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Standardising the collection of patient-reported experience measures to facilitate benchmarking and drive service improvement

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Standardising the collection of patient-reported experience measures to facilitate benchmarking and drive service improvement

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Abstract

Patient experience teams in NHS Wales' Health Boards and Trusts are working across the country to collect patient experience feedback from members of the public who access health care services. Although this work is advanced in many areas, there is currently no way of benchmarking across organisations, reducing opportunities for shared learning. We aimed to work with patients and colleagues across Wales to agree a set of universal Patient Reported Experience Measures (PREMs) questions. Working with patient experience teams, patient groups and Welsh Government, the NHS Wales Patient Reported Outcome Measures (PROMs), Patient Reported Experience Measures (PREMs) and Effectiveness Programme team has agreed a national set of PREMs questions for use across Wales. This process led on from previous work and included patient focus groups, patient experience leads and clinical input. Patients using secondary care services in Wales will be invited to complete the agreed PREMs survey along with patient outcome measures, via an electronic platform. This will provide a consistent method of data collection which will allow us to benchmark across hospitals and organisations in NHS Wales, identifying areas of good practice, as well as areas where patients report poorer experiences. This will allow local patient experience teams to target more in-depth experience gathering initiatives and carry out appropriate improvement programmes, making better use of resources. Identifying and sharing good practice will allow NHS Wales to advance patient experience, while triangulation with patient and clinical outcomes will drive the Prudent Healthcare agenda.

Keywords

Patient experience, patient engagement, partnership, collaboration, process improvement, service improvement

Introduction

In most health care systems, vast amounts of data are gathered from clinical teams, yet outside the clinic environments patients generally have limited opportunities to provide information about their symptoms, priorities or experiences. The term “co-production” (Batalden 2015) is being used increasingly in the NHS to describe methods of working which involve health service users and health professionals working in equal partnership to share decision making (Leng 2017). It recognises that patients are often best placed to assess which aspects of healthcare matter to them the most. They are also able to provide essential feedback on the quality and experiences of the care they receive. The 2008 Report “High Quality Care for All” (Darzi 2008) highlighted the importance of understanding patient satisfaction with their own experiences and proposed the use of patient outcome and experience measures. In 2012, the National Institute for Health and Care Excellence (NICE) published a Quality Standard for patient experience in the NHS, suggesting the use of patient surveys as part of the process of measuring

quality. This fits with the aim of Prudent Healthcare to create a patient-centred system in which patients contribute to their own health and wellbeing through full involvement with decision making and receive treatments which are most appropriate for them. Prudent healthcare promotes the following principles:

- Public and professionals are equal partners through co-production
- Care for those with the greatest need first
- Do only what is needed and do no harm
- Reduce inappropriate variation through evidence-based approaches.

PREMs fit with these principles by inviting patients to provide feedback on their experience which can then be used as evidence to improve patient care by identifying weaknesses and learning from best practice. These aims align closely with those in other healthcare systems including The Institute of Medicine in the US which has a framework including the six aims for healthcare (Agency

for Healthcare Research 2015). Similarly to the Prudent Healthcare agenda these include patient centred care and equitable healthcare, and it is recognised that engaging patients and their families in their care can support these aims. Patient experience of care is also recognised by the Institute for Healthcare Improvement (IHI) as a key driver in optimizing the performance of health care systems (2018). The IHI proposes a triple aim framework composed of three dimensions which suggest that improving experience of care, improving health population and reducing per capita costs are essential elements in driving improvement. These aims including measuring patient experience are well supported by the PROMs, PREMs and Effectiveness Programme.

NHS Wales covers all secondary, primary and tertiary care services along with patient transport within Wales. It has focused increasingly on providing patient centred care, with the 1000 Lives Improvement service producing a White Paper in 2013 on “Ensuring care is person-centred in NHS Wales” (1000 Lives Improvement 2013a). This was supported by their “Co-producing services, co-creating health” Tools for Improvement guide, detailing key determinants of a good patient experience (1000 Lives Improvement 2013b). This guide details the importance of gaining user feedback via multiple collection models such as surveys and patient stories to understand patient experiences of care.

A national set of core patient experience questions was first launched in NHS Wales in 2013 (Welsh Government) having been developed by a sub-group of the National Service User Experience Group, a network of patient experience leads in NHS Wales. The core questions were developed to support NHS Wales with their real time methods of gaining patient experience feedback as set out in the Framework for assuring Service User Experience (Welsh Government 2013). The Framework identified the following three domains which describe the key determinants of a good user experience:

- First and lasting impressions
- Receiving care in a safe, supportive, healing environment
- Understanding and involvement in care

The core questions were developed around these three domains, as detailed in the 1000 Lives Improvement Co-producing Services Guide (2013b). Following a review of national and local evidence a range of established and validated surveys were examined and key questions were identified for inclusion in the core questions. The literature review and other work undertaken by the 1000 Lives team aimed to ensure that the survey developed focused on safety and quality of patient care with co-production at its centre. While the set developed did not undergo any

formal validation processes, the questions were piloted across a range of healthcare settings.

As well as providing the key determinants of a good user experience, The Framework for Assuring Service User Experience (2013) suggested that these should be measured by a variety of user feedback methods to ensure a completed picture is gained. The Framework was updated in 2015 following a report (Evans 2014) emphasising the need to see patient complaints as an opportunity to improve. This report promoted the consistent routine use of data, held at an all Wales level to share good practice and learn for improvement and not blame. The NHS Wales Framework subsequently included the need to gain feedback from concerns, complaints, compliments and clinical incidents. It also linked with the revised Health and Care Standards (Welsh Government 2015) which include a standard to promote listening and learning from feedback, with criteria including using patient feedback to influence/drive changes to service provision and delivery. It was in the updated version of the Framework that the use of PROMs and PREMs in NHS Wales was formalised.

Many strategies are in place throughout the NHS Wales Health Boards (HBs) and Trusts to gather patient experience feedback. These use a range of sources including concerns and compliments, clinical incidents, surveys and patient stories to gather both qualitative and quantitative data. However, capacity to collect and manage patient experience feedback varies, and there is currently no standardised method to conduct PREMs surveys in NHS Wales. This reduces the ability to benchmark within and across organisations, and hampers opportunities for shared learning.

Background

In late 2015, a successful bid was made to the Efficiency Through Technology Fund (ETTF) to develop a national electronic platform to collect Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) in secondary care across Wales. This ambitious project proposed a long term aim of inviting all patients in secondary care to complete PROMs surveys pre and post treatment, and to provide PREMs feedback following contact with secondary care. The All Wales PROMs, PREMs and Effectiveness Programme (PPEP) was subsequently set up to facilitate this work. The group is supported by the Planned Care Programme Board at Welsh Government, all NHS Wales Health Boards and Trusts, NHS Wales Informatics Service (NWIS) and Cedar Healthcare Technology Research Centre. The PPEP team includes technical and analytical teams, an engagement and implementation team, and clinical leads in each of the HBs/Trusts. The aim of the programme is to use patient level data to support collaboration and engagement, and to

evaluate the patient experience, effectiveness, cost effectiveness and utility of the care provided in secondary care in Wales. Since its inception, the programme has developed an agreed universal PROM which comprises the EQ-5D-5L (Oppe 2014) and the Work Productivity and Activity Impairment (WPAI) questionnaire (Reilly 1993) together with demographic and lifestyle information. This is used alongside condition specific tools where these have been agreed. An electronic portal integrated into the national IT infrastructure has been established and PROMs collection has been piloted in all eight Health Boards.

Objectives

As well as expanding PROMs collection across Wales and increasing the range of condition specific tools available, the PPEP aimed to work with patients and patient experience groups to agree a suitable PREMs survey. The PREM will aim to act as a universal core of experience questions for use across NHS Wales both on the electronic platform and via other media. While it is proposed that these questions can be added to as required in different settings, the use of a universal set will ensure there is consistency across Wales. This will allow organisations to benchmark both PROMs and PREMs within and across organisations and will facilitate shared learning. A standard approach will mean that Patient Experience teams will be able to focus on specific clinical areas, to maximise their potential.

Method

The development of the PREMs survey consisted of four phases: i) a workshop with Patient Experience leads to discuss aims, limitations and methodology; ii) focus groups with patients to identify questions for inclusion; iii) Welsh Government approval; iv) a Community Health Council Workshop to discuss access options.

Patient Experience Lead Workshop

To discuss the most appropriate way to progress the PREMs survey development, patient experience leads and clinical leads from each of the HBs and trusts were invited to a workshop in January 2017. All of the HBs and trusts were represented as were Welsh Government and the Patient Portal Programme at NWIS. Feedback was provided from each of the organisations represented, with similar themes and challenges recognised across Wales:

- Multi model approaches are applied by all NHS Wales organisations with universal core questions adapted to reflect the needs of non-acute services/settings.
- Capacity is generally an issue across Wales, particularly around the ability to analyse and triangulate all experience information collected.

- Although lessons are regularly learned based on experience feedback, and issues are resolved at local/clinical level, improvements are not reported centrally to inform organisational level learning.
- Data collection is still primarily focused within secondary care, with limited pockets of work in primary and community settings.

While there were concerns that National PREMs collection alongside existing patient experience feedback initiatives may overburden some patients, overall a coordinated system of collection was felt to be a positive move. Due to safety and governance concerns regarding the collection of free text data the PPEP team proposed that while the long term aim of the Programme would be to consider the inclusion of both qualitative and quantitative patient experience feedback, initially only quantitative responses would be sought. This was related to the possibility that personal information might be provided, or that clinically urgent information could be included in patient responses and would not be acted upon in a timely manner. The Patient Experience leads felt that free text data is the “Gold standard” of experience data collection, and concern was expressed about the value of sole quantitative data collection. It was acknowledged within the group that the data collected will have limited value for service improvement in its own right. However, whilst some reservations remain, overall it was agreed that large scale quantitative data collection would be a pragmatic way to overcome some of the challenges faced within areas of Wales and would allow benchmarking and targeting of local programmes which are able to collect more detailed feedback.

Using the group’s collective experience with the 2013 national core questions in different settings across NHS Wales, the experience leads were asked to consider what changes they would want to make to ensure the core set could be universally adopted across Wales. As a result of this exercise the group suggested a smaller set and amendments to some of the existing questions may be more applicable as a whole system PREMs for use across primary and secondary, urgent and planned care. An overall satisfaction question from the core set was felt to be an essential inclusion as an overview on experience of care. The group however was keen that the new and revised set be developed through focus groups with members of the public from across Wales and be validated before it could replace the 2013 core set.

As part of the process, the PPEP agreed to work with NHS Wales to further develop and validate the revised set of experience questions. This initial process related to two distinct aspects of validation:

- Face validation
- Content validation

Face validation relates to whether the survey “looks right”. This is a subjective measure which ensures that from a reader’s point of view, the survey appears to measure what we want it to measure and that it looks well constructed and easy to read. Content validity relates to whether a survey is representative and fully inclusive, covering all of the attributes which are relevant to the population being surveyed.

Patient focus groups

It was agreed that as part of the process to develop the National set of PREMS questions, each HB and Trust would be invited to host a focus group. These should include approximately 10-15 members of the public, and organisers were encouraged to include a diverse population with a range of characteristics. The focus groups were to take place before the end of April 2017 to ensure the work would be completed ready for the PREMs to be added onto the portal in a timely manner. This was subsequently extended to the end of May 2017 to allow more time to organise the groups. Limited funding was available from the PPEP to run workshops which took place before the end of March 2017, however all subsequent workshops had to be cost neutral or be funded by the HBs/trusts who organised them. Each HB and trust was responsible for arranging the venue and coordinating the cohort of attendees. The aim of the focus groups was to discuss the revised set of PREMs and ensure that the questions included were clearly worded and appropriate, covering all of the issues which are most important to patients themselves.

Ultimately four focus groups were arranged within the time scales available. These were conducted between March 22nd 2017 and May 11th 2017. A total of 35 service users attended the events, as detailed in Table 1. Each focus group was run with the same format, and each was facilitated by the same two members of the PPEP, providing a consistent approach to all events. Only Cardiff and Vale UHB attendees were rewarded for their attendance, with their attendees receiving a Time Credit for each hour of the focus group they attended. This

workshop was developed in collaboration with the Neighbourhood Partnership who funded the Time Credits. To encourage the participants to speak freely, discussions were not audio recorded. In order to accurately capture the details of the discussions a minimum of two scribes attended each event, with each hosting HB and the PPEP provided at least one scribe each; additionally, observers from the Welsh Government patient experience team attended one event and scribed discussions. In order to promote the feeling of anonymity and facilitate free dialogue, 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 being carers.

The focus groups commenced with introductions and an overview of the programme, followed by a description of the aims of the day. A group exercise was then undertaken to encourage the participants to be confident in sharing their thoughts with the room and to think of experiences from different perspectives. Using fictitious case studies, the group discussed the existing patient experience core questions and considered how appropriate each of the questions was in measuring the experience of care received by the patient in the story. Individual questions were discussed in turn, with the facilitators using probing questions to investigate participants’ thoughts. Each delegate was then provided with a set of core questions and was asked to prioritise six questions and rank these in order of importance. The group were also asked if there were any questions or themes not covered by the existing questions, and these were added to a flip chart for further discussion within the group. If the majority of the group agreed that a particular additional question would have made their final selection, it was presented to the next focus group for consideration. Throughout the focus groups six questions were consistently ranked as being most important to the patients involved. These are detailed in Table 2. For one question which was felt to be

Table 1. Four focus groups

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

¹14 people attended the focus group, but only 11 took part in the scoring / ranking exercise.

Table 2. Questions asked of focus group participants

Question	Count
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

important in content, the patients in each of the focus groups felt that the wording was slightly inappropriate. “From the time you realised you needed to use this service, how long did you wait?” which had response options of “A short time, a little longer than needed, a long time”. Focus group participants felt that length of wait and expectations would depend on the type of admission, e.g. whether it was an emergency or urgent referral compared to a standard referral. The feedback suggested that while a wait for an ambulance for example, may be a short wait, it could still be too long. The groups discussed this at length and proposed that more appropriate wording would be “From the time you realised you needed to use this service, was the time you waited:” Response options were subsequently developed to fit this adaptation: “Faster than expected, About right, A bit too long, Much too long”.

Regarding additional questions, most of the suggestions proposed were not felt by the groups to be important enough to include as a universal question. However, one 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?”

Although this question was not considered by the first focus group it followed the theme of 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 universal set, they

suggested revising the wording to: “How well cared for did you feel?” with answers based on a scale of 1-5. The PPEP research team subsequently recommended that a combination of the two versions was adopted for consistency of responses: “Did you feel well cared for?” with answers of “Always, Usually, Sometimes, Never”.

Following the focus groups a set of seven universal questions was developed. These were added to the overall satisfaction question as per agreement at the January PREMs workshop. These were subsequently forwarded to Welsh Government with a recommendation for their use across Wales.

Focus groups – General feedback

During the focus groups several key themes were raised. All of the groups expressed admiration in the work of NHS Wales, with even those who had experienced episodes of poor care expressing a feeling of satisfaction with the service it provides. The groups noted that experiences are very personal and subjective. However, attendees noted that the focus on patient feedback is often related to feedback from negative experiences such as complaints and concerns. They felt that more should be done to capture and promote the positive difference made by the staff delivering care provided every day. There was a consensus that there should be more opportunities for patients to feedback on their care, and the concept of the PROMs & PREMs portal was felt to be an excellent way of collecting this feedback in order to get a varied range of patient views. While there was concern expressed that an electronic platform would disadvantage some groups, it

was generally felt to be a sensible method of managing large volumes of feedback, provided that alternative opportunities were still available.

Experience versus expectation was a theme that was common throughout the four events. This was particularly evident in relation to hygiene, where it was felt that while cleanliness and hand hygiene should be fundamental within healthcare it should not be measured within patient experience as it should be expected as a minimum standard. It was also suggested that while you would expect staff to have cleaned their hands before physically touching a patient, in some circumstances such as in some therapies, it may not be necessary. Additionally, participants noted that not having seen it happen is not an accurate indicator that it did not happen and it was therefore felt to be an unfair measure, particularly in emergency situations where it was less likely to be noticed. The different expectations in routine versus emergency care were highlighted by individuals in each of the groups. Some participants felt it was almost impossible to measure emergency care against the same standards as routine care as patient priorities may be very different.

Feedback forms were provided following the focus groups, and two of these were completed. Both responders were very positive, indicating that they were able to participate fully in the discussions. They also noted how much they felt their opinions were valued.

Welsh Government Approval

The Welsh Government policy leads for patient experience were fully involved in the methods of developing the PREMs questions. Once the proposed universal set was received, the questions were considered for approval by the Listening and Learning from Feedback Group which includes representatives from all Health Boards and Trusts as well as a range of key stakeholders. Whilst the chosen questions were felt to be acceptable, the Welsh Language Act places an obligation for public sector services in Wales to treat Welsh and English on an equal basis. It was felt essential that in order to measure this, the

original core question “Were you able to speak Welsh to staff if you needed to?” should remain. The Listening and Learning from Feedback Group approved this final set of nine universal PREMs questions for use across Wales in July 2017 (see Table 3).

Community Health Council Workshop

A PREMs workshop attended by clinical and patient experience teams was held in July 2017 to discuss when PREMs would be collected and who would access the responses. Discussions in the workshop suggested that there is often a disconnect between clinicians and patient experience teams. Within the NHS, patient experience is generally managed by the Director of Nursing. Unless a specific issue is raised, patient experience is not routinely fed back to staff on an individual basis and may only be looked at on a ward or even hospital level. The clinicians present at the workshop were keen that clinical colleagues should be given an opportunity to take greater ownership and involvement in patient experience, and that access to all patient experience feedback collected on the PPEP should be available to them on a patient level basis. The patient outcome responses (i.e. PROMs) collected by the programme will be available for the clinical teams to see in order to monitor progress and facilitate patient-clinician discussions. PREMs responses however are traditionally anonymous, in the belief that this will encourage openness. Some clinicians at the workshop suggested that this may be an incorrect assumption, and that as a programme we should investigate the possibility that some patients may be happy for their responses to an experience survey to be available to clinical teams to aid improvement. It was felt that this would be a way for clinicians to directly link with a patient to understand and potentially resolve any issues, which could in turn facilitate improvements in patient experience. However there were concerns that if all individual patient experience measures were automatically available to clinicians this would influence responses, leading to bias, and patients who reported negative experience could be open to (or at least in fear of) reproach by clinical staff. To seek guidance on the most appropriate way forward, advice was sought from a local

Table 3. Approved universal PREMs questions

Question	Answers
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, Not applicable
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
Were you able to speak in Welsh to staff if you needed to?	Always, Usually, Sometimes, Never, Not applicable
Using a scale of 1-10 where 0 is very bad and 10 is excellent, how would you rate your overall experience?	

Community Health Council (CHC). Within Wales, the function of the CHC's is to represent the interests of the public in respect of the Health Service.

A focus group was subsequently held, and attended by 10 local CHC members, with a Director of Nursing, the National Clinical Lead for the PPEP, and a patient experience lead representative also attending to put forward different perspectives. The CHC group could see the potential benefits of sharing responses with clinicians, but were also aware that some patients may be reluctant for clinicians to see identifiable feedback. The group noted that the concept of identifiable patient experience data being shared in this way is a significant culture change and felt that not all patients would understand its significance.

It was agreed that for a trial period, the consent form would include an option for patients to allow their identifiable feedback be made available to clinicians. This option provides patients with freedom of choice, while allowing the programme to collect data from both groups of patients (consenting and non-consenting) for comparison, in an anonymised way. The Programme will not automatically make any of the identifiable information available to clinical teams, unlike individual PROMs which are made available in the clinic environment to support shared decision making. The Programme will provide completed PREMs to the information department as part of their weekly data returns and will work with all Health Boards and Trusts information and experience teams to identify safe and effective ways to provide information to clinical teams in an ethical way according to local existing process and protocols.

Results

Working with patients and patient experience leads across Wales, a set of standardised universal PREMS questions has been developed and agreed. These have been approved by Welsh Government for use across NHS Wales and data sharing issues have been discussed.

The questions will be used across all settings in various appropriate formats including on the electronic PROMs & PREMs national portal. They will be added to the PPEP Portal in early 2018. As a large scale data collection facility, the portal is an ideal opportunity to invite feedback from a large volume of patients in a range of settings. When an appropriate number of responses has been received we aim to carry out further analyses to measure the construct validity of the PREMs questionnaire using Cronbach's alpha to assess internal consistency.

Both the PROMs and PREMs surveys are available for completion in person or by proxy, so that patients who are unable to access and complete the surveys themselves are still able to participate. For proxy completions, the relationship to the patient and the reason that support is

required is requested. In the future, this will allow us to carry out comparative analysis to assess whether responses vary depending on these factors. This will enable us to look at any differences in the way experience is interpreted depending on whether a person is an observer or a participant of care. We will also look at the issue of anonymisation of PREMs, and carry out additional work to investigate patient preferences in sharing PREMs responses. Although historically these have generally remained anonymous, it is important that the NHS, as other organisations, remains willing to adapt and keep in touch with patient preferences. Offering patients the option to provide feedback on their experience directly to their clinician is a relatively novel concept and could initiate an opening of patient-clinician dialogue for some patients.

PREMs collection will initially include adults only; however, for both PROMs and PREMs we are investigating generic surveys for use in paediatric populations which will be used alongside condition specific tools where appropriate. Once these have been agreed, children across Wales will also be invited to complete appropriate surveys. We are aware that particularly for younger children responses are likely to be primarily by proxy completions. However, children's opinions on experience of care are often difficult to gather, and our platform will provide an additional method of gathering some feedback from this patient group.

The programme team is keen to ensure that our findings can be used to support and inform local initiatives and will continue to work with patient experience leads to integrate the PPEP and PREMs collection with other work wherever possible. Our long-term aim is to extend the capacity of the PPEP to facilitate the collection of free text data. This will be a significant advance in the large-scale collection of PREMs in Wales and would be an important step in supporting the work of local patient experience teams and drive service improvement across the country.

Strengths & Weaknesses

As previously noted, the primary weakness of this set of PREMs is the absence of qualitative data collection. While the programme acknowledges that within patient experience, free text is the Gold Standard, as the 1000 Lives 2013 guide noted, multiple collection models are essential in gaining a thorough understanding of patients' experiences. While the PPEP programme develops to overcome the safety concerns regarding collection of free text, we feel that the collection of quantitative data will allow the patient experience teams to target their resources and will allow us to triangulate PROMs and PREMs responses across Wales.

The universal set of PREMs was developed from work previously carried out in 2013 and did not use standard

item generation and questionnaire development methodology. While this was partly due to time and funding limitations, it was also felt that the original set were well developed and primarily required patient validation and updating to ensure they were suitable for modern formats. The set will be monitored over time and changes considered based on feedback and the outcome of further analysis.

The use of an electronic system will inevitably exclude some patients groups who are less able or inclined to use technology. Deprivation and increased age are known to be associated with lower use of the internet, and a 2013 study finding indicated that younger, more affluent patients were more likely to use an electronic PROMs system (Ashley et al). Despite this, electronic collection of patient reported data has been carried out successfully in the UK (Malhotra et al 2016). Electronic data capture is less costly than traditional paper based methods and removes the need for data entry.

As discussed, the Gold Standard of PREMs is the use of qualitative data, which has not been included in the universal set. While this is a limitation for the electronic collection, we feel the large numbers of patients who will be able to provide feedback will facilitate shared learning across Wales. The use of a national collection system will ensure that data is used consistently: this will help drive improvement by ensuring that patient experience teams can focus their limited capacity to those areas that have been identified as being in need, using focused in-depth qualitative feedback mechanisms. Furthermore, the universal set is intended to be used as a minimum with additional questions added in appropriate settings, so it can be extended as necessary to meet local requirements.

The ability for patients to choose whether responses are anonymous on the electronic collection system is relatively novel and will help examine patient preferences and whether responses vary depending on anonymity. This is an interesting area which has been poorly investigated to date.

Conclusion

Quantitative feedback will facilitate the direct comparison across clinics, hospital sites, HBs and trusts, and will allow each Health Board to identify the areas of excellence and those with poorer feedback. This will allow the patient experience teams to target areas with additional in-depth feedback and improvement programmes. Identifying areas with good feedback will also allow us to use these as exemplars to celebrate positive experiences and facilitate shared learning.

Building standardised routine patient experience and outcome collection into the patient pathway will normalise the feedback process and ensure a wide range of patient

views are represented. Using an online system provides a mechanism for collecting and analysing large volumes of data in a safe and economic way and will also facilitate data linkage. The aim of inviting a national cohort to provide feedback on their experience and outcomes of care is highly ambitious, but clearly aligns with other quality improvement initiatives including the IHI (Institute for Healthcare Improvement) triple aim. Using the data collected, triangulation of experience and outcomes will be feasible on a large scale. This, together with cost effectiveness analysis will support co-production and the prudent healthcare agenda.

References

1. Batalden M, Batalden P, Margolis P, et al. Coproduction of Healthcare Service. *BMJ QualSaf*. 2016; 25: 509-517.
2. Leng G, Ingham Clark C, Brian K, Partridge G. National commitment to shared decision making. *BMJ* 2017; 359:j4746.
3. Darzi A. High quality care for all: NHS Next Stage Review final report. 2008. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/228836/7432.pdf [accessed 16 May 2018].
4. National Institute for Health and Care Excellence. NICE Quality standard 15. Patient experience in adult NHS services (2012). Available from: www.nice.org.uk/guidance/qs15 [accessed 04 Oct 2017]
5. Agency for Healthcare Research and Quality. The six domains of health care quality. 2016. Available at <https://www.ahrq.gov/professionals/quality-patient-safety/talkingquality/create/sixdomains.html> [accessed 23 May 2018].
6. Institute for Healthcare Improvement. IHI Triple aim initiative. 2018. Available online at: <http://www.ihl.org/Engage/Initiatives/TripleAim/Pages/default.aspx> [accessed 23 May 2018].
7. 1000 Lives Improvement Improving Healthcare White Paper Series – No. 11. The Listening Organisation. Ensuring care is person-centred in Wales. 2013a. Available from: <http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/1000%20Lives%20Plus%20-%20%27The%20Listening%20Organisation%27%20white%20paper%20WEB.pdf> [accessed 27 Oct 2017]
8. 1000 Lives Improvement. Co-producing services – Co-creating health. 2013b. Available from: <http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/T4I%20%288%29%20Co-production.pdf> [accessed 27 Oct 2017]
9. Welsh Government. Your NHS Wales Experience Questionnaire. (2013). Available from <http://www.wales.nhs.uk/sitesplus/documents/1064>

- /WG18976%20health%20and%20social%20services%20Eng_web.pdf [accessed 12 Oct 2017]
11. Welsh Government NHS Wales Listening and Learning from Feedback: Framework for Assuring Service User Experience 2015. 2015. Available from: http://www.wales.nhs.uk/sitesplus/documents/1064/Healthcare%20Quality%20-%20FINAL%20ENGLISH%20-%2025789_Revised%20Framework%20for%20Assuring%20Service%20User%20Experience_E_WEB.pdf [accessed 04 Oct 2017]
 12. Evans K. Review of concerns (complaints) handling within NHS Wales: 'Using the gift of complaints'. 2014. Available from: <http://www.wales.nhs.uk/usingthegiftofcomplaints> [accessed 04 Oct 2017]
 13. Welsh Government. Health and Care Standards. 2015. Available from: http://www.wales.nhs.uk/sitesplus/documents/1064/24729_Health%20Standards%20Framework_2015_E1.pdf [accessed 18 Jan 2018]
 14. Oppe M, Devlin NJ, van Hout B, Krabbe PF, de Charro F. A program of methodological research to arrive at the new international EQ-5D-5L valuation protocol. *Value Health* 2014; 17(4):445-453
 15. Reilly MC, Zbrozek AS, Dukes EM. The validity and reproducibility of a work productivity and activity impairment instrument. *Pharmacoeconomics* 1993; 4(5):353-65.
 16. Ashley L, Jones H, Thomas J, et al. Integrating patient reported outcomes with clinical cancer registry data: A feasibility study of the electronic patient-reported outcomes from cancer survivors (ePOCS) system. *J Med Internet Res*. 2013; 15(10):1–19.
 17. Malhotra K, Buraimoh O, Thornton J, Cullen N, Singh D and Goldberg AJ. Electronic capture of patient-reported and clinician-reported outcome measures in an elective orthopaedic setting: a retrospective cohort analysis. *BMJ Open*; 2016; 6(6):e011975. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4916591/> [accessed 09 Oct 2017]