

## Can PROMs really influence service change?

### Audience Questions – pre event **‘What do YOU want to know about PROMs?’**

Answers were provided by Katherine Withers, Value in Health Lead, Principal Researcher (Cedar), Honorary Research Associate (Cardiff University)

#### Little to no knowledge:

What is PROMS

I want to know a fair amount

Everything would be useful

Looking for a general overview on PROMs

*A PROM is a scientifically designed questionnaire can be used to measure a patient’s health status or health related quality of life (HRQoL). Often called “tools”, PROMs are usually self-completed, allowing clinicians to understand a person own opinion of their health, and they give a snapshot of information which might include things such as severity and frequency of symptoms, ability to function, or impact on life and daily activities.*

*PROMs are often completed before and after a procedure or treatment to help us understand whether there has been any change in HRQoL due to the care received. However, they can also be used to measure HRQoL over time, allowing us to monitor the health of people with chronic conditions for example.*

*There are broadly two different types of PROMs tools, generic and disease / condition specific. Generic tools like [EQ-5D-5L](#) or [SF-36](#), can be completed by anyone at any time, and measure general health while condition specific tools (like the [Oxford Knee Score](#)) assess the impact of a particular condition on a patient. Some PROMs can be used in health economics and allow us to measure the cost – effectiveness of different treatments.*

#### VBHC

How are PROMs used to improve value?

*In a number of ways. Firstly we can use them to personalise care and focus treatment on the things that are most important to patients as the PROMs responses allow us to understand their problems, challenges and aims in a measurable way. They support triage and decisions around treatment choices. Aggregated PROMs can be used in Health Economic assessments and service evaluations to identify which treatments, pathways and care options are getting the best outcomes and are the most cost effective. It can allow us to compare within groups e.g. allowing us to compare the most cost effective hip implant, and can also allow us to compare between different treatments and even different diseases. This can help us with procurement and can help inform decisions around funding.*

How do we select the most appropriate PROMS to ensure we are measuring the most important outcomes?

*Your value based healthcare team and the Welsh Value in Health Centre can provide advice and guidance*

## Implementation

Are PROMS of use in screening health status and stratifying surgical patients on our waiting lists?

They can be (as part of the decision making), but their use varies between health boards and departments.

How to create PROMs to use with patients on our ward

*The process for developing and validating PROMs is long and complex and usually requires a research study. There are many PROMs that already exist and often it is possible to find one that is suitable for your needs. Patient Reported Experience Measures (PREMs) can be developed to suit your particular needs, but these need to be developed carefully too, so that we can be sure that the data collected is useful. If you need a PROM, try contacting your value based healthcare team or the Welsh Value in Health Centre for advice and guidance. Your patient experience team may be able to help with PREMs.*

How they are developed, and how they can help with recording outcomes

*PROMs are developed using rigorous scientific processes and include input from patients, clinicians and the literature before they are tested in a patient cohort over time. The responses then undergo statistical analysis to make sure they are responsive, sensitive and robust. Because of the way they are developed, we can be sure that the data they collect is an accurate representation of patient symptom and need, and can allow us to track their progress over time.*

## Data & Tools

How long do you need to collect PROM data before you can make effective use of it?

*It depends. On a patient level it is useful immediately, on a cohort level it depend on how clean the data is. If it has been collected at clearly defined time points with the cohort data aligning at these, even a relatively small aggregated dataset can give us insights. If the data is messy with responses at different time points it is more challenging and more data are needed.*

Validated tools in acute setting

*A number of tools exist. Your value based healthcare team and the Welsh Value in Health Centre can provide advice and guidance*

Examples of PROMs tools

*There are literally thousands for use in many, many different clinical areas. If you have a particular interest, your value based healthcare team and the Welsh Value in Health Centre can provide advice and guidance*

Support in finding or creating the right one.

*Lots already exist and we would usually advise against creating new ones. PROMs are developed using rigorous scientific processes and include input from patients, clinicians and the literature before they are tested in a patient cohort over time. The responses then undergo statistical analysis to make sure they are responsive, sensitive and robust so it takes some time to develop new ones (and is expensive!). Your value based healthcare team and the Welsh Value in Health Centre can provide advice and guidance on how to identify suitable tools.*

What types of PROMS are available/can be used for service improvement and how to implement it within the team.

*There are literally thousands for use in many, many different clinical areas. If you have a particular interest, your value based healthcare team and the Welsh Value in Health Centre can provide advice and guidance*

What is a good one to use to capture feedback for a multidisciplinary and multiagency service?

*More information about your clinical area might help us give more useful advice. Please contact your value based healthcare team for advice and guidance*

## **Patients**

How they are used to inform patient experience?

*They can affect patient experience by providing a means of involving patients in the exchange of information and decisions about their care. Their use is beneficial in shared decision making which is an important part of the patient experience. There have been numerous examples where PROMs have been used to improve care and outcomes, and this often goes together with patient experience.*

What outcome measures are most important to patients and how these compare to ones as HCPs?

*It depends on the condition / disease etc. The important thing about PROMs is that they have been developed to include questions about the things that are most important to that particular patient group. While these are sometimes the same things that are important to HCP, sometimes they differ. The MOST important ones will also differ dependent on the individual which is why they are so useful in helping HCPs provide personalised care as we can easily understand what is important to THAT patient.*

How to improve response rates?

*This is partly about education (clinician and patient) around how useful PROMs are in providing information to improve the care we provide on an individual and cohort level. Making PROMs an expected part of the clinic experience is likely to be the best way to improve responses. For patients and clinicians being able to see the result of the efforts also helps – can the PROM be used during the consultation? Things like, making sure a patient knows to expect a PROM to complete can help and anything that personalises it is also useful (as in sending to a named person, from a named clinician/hospital/HB). Reminders are also very useful in increasing responses.*

## **Influence and Service Change**

Can PROMs be used for service improvement?

*Yes! By allowing us to understand what is working and what isn't. Particularly if they are coupled with PREMs and other data.*

## **Other**

Ideas of how they could be used to support progress in learning disabilities services

*This is likely to be feasible, but we would need more detail to advise. Please contact your value based healthcare team for advice and guidance*

Utilising PROMs in those with cognitive and communication defects

*This is likely to be feasible, but we would need more detail to advise. Please contact your value based healthcare team for advice and guidance*

Can PROMs work for capturing bereavement outcomes?

*This is likely to be feasible, but we would need more detail to advise. Please contact your value based healthcare team for advice and guidance*

Can we use PROMs responses to predict long-term outcomes?

*Yes, at least in some clinical areas. PROMs collection is relatively new in some settings so it will take time to develop these models. See some examples below.*

<https://online.boneandjoint.org.uk/doi/abs/10.1302/0301-620X.102B9.BJJ-2019-1642.R1>

<https://www.health.org.uk/funding-and-partnerships/programmes/predictive-modelling-of-major-trauma-proms-using-machine>

<https://www.sciencedirect.com/science/article/abs/pii/S0002961022003178>