Spotlight on: **Measure What Matters: an introduction to PROMs and PREMs.**

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Part 1 Why?

Health and care services create an enormous amount of information, but not much that helps us see how well we are doing. We measure what we spend on health and care activities, who does them, when, and where, but seldom whether they help patients or their families.

With not enough money to go around, health and care services are struggling. Cost cutting has a negative impact on quality, but a focus on quality can save money, if we can get it right first time.

Clinicians see health and care as being extremely complex. Patients have thousands of conditions, and thousands of treatments. Many patients have multiple conditions and polypharmacy. On the other hand, we all want the same things – whether we be patients, clinicians, commissioners or policy-makers – we want to be as happy as possible, healthy now and in the future, to feel in control of our own lives, and to have excellent service always. This is what matters to us all.

To monitor what matters, we need measuring tools that can be used across all types of patient care. Such tools should apply to all patients, irrespective of their conditions, be quick to use, easy to understand and validated. Two categories of these tools are person-reported outcome measures (PROMs) and person-reported experience measures (PREMs). PROMs focus on patient outcomes, PREMs on provider service. The people doing the reporting may be patients, staff or carers.

Part 2 What?

PROMs capture each users rating of how they feel about all aspects of their health that matter to them. The outcome is the difference between their ratings before and after care or treatment. They are not just about health status, but cover multiple dimensions.

- Health status covers how they feel physically and mentally, how much they can do and how much help they need from others;
- Personal wellbeing covers both long-term reflections, such as satisfaction with their life as a whole and worthwhileness of what they do, and short-term aspects, such as feeling happy or anxious during the past day or so.
- Health confidence depends on their knowledge of their health (health literacy), how capable they are at managing their health (self-efficacy), access to relevant help and shared decision-making.
- Acceptance of change covers recognition of that change and taking action to move on.
- Self-care covers their ability to manage specific aspects of their health, such as diet, weight, exercise and medications.

Experience measures (PREMs) capture each user's rating of a specific health or care service. Perception of service excellence depends on their clinical relationship (are they treated kindly, are they listened to and is everything explained well; service efficiency), as well as things influenced by the provider management (such as seeing them promptly and being well organised) and how well collaboration works across different services.

Part 3 Staff and Carers

R-Outcomes has developed closely-related families of patient, staff and carer-reported outcome (PROMs) and experience measures (PREMs).
Staff measures include work wellbeing (job satisfaction); job confidence (ability to do your job) and staff's own perception of the level of service they provide. Staff-reported experience may be at the individual level (kindness and communication), the provider level (promptness and organisation), and collaboration between providers. Staff-reported measures are usually anonymous and are often used alongside the NHS Staff Friends and Family Tests, which ask how likely staff are to recommend their organisation as a place for care and treatment, or as a place to work.
Carer wellbeing is increasingly recognised as being vital. Carer-reported measures capture their wellbeing, confidence and their perception of the support they receive from health and social care services. These modules help understand and support carers' needs.
Staff and carers can rate patient's care acuity using the howRthey module, which was developed to capture the needs and risks of people in care homes or receiving care at home. HowRthey can be used for benchmarking and to trigger timely intervention in the event of deterioration. It captures staff or carer's perception of how much help a person needs for their physical care, pain and/or distress, unpredictable needs and behaviour problems. The howRthey module is useful in care situations when it is not appropriate to ask all patients themselves, perhaps because of dementia or receiving palliative care.

Part 4 How?

The implementation of PROMs and PREMs can be mapped to the PDSA (Plan, Do, Study, Act) improvement cycle.
Plan: Decide what you want patients staff or carers to record. Validated questions are usually the result of much research, so don't reinvent the wheel without good cause.
Do: Be crystal clear about your aims and communicate these to the front line. Work out how best to ask people to complete the surveys and adapt the methods to local conditions as part of your routine workflow, not as an optional extra. Whatever method you choose (digital device such as a tablet, or printed forms), make sure it is quick and easy for all patients.
Study: Reporting is useful at three different levels.

1. Tailoring individual patient care to optimise outcomes (PROMs)
2. Helping local service management improve quality (PREMs)
3. Compare similar units using benchmarking (PROMs and PREMs).

People need feedback immediately – not months later – through up-to-date interactive dashboards that let users investigate the results themselves. For cohorts of patients we like to show mean scores on a 0-100 scale, where 0 means that all chose the worst option and 100 that they all chose the best option. A high score is always better than a lower score.
Act: The reason for using PROMs and PREMs is to understand better what is going on. Unexpected findings are often right and offer useful new perspectives, providing individuals and organisations with the intelligence to make changes and check that they have the impact predicted.

Part 5 Common Features

R-Outcomes PROMs and PREMs are an example of a modern suite of tools, with a common look and feel. Modules are mixed and matched to make up short surveys for completion by patients, staff or carers.

Each module addresses a separate domain, but is suitable for all types of patient, irrespective of their condition or mode of treatment. This generic property is useful when patients are heterogeneous or have several conditions.

Each module comprises four question items with four response options each. The options are displayed with the best on the left and the worst on the right, colour coded (green, yellow orange and red) with a smiley-face emoji. NB use of colour and emoji are not core requirements. Responses are optional.

The scoring scheme for individual items is 0 to the worst option and 3 for the best option, with 1 and 2 for intermediate options. The item scores in a module can be added, giving a summary score with a range from 0 (all worst) to 12 (all best).

The number of words in any module is less than 50 and the reading age less than 10, making it quick and easy to understand. When using paper forms, we try to keep all of the questions on one side of a sheet of A4 paper. A free text comment box is provided and we encourage its use. Typical demographic data collected include gender, age in deciles and number of medications, as a proxy for multiple conditions.

Part 6 Innovation

Health care innovations need to be evaluated so we can learn what works and what does not. We need a better understanding of why innovations that work well in one place do not always work well in different contexts. Based on practical experience and understanding of the literature, R-Outcomes has developed a set of four modules that capture some of the reasons why innovation spread varies so much. These dimensions are innovation readiness, adoption process, user digital confidence and application satisfaction.

Innovation Readiness rates where users and organisations lie on the innovativeness spectrum, covering individual's openness and being well-informed, and organisation's receptiveness and capability to innovate. This module is based on Everett Rogers' classification of innovators (early adopter, early majority etc.)

Innovation Adoption covers the whole innovation process from start to end. It covers the coherence of the original vision during implementation, the work on planning, collaboration to make it work during implementation and reflexive monitoring to make it better. The concepts are based on Carl May's Normalisation Process Theory (NPT).

Digital Confidence is a user's digital literacy and confidence to use digital products, covering aspects of familiarity, social pressure, available support and digital self-efficacy. It is primarily aimed at older people, many of whom are not digital natives.

Application Rating is the user's assessment of a specific digital product in terms of their user experience and satisfaction. It is a combination of usefulness (does it do what I want?), ease of use, access to support and overall satisfaction

Part 7 Barriers

Anyone wanting to implement PROMs and PREMs needs to recognise the barriers and other risks.

PROMs offer potential for tailoring individual patient care, as well as for monitoring and benchmarking. However, use at the individual level ideally needs PROMs data to be entered into electronic health records (EHRs) as patient history. The data are similar to clinical laboratory data and should be handled in much the same way.

EHRs are typically coded using Read or SNOMED CT codes, and most PROMs do not yet have the relevant codes at the individual item or even summary level. The systems used to manage PROMs and PREMs data are seldom integrated with EHRs. As a result, it is not easy for clinicians to track changes in PROMs, even if patients have recorded the data. Who is responsible if important PROMs changes are reported but not followed up?

The collection and analysis of PROMs and PREMs data has a cost that is often not made sufficiently explicit. Focus on quality saves money, but only if it leads to improved ways of working. Much effort is devoted to reducing the numbers of A&E visits and emergency admissions to hospital and we often find a strong association between better PROMs and PREMs scores and fewer hospital visits. Ideally, commissioners should pay for evidence of value to patients, not just for activity.

PROMs and PREMs data are relatively new types of information and it will inevitably take time before everyone understands their strengths and weaknesses. Education is needed to get everyone up to speed.

Tim Benson is the Founder and Director of R-Outcomes and also recently became a member of **Q.** This is the third of a series of articles he has written for CSQIP and he can be contacted at: tim.benson@r-outcomes.com. More information on R-Outcomes can be found on their website here.