

**Title:****NHS Wales Patient Experience Reported Measures (PREMs) Validation report****Authors:** S.Puntoni, K. Withers, A. Percival, A. Willacott**Summary:**

The PROMs, PREMs and Effectiveness Programme in partnership with NHS Wales organisations ran focus groups with members of the public to validate a core set of experience measures that could be used across the whole health care system in Wales.

This reports highlights the background, methodology and outcomes from these events, including three key themes that were highlighted during the events:

- Listening is learning
- Experience vs expectations
- Experience in emergency care

And the final set of core question recommended:

<b>Questions</b>	<b>Answers</b>
Did you feel that you were listened to?	Always, Usually, Sometimes, Never
Did you feel well cared for?	Always, Usually, Sometimes, Never
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
If you asked for assistance, did you get it when you needed it?	Always, Usually, Sometimes, Never
Did you feel you understood what was happening in your care?	Always, Usually, Sometimes, Never
Were things explained to you in a way that you could understand?	Always, Usually, Sometimes, Never
Were you involved as much as you wanted to be in decisions about your care?	Always, Usually, Sometimes, Never

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## **Introduction:**

The Patient Reported Outcomes Measures (PROMs), Patient Reported Experience Measures (PREMs) and Effectiveness Programme (PPEP) has collaborated with NHS Wales Health Boards to deliver four focus groups with members of the public to validate a national set of generic PREMs applicable to all settings within the healthcare system in Wales.

This report provides insights into the four workshops and recommends a final set of generic PREMs for NHS Wales and Welsh Government consideration.

## **Background**

A national set of core questions was first launched in NHS Wales in 2013 as part of the Framework for assuring patient experience. The questions were intended to be applicable across all NHS Wales services as a consistent data set for measuring patient experience.

Over the years it became apparent that the core set is well served for use in secondary care but requires adaptations in other settings, particularly for use in community, screening and patient transport services.

The PPEP requires all patient reported measures to fit a number of criteria for inclusion within the programme, one of which is that all measures need to be validated tools. As the original set of PREMs had never been validated as a complete set, the Programme agreed to work with NHS Wales to run a number of focus groups to validate a revised set. This process related to two aspects of validation:

- Face validity, i.e. do the questions 'look' right?
- Content validity, i.e. are they representative and fully inclusive?

Due to the monitoring and safeguarding required to safely collect large quantities of information, which may include clinical information, the PROMs/PREMs national portal is currently unable to safely handle narrative feedback. Therefore for the purpose of this exercise, questions requiring qualitative, free text responses were not explored. The overall satisfaction question "Using a scale of 1-10 where 0 is very bad and 10 is excellent, how would you rate your overall experience?" was also not included in this exercise as per agreement at the January PREMs workshop.

The inclusion of PREMs on the platform will allow areas of excellence and areas of concern to be identified for further investigation. It will also provide the first opportunity to benchmark and compare patient experience across Wales.

During a workshop in January 2017 experience leads from across all NHS Wales organisations reviewed the core questions and agreed that a revised, shortened selection would be more appropriate than the existing set. A proposed revised set was collated based on the operational experience gathered over the years of using the original core set of questions.

During this workshop, it was agreed that each Health Board and Trust would be invited to host a focus group to validate a final set of core questions, applicable to all care settings and that could be included for collection through the national PROMs/PREMs platform.

## Setting up the focus groups:

Each Health Board/ Trust was invited to host a focus group for approx 10-15 members of the public during March – April, although the PPEP extended the focus groups to the end of May to allow more time to coordinate the events.

Two organisations requested a further extension until June; unfortunately we were unable to accommodate this due to time constraints.

The aims of the workshops were to validate a core set of PREMs applicable to all care settings, and explore barriers and opportunities for the PPEP.

Each Health Board was invited to host one event (including arranging a venue etc) and identify their preferred cohort of attendees. All communication to members of the public was solely managed either by the hosting Health Board or the Local Authority.

Health Boards and Trusts were encouraged to reach out to members of the community with protected characteristics, ensuring diverse representation. Four workshops were held in total:

Organisation	Date	N of participants
Abertawe Bro Morgannwg UHB	22 <sup>nd</sup> March 2017	9
Powys tHB	27 <sup>th</sup> March 2017	6
Betsi Cadwaladr UHB	28 <sup>th</sup> March 2017	6
Cardiff and Vale UHB	11 <sup>th</sup> May 2017	14 <sup>1</sup>

Each workshop was run with the same format, however due to time constraints only the first focus group included a section asking participants for feedback on specific patient information material developed by the PPEP.

All focus groups were facilitated by the same two members of the PPEP, providing a consistent approach to all events.

A minimum of two scribes also attended each event to help capture discussions. Each hosting HB and the PPEP provided at least one scribe each; additionally, observers from the Welsh Government Patient experience team also attended one event and scribed discussions.

The events were not audio recorded to facilitate the participants to speak freely, therefore the notes from the scribes are the record for each event, hence the requirement for at least two scribes per focus group.

In order to promote the feeling of anonymity and facilitate free discussions, participant demographics were not requested. However the discussions identified that the focus groups included a range of patient ages (estimated from early 20s to late 70's) and a range of ethnic and social groups including asylum seekers. Several participants identified themselves as disabled or as having chronic health conditions, or as been carers. Only Cardiff and Vale UHB attendees were

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<sup>1</sup> 14 people attended the focus group, but only 11 were still present at the time of the scoring/ ranking exercise.

rewarded for their attendance, thanks to the generosity of the Local Authority neighbouring team, all attendees received a time credit for each hour of the focus group they attended.

### **Focus groups format:**

Each event started with a brief introduction to the aims of the day and an overview of the PROMs/PREMs national portal was provided to three out of the four focus groups. The introduction was limited during the fourth group due to the large group size and time constraints. This introduction was followed by some time for group discussions and for the participants to be able to ask questions on the PPEP.

Information and questions asked during these introductions will be used by the national programme to inform their Q&A and public facing material and also to inform future developments.

The PPEP developed four case studies/ patient stories (included in appendix 1) to be used as part of the validation process:

- Emergency
- Primary care
- Planned care
- Cancer (never used due to time constraints)

Following the introduction all participants were handed a copy of the 'Emergency' story and a facilitator read it aloud to the group.

A second handout with the existing patient experience core questions was also shared with each participant. The group was then asked to consider how appropriate each core question was for measuring the patient experience of those involved in the case study under consideration. The group went through each question in turn and probes were used to investigate the participants' thoughts on how relevant these would be to the patient involved in the case study.

This activity aims to help the group work together and individual attendees become confident about sharing their thoughts amongst peers. By using fictitious case studies, the facilitators would focus the group's attention away from individuals' real life experiences to a generic and more neutral group for consideration.

Each story would be introduced individually and each question considered against it, before the facilitator would move on to the next story. All stories would be read to the group by the facilitators to ensure all delegates would hear it together, at the same time, and to account for any literacy issues.

The case studies were designed to be short and simple, and to provide examples of different care settings and scenarios. Due to the length of the cancer story, we were unable to use this scenario in the four workshops delivered.

All groups were able to discuss at least two stories, with one group able to cover three in one session.

Delegates were also encouraged to consider additional questions that may be missing from the existing set; these were noted on a flipchart for consideration by the group.

Once the group had considered at least two stories, they were introduced to the next activity which saw them work independently instead of as a group.

Each delegate was provided with a set of core questions individually printed and were asked to prioritise six questions and rank the six in order of preference, with the top as their most important when considering patient experience across all NHS Wales.

People would be invited to share their ranking with the group and also to consider the additional questions that had been considered during the earlier exercise and at previous focus groups.

If the majority of the group agreed that a particular additional question would have made their final selection, it was then presented to the next focus group for consideration.

### **Themes from the focus groups**

Throughout the four focus groups some key themes were raised, these are discussed below:

- Listening is learning
- Experience vs expectations
- Experience in emergency care

#### Listening is learning

It was apparent throughout the four workshops that members of the public hold NHS Wales in high esteem and regard it with a great sense of pride and admiration. Although it was clear that many had experienced degrees of care that either caused physical/ mental harm or distress, all groups held an extremely positive view of NHS Wales as a whole, as well as its staff and the services provided.

All groups agreed that experiences are very personal and subjective and although provide helpful information to improve care and service provision, often the focus seems to be on lessons learnt from negative feedback or stories, and more should be done to capture and promote the positive difference that staff delivering care provides every day.

There was a consensus across the groups that more opportunities to provide feedback should be available, and that a personable approach was needed to understand people's experiences and learn lessons when things don't go well.

A repeated concern was that electronic models of feedback (and, in some cases, care) could be replacing face to face interactions. All involved agreed that face to face interactions will always be the 'gold standard' and most recognised that services needed to achieve a balance between managing large volume of care and feedback electronically, while also improving personable, face to face opportunities for the individuals at time of need.

Many also felt that the health service should do more to educate members of the public on its workings as some felt that people's expectations were sometimes unrealistic due to a lack of understanding of the complexities of care delivery today.

### Experience vs expectations

This was a common theme that was aired throughout the four events.

Members of the public agreed that issues such as hygiene, and infection control are fundamental standards in healthcare, most however felt that their monitoring should not be met through patient experience, as it should be expected as a minimum standard. There was a general agreement amongst all groups that cleanliness (which was always discussed in association with infection control) can play a major part in someone's experience of care, in the same way as any healthcare associated harm. Many also agreed that patients should be able to raise concerns at the point of care or be able to challenge staff where standards may not be met. However most felt that the healthcare system should use different monitoring strategies to evaluate cleanliness as it would not be a true and universal measure for experience.

A number of discussions also focussed on examples of care where hand washing may not be expected or necessary as a matter of course (mental health, some GP, pharmacist, or therapies consultations, etc) and/or could happen out of sight and therefore patients would be unable to fairly respond. For this reasons some felt that to include it as a patient experience measure could unfairly raise expectations.

Members of the public agreed that although hygiene and cleanliness are a fundamental aspect of care that should be monitored and challenged, many felt that it would not be appropriate as a core experience measure.

### Experience in emergency care

During all four workshops, at least one member of each group noted that in the case of a blue light emergency, patients just want the health care service to focus on saving lives and emergency services should not be measured against the same standards, as priorities would be very different under these circumstances.

This theme was never strongly featured in conversations; however it was consistently raised by at least one individual in each group. Both facilitators felt that these comments were made consistently enough across the four groups to be reported and this area could benefit from some further work to understand experience during high priority emergency care.

### **Core question selection**

During the focus groups individuals were asked to select six out of the original 14 core questions, they were then asked to rank their six according to which they considered most important when measuring patient experience across all NHS Wales.

Below is the table showing the ranking, with the scoring in red showing the questions that received the highest scoring:

Do you feel that people were polite to you?	9
Do you feel that you were listened to?	25
Do you feel that you were given enough privacy?	8
Were you given the support you needed to help with any communication needs?	10
Were you able to speak Welsh to staff if you needed to?	1
From the time you realised you needed to use this service, how long did you wait?	23
Thinking about the place where you received care, how clean was it?	10
Did you see staff clean their hands before they cared for you?	8
Did you feel that everything you needed for your care was available?	10
If you asked for assistance, did you get it?	4
If you asked for assistance, did you get it when you needed it?	19
Did you feel you understood what was happening in your care?	21
Were things explained to you in a way that you could understand?	25
Were you involved as much as you wanted to be in decisions about your care?	21

Six questions (scoring showing in red) ranked considerably higher than the others (showing in black).

All the groups noted that the six were the most meaningful when considering patient experience, and as reported previously, although issues such as cleanliness and hand hygiene are fundamental to healthcare they were not felt as meaningful when measuring patient experience.

### Amendments to selected questions

Of the selected questions, one was repeatedly singled out for changes to its wording and answers:

	Existing	Amended
<b>Question:</b>	From the time you realised you needed to use this service, how long did you wait?	From the time you realised you needed to use this service, was the time you waited:
<b>Responses:</b>	A short time, a little longer than needed, a long time	Faster than expected, About right, A bit too long, Much too long.

All groups felt that the waiting time was subjective depending on people’s experiences and circumstances. The appropriateness of a wait for treatment is also dependent on the urgency. For example a wait of 24 hours is meaningless unless we know if this is in the context of an emergency or normal hospital referral.

All agreed that this is an important measure for experience however participants felt that the original core question was unfairly worded as it did not allow for context, or variations in individuals expectations.

**Addition:**

One question was recommended for consideration during the second focus group and was favourably considered by the following two groups:

The original proposal was “Did you feel you were cared for?” using Always, Usually, Sometimes, Never as the answers.

Although this question was not considered by the first focus group it follows some of the discussions held, mostly around the existing core question of politeness, which all groups felt was not suitable.

The last focus group specifically argued that although they agreed with the sentiment of the question and that it would be a suitable addition to a core set, they suggested revising the wording to:

“How well cared for did you feel?” with answers based on a scale of 1-5.

We recommend that a combination of the two versions is adopted for consistency:

“Did you feel well cared for?” answers: Always, Usually, Sometimes, Never.

**Recommended final set**

Domain	Question	Answers
1	Did you feel that you were listened to?	Always, Usually, Sometimes, Never
1	Did you feel well cared for?	Always, Usually, Sometimes, Never
2	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
2	If you asked for assistance, did you get it when you needed it?	Always, Usually, Sometimes, Never
3	Did you feel you understood what was happening in your care?	Always, Usually, Sometimes, Never
3	Were things explained to you in a way that you could understand?	Always, Usually, Sometimes, Never



3	Were you involved as much as you wanted to be in decisions about your care?	Always, Usually, Sometimes, Never
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The above set combined with the existing question “Using a scale of 1-10 where 0 is very bad and 10 is excellent, how would you rate your overall experience?” will be incorporated into the national PROMs, PREMs and Effectiveness Programme and it is anticipated that this will be ready for collection in Health Boardss from October, aligned with condition specific PROMs.

The two additional qualitative questions within the existing core set (“Was there anything particularly good about your experience you would like to tell us about?” and “Was there anything that we could change to improve your experience?”) will not be incorporated at this stage due to the safe collection of qualitative information.

However these two should remain part of the national set of core questions for use by NHS Wales Health Boards and Trusts as these will provide the most detailed information to advance improvement work locally.

## **Appendix 1**

### **Emergency:**

Rhys is 16 and very active, he likes school (most of the time) and plays rugby for his local team. He lives with his mum and dad and his little sister Megan, who's 11.

On Wednesday morning as he was cycling to school he was hit by a car at a crossing. Fortunately, he was wearing his helmet which split from the impact of the fall as he hit the ground hard.

The driver that hit him and a few of the passers by all rushed to help Rhys. The driver called the local police to report the accident and also called an ambulance as Rhys seemed quite shaken up and bruised from the fall. 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 couple of 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 X-ray suggested Rhys had broken his wrist, but they asked him to attend fracture clinic three days later 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.

Rhys and his dad attended fracture clinic three days later where the plaster on his arm was taken off to be X-rayed again, which allowed the hand consultant to confirm he had broken his wrist. He was put back in plaster and asked to return after six weeks.

The six weeks in plaster were very boring for Rhys and he couldn't wait to take his plaster off and ride his new bike. His parents and Megan were also looking forward to Rhys being back to his normal self and able to help around the house more.

After six weeks the plaster came off and Rhys was given a clean bill of health, he's framed his X-ray which now takes pride of place in his bedroom.

### **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 pump 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.

### **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.

### **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 7<sup>th</sup> 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.