felt to put the onus on the service user to identify potential improvements when sometimes there is a bad experience but no single obvious solution. It was also noted that it is not up to the service user to identify solutions. Additionally some patient

experience representatives noted that sometimes even when improvements are suggested these cannot be implemented for various reasons, making this feedback obsolete.

“you put the onus on the person filling it to make a suggestion about what needs to be changed rather than telling you what it was about. I kind of don’t like it. So I had this question before come up and thought I don’t actually know what you could change, but I know what I didn’t like, and I know that I didn’t like the fact that a doctor was rude to me, or that I had to wait for ages”. Service user, Focus Group 2.

“I think when I first saw it as a service user, my first thought was well, I’ve got nowhere to put my bad experience..... at the moment, it doesn’t give the opportunity for a service user to say what they didn’t like about that experience without giving some sort of improvement option with it”. Service user, Focus Group

“I think it’s a bit of a spin, isn’t it? We need to be brave and have the two questions asking the same, you know, to get those answers, so yeah, what was good, what was bad”. Patient Experience staff. Focus Group 5

This ‘suggested improvements’ question was generally considered to be inappropriate and could prevent people providing useful critical feedback. There were discussions around the use of three free text questions, one for positive feedback, one for negative feedback, and one for improvements and suggestions. A further question asking ‘Is there anything else you would like to add?’ was also suggested, however, two free text questions were considered to be enough overall. There was also some discussion around whether a question about bad experience should come before the question about good experience but generally, people considered it was most appropriate for the question about good experience to come first. Alternatively one group suggested that a single free text box would be enough, with a simple overarching question “is there anything you'd like to tell us about your experience?”.

The free text questions were also thought to be slightly wordier than necessary and suggestions were made to remove unnecessary wording. Considered wording included ‘Please tell us what was good about your experience’ but this

suggests it should be completed, so the meaning of the wording has been retained so it remains optional.

Conclusion: This question is out of scope of the Core PREM refresh, and the feedback has been included for information purposes only. However, for the purpose of having a complete set of questions it will be included in the validation phase. This will include shortened wording and adapted so one question invites people to provide information on what they thought was good, and one asks about what was bad.

3.5.15 Suggestions for new questions

A number of topics were proposed for new questions and these were discussed at length throughout the focus groups as potential changes to the Core PREM. Several participants mentioned 'signposting to additional services', but this was generally thought to be relevant for some services more than others. 'How easy was it for you to access care?' was suggested as an addition, to include practical aspects such as parking, or managing remote consultations, and physical accessibility. It could also measure people being able to afford bus fare for example. However, participants worried that without providing a detailed explanation, it was too vague and would easily be confused with waiting times which is already covered in the PREM.

'Were all of your concerns addressed?' was suggested as a question to cover both healthcare and social care issues (such as Gwen's worries about her cats in scenario six). While some participants thought this question was sensible, the theme was already considered to be touched upon in the existing question 'Did you feel you were listened to?' and it was not different enough to be an additional core question. Patient experience lead participants were also quick to point out the excellent support and signposting services available in many clinical areas that offer support in these and similar circumstances. Another suggestion: 'Did you have an opportunity to ask questions?' was also considered to be outside of the scope of the core set for the same reasons.

(About having concerns addressed and asking questions) "So yeah, it is covered, in being listen to, because the key thing about listening is that you don't make assumptions about what's important to that person". Service user, Focus Group 2.

The theme of self-management was raised in several discussions, i.e. 'Were you given enough information to self-manage / care for yourself?' and this was thought to be very important in some settings but irrelevant in many other settings /

circumstances (such as WAST). It was also pointed out that some people may be unable to self-care due to physical or mental limitations. The concept had quite polarised views, with some participants feeling it was important while others had quite strong feelings that it was inappropriate as a core question and one that would easily cause offence in such a generic set.

'Were you treated with kindness and compassion?' was raised in a few discussions and was liked, but a similar question 'Were you treated with dignity and respect?' was not opposed by anyone and most people were strongly in favour of including this in the core set. This was felt to cover many aspects of healthcare provision and was seen as particularly important in the current climate where there are reports of NHS staff being under significant ongoing pressure. The term 'compassion fatigue' was mentioned and this question was seen as a way of measuring high quality provision.

"things like dignity and respect, kindness, being listened to, assistance. You know, those are your headliners..... I definitely think the dignity and respect one is really important." . Patient Experience staff, Focus Group 3.

"that one about the dignity and respect is very important because obviously when you're in a medical situation, there's so much stress and anxiety in some situations that you can obviously feel that you're being treated rudely or you're treating the other person rudely". Patient advocate, Focus Group 3 .

"I think that comes down to the crux of our entire healthcare system, doesn't it really?". Patient advocate, Focus Group 5

It was noted that the existing answer options would be suitable for this question.

Conclusion: Add 'Were you treated with dignity and respect?', with the same answer options as per other questions.

3.5.16 Question order

The order of the questions was discussed particularly in view of the changes to the included questions. Some were thought to fit together naturally. The question on

wait was seen to be an obvious first question. The overarching questions related to being well cared for was and being treated with dignity were thought to sit together, as did being listened to, being involved in decision about care and having things explained.

Conclusion: Reorder.

3.5.17 Miscellaneous

The consistent answer options in the current PREM were popular and this was retained in the update. It was suggested that this lends itself to having the option of formatting some of the questions as a table instead of individually. While this will not be tested during the validation phase, it may be useful to consider for future options.

“they could have put matrix questions in because of the same answers available on all those questions and it makes it feel shorter..... So I think anything where you can put that into a matrix rather than separate questions. It just reduces the number of times you've got to scroll, you know”. Patient Experience lead, Focus Group 6.

The number of questions in the PREM was also considered to be appropriate and people were keen that the set should not be any longer than it currently is if possible. Where new questions were suggested, the feedback was that they should replace less essential existing questions and not be added to the current set.

One group were keen to know whether people are thanked for completing the PREM. Details were provided around how the PREM is used differently across NHS Wales with different methods of distribution. However, reassurance was provided that service users would be thanked for their time. A statement of thanks has been included in the updated draft PREM.

This group also asked if people who complete the PREM get a copy of their responses, and suggested this as a useful function where available.

A number of participants were keen to point out that accessibility is an important consideration for any survey or questionnaire. Reassurance was provided that there is widespread work across NHS Wales to make sure that information is provided in a range of formats such as easy read materials. Careful consideration of the colour of text and background, and the font used was also seen as important for accessibility. As the PREM is likely to be available via different

formats, the importance of user testing on different devices and in different formats was also discussed.

As noted previously understanding how the PREM is used was very important and this included who sees the data and making sure it is all used effectively. Related to this, one patient experience lead noted that they thought that the demographic data linked to the PREM requires updating.

Numerous stakeholders who were involved in the focus groups and interviews expressed their thanks and enjoyment in taking part.

Generally stakeholders mentioned that their experience of care was heavily influenced by the level of communications they received both before, during and after a healthcare interaction. This included being informed of expected waiting times and receiving updates on these, as this helps to manage expectation and reduce stress. They suggested that if you know you are going to be on a waiting list for a long time, while it may be frustrating, at least you know there will be a wait and you prepare for it, and not worry about whether you have been missed.

4 Next steps

Phase Two of the project is ongoing with an online version of the PREM built ready for deployment to the full stakeholder group. This will collect responses from as many people across Wales as possible to gather data for the statistical validation of the PREM. Participants will be asked if they are willing to complete the PREM a second time so that a subset can complete the PREM on two occasions to support test-retest validation.

The PREM will also be translated into Welsh and validated with Welsh speaking service users following international standards (Wild et al, 2005). A final report detailing the complete project will be produced on completion.

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5 Appendices

5.1 Appendix 1- 2018 National PREM



Llywodraeth Cymru
Welsh Government



Your NHS Wales Experience

Questionnaire

Your NHS Wales Experience

The experience that you have of care is important to us. This might be an appointment with your doctor or health visitor, a hospital stay, an outpatient visit or something else. We would be grateful if you could complete this survey so that we can understand this better.

The questions are based on the things that patients have said matter most. We will ask you questions about your latest experience of healthcare. Please help us by giving your honest opinion.

The questions mostly have 4 options and you are asked to tick the answer that you feel best describes how you feel.

Some of the questions have 'not applicable'. Please tick this if the question is not relevant to your experience.

We do not need to know your personal details but have asked some general questions at the end about who you are. This is so we can make sure we are asking all groups of people about their experience.

If there is anything we have not asked you, please use the space at the end of this survey to tell us.

If you would like to discuss this survey or ask any questions about it please contact:

How recent was the experience you are thinking of?

- In the last 6 months
- Between 1 and 2 years ago
- Between 6 months and 1 year ago
- More than 2 years ago

Thinking about your overall first impressions of the care you received

1 Did you feel that you were listened to?

- Always Usually Sometimes Never

2 Were you able to speak in Welsh to staff if you needed to?

- Always Usually Sometimes Never
- Not applicable

3 From the time you realised you needed to use this service, was the time you waited:

- Shorter than expected About right A bit too long Much too long

Thinking about the place where you received your care

4 Did you feel well cared for?

- Always Usually Sometimes Never

5 If you asked for assistance, did you get it when you needed it?

- Always Usually Sometimes Never
- Not applicable

Thinking about your understanding and involvement in care

6 Did you feel you understood what was happening in your care?

Always

Usually

Sometimes

Never

7 Were things explained to you in a way that you could understand?

Always

Usually

Sometimes

Never

8 Were you involved as much as you wanted to be in decisions about your care?

Always

Usually

Sometimes

Never

Overall Experience

9 Using a scale of 0 – 10 where 0 is very bad and 10 is excellent, how would you rate your overall experience?

0

1

2

3

4

5

6

7

8

9

10

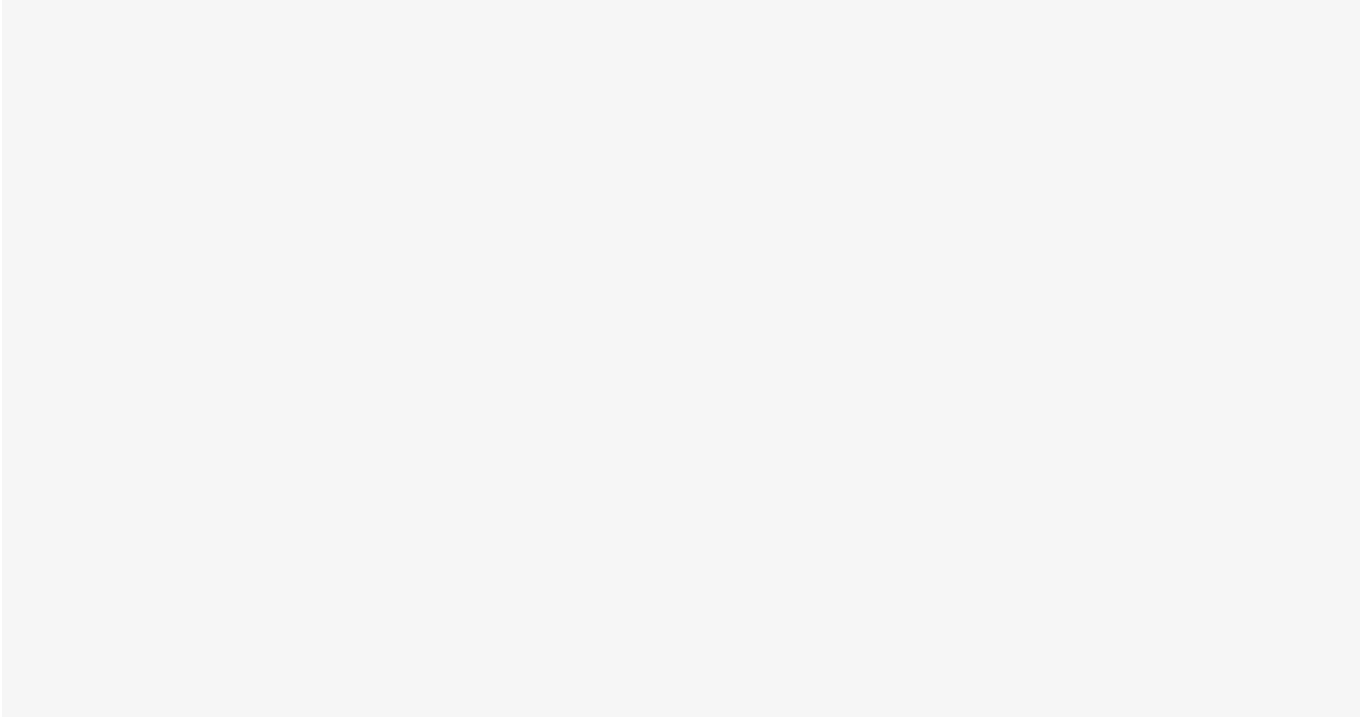
Very Bad

Average

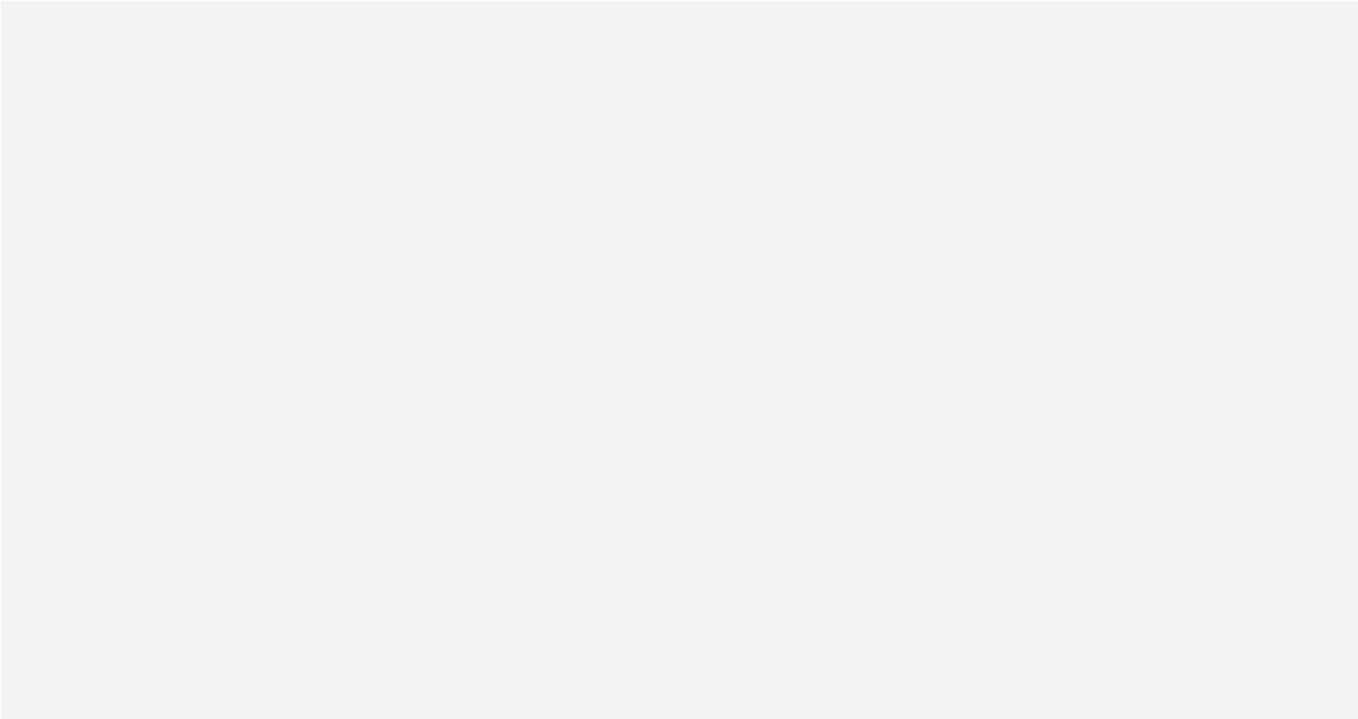
Excellent

Thinking of your responses

10 Was there anything particularly good about your experience that you would like to tell us about?

A large, empty rectangular text box with a light gray background, intended for the user to provide their response to question 10.

11 Was there anything that we could change to improve your experience?

A large, empty rectangular text box with a light gray background, intended for the user to provide their response to question 11.

5.2 Appendix 2 – PREM Scenarios

1 Maternity:

Naya is 32 and is 20 weeks pregnant, she recently had an ultrasound scan where she was told everything was developing normally with her baby. She and her husband Jai have found that very reassuring as she has had four early miscarriages before this pregnancy.

Early one morning while Jai is away she wakes up with some stomach cramps and is alarmed when she realises that she has some vaginal bleeding. She contacts her midwife who arranges for her to be seen in hospital at the obstetrics and gynaecology unit later that morning. When she gets to the appointment, the doctor listens to the baby's heartbeat, and she has an examination and a scan. There is a trainee in with the doctor she is seeing which she doesn't mind, but the doctor and the trainee are talking to each other using lots of big medical words which she doesn't really understand. They explain some things but she feels that there are some things they aren't telling her and when she asks if her baby will be OK, they can't really answer her. Eventually they say they can't find anything wrong and tell her she is safe to go home. They also say that she should stay on bedrest at home until the bleeding settles which worries her too, and that she should get in touch if she has further problems. Naya leaves feeling very worried and can't help but think that it would have been better if Jai was there to ask questions.

2 Emergency Care

After an afternoon nap, Kay woke up with some back and chest pain which quickly became really uncomfortable. Although she used to be quite active, she's currently quite unfit and has gained quite a lot of weight since she turned 60 a few years ago. After about 15 minutes where the pain gets worse and worse, Kay calls her son John who lives nearby because she's worried it's a heart attack. They live near the hospital so her son quickly takes her to A&E in the car.

At the hospital she is quickly given an ECG and some pain killers and is put in a cubicle to wait for a doctor. Although the pain has settled a little bit, Kay is starting to feel nauseous and asks a nurse for a sick bowl. The nurse says she will get one as she leaves, but doesn't come back for a long time, and as she comes back, Kay vomits, getting some sick on herself and some on the floor. Although John tells her not to worry about it, Kay is really embarrassed and anxious about being sick everywhere and is even more distressed than she was before. Although everything is quickly cleaned up Kay can't help feeling upset about what has happened.

When the doctor comes to see her he reassures her that her heart is fine and he gives her some medication for the nausea. After some further tests and a night in hospital Kay is pain free and feeling much better. The consultant has diagnosed

her with gallstones and she is told that she may need her gall bladder removed depending on how well things settle down.

The whole experience was really horrible for Kay, the pain was scary and being sick on the floor with other people watching made a bad situation even worse.

3 Primary care:

Felicity is 60 years old and married with two children. The children have moved from home and Felicity and her husband are starting to make plans for retirement. She still works part time in a stressful but rewarding job and is often away from home with work.

Felicity has been trying to get fit over the past six months, she's always been a bit over weight but since the kids were little her weight has dramatically increased, she partly blames her depression medication for the weight gain, but she's also aware that she doesn't move as much as she should and her diet is not as healthy as it could be.

She's noticed that lately she's needed more toilet breaks and is always tired, and thirsty. She's decided to go see her GP but as she's not an urgent appointment she has to wait four weeks for an appointment, this is annoying but she's not so worried so she's happy to wait.

The GP asks a few questions and orders some tests and has referred her to a specialist, he thinks she has developed diabetes, which comes as a real shock to Felicity.

Her specialist appointment is just a few weeks later and the diagnosis is confirmed. It's all very efficient and she's given a device to measure her sugar levels and medicines to control it.

Her specialist nurse is very experienced and re-assures her that she can still live a full life but that she'll need to make some changes to her life. She's given some information about diet and diabetes and she's been enrolled on an Expert Patient programme near where she lives.

Felicity attends a number of appointments with the diabetic team and is starting to get over the shock and to make adjustments to her life. She does however feel very down and is worried she's starting on a downward spiral again with her depression.

Her husband urges her to visit her GP who is very helpful and comforting, she's prescribed some new medications to help her sleep at night and manage her

anxiety. Her GP suggests she makes contact with her local diabetes UK group to meet others in her situation.

Her new medications are helping Felicity come to terms with her new condition and the changes she has to make and she's gradually starting to see an improvement in her health and her BMI is reducing for the first time in years, which is giving a good boost to morale.

It's taken her a few months but she now feels back in control of her life, she has made a new network of friends via the Expert Patient programme and Diabetes UK and feels more positive for her future. She's still taking her anti depression medications, but she's starting to consider that she may be able to stop them soon.

4 Primary care

Dafydd is 76 years old and has been in declining health for some time. He's quite confused at times, and this has got worse since his wife died six months ago. Dafydd usually speaks Welsh and although he can also speak English, he doesn't use it much at home. When he's confused he much prefers to speak Welsh and is better at explaining himself in his native language.

He's recently been quite short of breath and one morning when he is worse than usual his daughter Helen persuades him to go and see the GP to get checked out. Dafydd is quite proud and wants to go into the appointment on his own, however, as he is a bit confused Helen is worried that he won't be able to express himself properly.

When they get to the surgery they find out that Dafydd will be seeing a GP that Helen knows doesn't speak Welsh, and she's even more worried that her Dad won't be able to explain what is wrong clearly.

After he's been in the appointment for a long time, Helen is surprised when she sees her dad being escorted back to her, smiling and chatting happily with one of the practice nurses. He looks relaxed and tells her that the doctor is going to get him seen in hospital soon.

Back home he explains that although the doctor couldn't speak Welsh, he realised that Dafydd was struggling to tell him what he needed to and asked one of the Welsh speaking nurses to come in to the appointment as a chaperone. The nurse, Sue, had known Dafydd's wife before she passed away, and they were able to reminisce together which reminded him of old times. Sue had asked Dafydd how he was managing without his wife and it was good to talk about her again. The conversation reminded Dafydd that he needed to be sensible and look after

himself properly, and he agrees to let Helen come to the next appointment with him.

5 Emergency:

Rhys is 14 and very active, he enjoys school and plays rugby for his local team. He lives with his mum and dad and his little sister Amara, who's 11.

Yesterday as he was cycling to school he was hit by a car at a crossing. Luckily, he was wearing a cycle helmet which split from the impact of the fall as he hit the car bonnet and the ground quite hard.

The driver that hit him and a few passers-by rushed to help Rhys, and as he was in a lot of pain, the driver called an ambulance and the local police to report the accident. Another passer-by called Rhys' parents who arrived soon after.

The police and ambulance arrived quickly and after assessing Rhys on the pavement decided he should go to hospital to have an X-ray done on his hand and arm.

The ambulance took him to his nearest A&E where he had to wait a few hours before he was seen by a nurse and had X-rays done on his hand and wrist.

Everyone in A&E is nice but very rushed, he's pleased his mum and dad are there as he's bored but also a little scared and his hand really hurts, especially when they were taking the X-rays and had to move it in different positions.

The doctor he saw said that the X-ray suggested Rhys had broken his wrist, but they asked him to attend fracture clinic in a few days to see a hand consultant to confirm the diagnosis. His arm was put in plaster - Rhys and his parents were shaken up but glad it hadn't been more serious.

6 Cancer Care

Gwen lives on her own with her much loved cats, many of whom she has adopted as strays. Although she has lots of friends she doesn't have any family, and her cats give her great pleasure and are fantastic companions. When she was diagnosed with bowel cancer a few years ago, the cats gave her a reason to keep fighting and having them with her each day helped calm her down when she was feeling most vulnerable.

About six months ago Gwen's cancer came back and although she has been having treatment things are getting worse and the tumour is growing. The doctors have told her that the chemotherapy she was on is no longer working and she needs to go on stronger medication. She's really worried that she won't be able to look after her cats properly, and she doesn't know how she will manage. She

spoke to the doctors about it but they said she has to prioritise looking after herself so she's not sure they understand.

Her friends will try to help, as they understand how important Gwen's cats are to her. One friend has suggested that Gwen speaks to her specialist nurse to see if they can suggest anything.

7 Planned care:

Tony is a 53 year old dad of two, he's generally very healthy, likes a drink or two but not to excess and he's been a smoker for many years now, he'd like to stop but never really had the motivation to. He's now a truck driver since leaving the army after 17 years; he likes to keep fit and loves spending time at the beach with his family.

He's been aware lately of a pain in his groin and he thinks he has developed a hernia. He had one before on the opposite side while in the army, when he was treated very quickly following the diagnosis and was back to normal after just a few weeks of rest.

He keeps meaning to go and see the doctor to get on the waiting list for surgery but it takes him four months before he actually finds the time to do so, by now his hernia is starting to be more than mild discomfort and actually be troubling him and stopping him from doing things like carrying the kids for long and walking long distances.

The doctor quickly confirms the diagnosis and refers Tony to his local hospital.

Tony keeps working as normal and waits for his appointment letter. After five months of waiting and his hernia progressively getting worse, Tony goes back to the GP to see if he can speed things up. By now Tony is struggling to even pick up the kids and working is becoming more difficult.

The doctor chases the referral as urgent and Tony goes back to patiently waiting for his appointment, although he's now starting to be quite demoralised by the long wait and frustrated with his worsening health.

He decides to take the opportunity to make a positive change with his life and makes contact with his local smoking cessation team who support him to stop smoking, for the first time since he was in his 20s. This makes him feel pretty good about himself, despite the worsening hernia.

Another three months pass by but finally he receives his appointment letter. The consultant confirms his hernia and that he needs surgery, he also confirms that the

hernia is now of considerable size. Tony is listed for surgery, but he's advised he'll have another three to four months wait before his operation.

The day finally arrives, 11 months since he first saw the Dr he is admitted to day surgery for his hernia operation. The procedure goes smoothly and he's told to rest for six weeks.

Tony goes back to work after six weeks, he's very pleased his hernia is finally fixed, although he still not quite right and he's still finding it difficult to walk long distances and carry the kids for long. Six months pass and although he's feeling better, he's never gone back to feeling like he did before the hernia. He wonders if he ever will feel the same again and is upset that he had to wait so long to have his operation and wonders if he'd been treated sooner he may have made a better recovery.

8 Cancer patient:

Sara is 48 years old, divorced with two children still in school. Her husband is still very involved with her and the kids and they've found a good balance between them for the sake of the kids.

Sara works part time and has recently started volunteering at the local community centre while she's studying to become a teaching assistant, something she's always wanted to do.

She's recently attended her breast screening appointment, she didn't think much of it but then she was asked to attend an appointment at her local hospital as the mammogram had shown an abnormality.

She's rather apprehensive on the day of the appointment, she hasn't told the kids as she doesn't want them worrying. She goes on her own, but really wishes she had someone who could have come with her.

At the hospital she was told that they had found a small lump on her right breast, it's so small that even when examined they can't feel it immediately. She's told she'll need to have the lump removed; this will be a day surgery probably within the next couple of weeks. They will then run a biopsy on the lump to assess what other steps may be required.

Sara is shaken up and in shock; she's worried about how the kids will take it and how they're going to cope while she's recuperating from the surgery. On her way home she called her sister, Agnes, who lives in Scotland, they agree that Agnes will come down to stay for a few days to help Sara and the kids.

The day of the surgery arrives, Sara's ex-husband has agreed to have the kids for the weeks so Sara doesn't have to worry and Agnes is visiting to help look after her. They go to their local hospital in the morning, she's in and out of theatre relatively quickly and the surgeon seems happy with how it went. They're confident they took the whole lump out and they now have to wait for the results to know if it was malignant or not.

Sara and Agnes are able to return home in time for tea. Sara is sore and scared but grateful she had her mammogram so the lump was found early and dealt with so quickly.

Two weeks later Sara received bad news, the lump was cancer and she'll need a course of radiotherapy at her local cancer centre.

The consultant explains that although it's cancer they were able to find it very early thanks to the mammogram and she has the best chances for making a full recovery and that it won't return.

The specialist cancer nurse looking after Sara is very kind and explains things very clearly, she feels like she can open up to her and all questions are welcome.

The kids are been very brave and are back living at home, which makes Sara feel much better, Agnes has gone back to Scotland but will be back in a few weeks and Sara's ex-husband has been very good helping out as he can with the kids.

Sara is not looking forward to more treatment but knows this is what she has to do, she just really hope the radiographers are females as she find it very difficult to be exposed in front of strangers, especially men.

Her first day of treatment arrives and she, pleasantly surprised, everyone is very friendly and the main radiographer is a woman, there's also a male colleague but doesn't come out of his booth and she feels more relaxed than she was expecting to be.

The sessions progress steadily, but on her 7th session her usual radiographer is not present, a male colleague is there instead and she finds his attitude very rude, she finds herself in tears back at home and all her confidence evaporates. She's really low and visits her GP to see if there's anything they can do to help her as she's not been able to sleep since her last radiotherapy appointment.

The GP prescribes her some anti-depressants and suggests Sara speaks to her specialist nurse, Sara doesn't want to make a fuss and just wants to finish her treatment as soon as possible and get back to normal.

Her next three radiotherapy appointments are very difficult for her, even though the first radiographer is back, she doesn't feel confident anymore and hates every second, so much so that she almost didn't go to her last appointment.

Her radiotherapy treatment, however difficult it was for her, was very successful and Sara is given a clean bill of health. She'll need to have tests every year for the next five years to make sure the cancer doesn't return, but the consultant and her specialist nurse all seem very confident.

Sara is glad it's all over, but she hasn't forgotten how the radiographer made her feel. After some thoughts she decides to contact the hospital and notes her concerns about his behaviour. A member of the patient experience team meets with her and listens to her story, Sara doesn't want to make a formal complaint, she just wants him to know he hurt her and make sure it doesn't happen again. She's offered the opportunity to join a patient group who is working with the local cancer centre to make improvements and she feels this is a good way for her to give back for all the care she had, but also to make sure improvements are made and others have a better experience.

5.3 Appendix 3 – Participant information sheet & consent form

Participant Information Sheet

Patient Reported Experience Measure (PREM) Refresh: Focus Groups

We would like you to invite you to take part in a focus group with an NHS researcher to provide your thoughts on the NHS Wales Patient Reported Experience Measure (PREM).

Before you decide whether or not to take part, please read the following information to understand what it is for and what it would involve for you. Please feel free to get in touch and ask questions if anything is not clear or if you would like any more information before you decide.

What is the purpose of this?

We are interested in finding out whether people think the NHS Wales PREM is fit for purpose and asks all of the basic questions that may be relevant to people who use NHS services in Wales. In particular, we would like to hear your opinion on:

- Is the wording clear and easy to understand?
- Are all of the questions relevant?
- Are there any questions that you think are missing?

Finding out whether the current PREM is well worded and contains all of the relevant questions will help us improve the way we collect patient experience feedback across NHS Wales.

Why have I been invited to take part?

We want to talk to a range of different people, including service users, NHS staff, and patient representatives to get their opinions on the NHS Wales PREM.

Do I have to take part?

No, it is up to you whether or not to take part. If you decide to take part you will be asked to sign a consent form. You can change your mind at any time without

giving a reason. If you choose not to take part, or change your mind about taking part, it will not affect the care that you or your family receive in any way.

What will I have to do if I decide to take part?

You will be invited to a focus group with a group of other people. We expect that the focus group will take approximately 1.5 hours. During the focus group, we will look at the current PREM and ask everyone's opinions on whether you think it should be changed in any way. You will not have to do anything to prepare for the focus group, but we will send you the current PREM together with some scenarios so that you can read through them if you wish.

The focus groups will be led by researchers who work at CEDAR which is part of the NHS in Cardiff & Vale. With your permission, we will record them so that we do not miss anything that is said on the day. The researchers may also take some additional notes.

Anything discussed will be anonymous, but we may use anonymised quotes in reports and feedback we provide.

What will happen to the information that I give?

The information from the focus groups will be used to help us understand more about people's opinion of the PREM so that we can make any changes required to improve it.

Will taking part be confidential and will my personal details be secure?

All information which you provide will be confidential (i.e. we won't use your name or any information that could identify you). The handling and storage of personal information will be covered by strict NHS data protection standards. We will aim to use the information we get from the interviews to write a report which anyone can read. Because all names and personal details will be removed, no one reading this report will be able to identify you. If you decide to take part, we will keep the information you provide, including your name and contact details, and the recording of the interview for one year after the end of the project. After that, all of

the identifiable information will be destroyed and only the anonymous feedback will be kept.

What will happen if I change my mind?

We would like to emphasise that it is completely voluntary to. If you decide to participate you are free to change your mind at any time without giving a reason.

What do I need to do next?

Your help would be greatly appreciated, and if you chose to take part we would request that you complete the consent form overleaf and return this to

Kathleen.withers@wales.nhs.uk

Thank you for taking the time to read this information.

Participant Consent Form

I agree to participate in a focus group regarding my opinions of the NHS Patient Reported Experience Measure (PREM)

I consent to taking part in the discussion and have understood the information contained within the Participant Information Sheet, a copy of which I have been given to keep.

I understand that the discussion will be audio recorded and that my anonymised feedback and quotes may be used in the future in reports and publications.

I understand I can withdraw my comments at any time and do not have to give any reason for withdrawing.

I understand that my personal information will remain confidential as outlined in the Participant Information Sheet.

Participant

Print Name:

Date:

Signature or mark:

Interviewer

Name: Kathleen Withers

Position: Research Scientist

Phone: 02921848610

E-mail: Kathleen.withers@wales.nhs.uk

The person named above has had sight of the Participant Information Sheet and has had an opportunity to ask questions.

Signature:



Date: 26th October 2023

5.4 Appendix 4 - list of stakeholder groups invited to focus groups

Policy area	Organisation
Black, Asian and Minority Ethnic	Ethnic Youth Support Team
	Llanelli Multicultural Network Lead
	BAWSO
	Race Equality First
Cancer	Macmillan
	Maggie's Centre
	Tenovus
	Brain Tumour Support
	Clic Sargent
Dementia	Dementia Champions Network
Education and youth organisations	Cardiff University
	University South Wales
	Cardiff and Vale College
	Cardiff and Vale Youth Board (within the Health Board)
Elderly people	Denbighshire County Council, Ageing Well in Denbighshire
	City & County of Swansea, Ageing Well Partnership
Health boards/ trusts/ NHS Wales orgs	Health Inclusion Service Senior Nurse ABUHB
	Patient Experience Branch Lead contact ABUHB
	Patient Experience Branch lead contact BCUHB
	Patient Experience Branch lead contact CTMUHB
	CTM 2030 Community Leaders Network
	CTMUHB Maternity
	Patient Experience Branch lead contact CVUHB
	Patient Experience Branch lead contact HDUHB
	Patient Experience Branch lead contact PTHB
	Women and children's services PTHB
	Service development manager for Therapies and Health Science PTHB
	Dementia lead nurse PTHB
	Patient Experience Branch lead contact PHW
	Population panel PHW
	Refugee and asylum seekers PHW
	Young ambassadors PHW
	Patient Experience Branch lead contact SBUHB
	SBUHB nominated link
	Patient Experience Branch lead contact WAST
Patient Experience Branch lead contact WHSSC	
All Wales Therapeutics and Toxicology Centre	

Visual and hearing impairments	Vision Support
	Guide Dog Cymru
	Wales Council for the Blind
	Centre of Sign Sight Sound
	British Deaf Association
	Royal National Institute of Blind People
Learning disabilities	LD Service Delivery Lead, Liveability
	Improvement Cymru LD Team
	Improvement Cymru LD Team
	Cwm Taf People First
	Operational Manager People First Bridgend
Llais	Llais - Cardiff & Vale
	Llais - Cwm Taf Morgannwg
	Llais - Gwent
	Llais - Neath Port Talbot & Swansea
	Llais - North Wales
	Llais - Powys
	Llais - West Wales
Mental health	Cardiff & Vale Action for Mental Health
	Recovery & Wellbeing college
Substance misuse	Caniad
	Recovery Cymru
	Compliance and Monitoring Officer, RCT
Third Sector	Cardiff Third Sector Council
Maternity Services	Director of Midwifery
	CTM Maternity Services

5.5 Appendix 5 - Topic Guide

Firstly, thank you all very much for taking the time to speak to us today. My name is Kathleen, and I am a research scientist who works for the NHS, based at Cardiff & Vale University Health board. I'm joined today by my colleague Ayesha/Mike who will be help run the focus group.

Before we go any further I thought it would be helpful to go over the background for this piece of work as I know some of you are more familiar with it than others - apologies if I am repeating what you already know. So a PREM or Patient Reported Experience Measure is a set of questions related to a person's experience of healthcare. It may ask questions about things like whether a person was given enough information about their condition or may be very specific like whether the waiting room was comfortable.

Lots of PREMs have been developed to be used in a specific clinic or for a particular condition, so they ask very specific relevant questions. Some are more general, and there is one called the National CORE PREM which is designed to be used in any healthcare setting in NHS Wales including GP surgeries, emergency situations, maternity and planned care. Because it is for use in lots of settings, the questions are very general and the idea is that clinical teams or health boards can use it to get general feedback and add extra questions to it if they need to ask about more specific things that might only be relevant to them.

Following the COVID-19 pandemic and the way that healthcare has changed over the last few years, Welsh Government are keen to make sure that the questions asked in the Core PREM are still relevant and cover the areas that are most important to people. So we are getting feedback from a range of people to review the current PREM and see

- 1 if the wording of the current questions is clear
- 2 are all of the current questions relevant?
- 3 Are there any questions that should be added?

Bearing in mind that these are questions that need to be relevant in any setting and that we want to make sure that it is not too long, we will go through the Core PREM today and get your feedback on if and how we can improve it.

We will be running a few groups to update the PREM and will then test the drafted PREM across Wales. Once the testing is finished we will write a report for Welsh Government that will be available on the CEDAR website for anyone to read.

Does anyone have any questions before we start?

If you want to comment at any time but don't want to interrupt, you can put your hand up and myself or Ayesha/Mike will call you in.

I've had permission off most of you already, but can you all confirm that you are happy for me to record this session please?

So before we start with the questions I thought it would be helpful for everyone to briefly introduce themselves.....

Go through PREM question by question to check wording and relevance

Any questions they would remove

Any additional questions

Go through Feedback points

Go through additional scenario's and go over the PREM again depending on time

5.6 Appendix 6 - Updated Core PREM

Your NHS Wales Experience

The experience that you have of care is important to us. This might be an appointment with your doctor or health visitor, a hospital stay, an outpatient visit or something else. We would be grateful if you could complete this survey so that we can understand this better.

The questions are based on the things that patients have said matter most. We will ask you questions about your latest experience of healthcare. Please help us by giving your honest opinion.

The questions mostly have four options and you are asked to tick the answer that you feel best describes how you feel.

Some of the questions have 'not applicable'. Please tick this if the question is not relevant to your experience.

How recent was the experience you are thinking of?

- In the last week
- Between 1 month and 6 months ago
- Between 1 week and 1 month ago
- More than 6 months ago

Thinking about your first impressions:

1. Was the time you waited:

- Shorter than expected
- About right
- A bit too long
- Much too long

Thinking about this experience:

2. Did you feel well cared for?

- Always
- Usually
- Sometimes
- Never

3. Were you treated with dignity and respect?

- Always
- Usually
- Sometimes
- Never

4a Were you able to communicate in your preferred language?

- Always Usually Sometimes Never

4b What is your preferred language of communication?

- | | | |
|-----------------------------------|-------------------------------------|--|
| <input type="checkbox"/> Welsh | <input type="checkbox"/> Urdu | <input type="checkbox"/> Gujarati |
| <input type="checkbox"/> English | <input type="checkbox"/> Portuguese | <input type="checkbox"/> Italian |
| <input type="checkbox"/> Polish | <input type="checkbox"/> Spanish | <input type="checkbox"/> British Sign Language |
| <input type="checkbox"/> Romanian | <input type="checkbox"/> Arabic | <input type="checkbox"/> Other, please specify |
| <input type="checkbox"/> Panjabi | <input type="checkbox"/> Bengali | _____ |

5. Did you feel that you were listened to?

- Always Usually Sometimes Never

6. Were you involved as much as you wanted to be in decisions about your care?

- Always Usually Sometimes Never

7. Were things explained to you in a way that you could understand?

- Always Usually Sometimes Never

8. If you needed help or support, did you get it when you needed it?

- Always Usually Sometimes Never
 Not applicable

Thinking of your overall Experience

9. How would you rate your overall experience?

- Very poor Poor Satisfactory Good Very good

10. Was there anything particularly good about your experience you would like to tell us about?

11. Was there anything particularly bad about your experience you would like to tell us about?

Thank you for taking the time to answer these questions