

National PROMs Programme Consultation

Dear NHS England Insight team

The NHS PROMs programme was established in 2009. In 2010, in a joint OHE/King's Fund publication, we noted that:

"The PROMs initiative is a truly remarkable development for the NHS – and a first internationally: the NHS will be the first health care system in the world to measure what it produces in terms of health, rather than in terms of the production of health care"

[\(Devlin and Appleby 2010\)](#)

Reflecting on the state of play in 2014, we noted:

"So how has this laudable initiative progressed since its initial success? The answer is, sadly, barely at all...the PROMs programme has effectively stalled. The restructuring of the NHS led to responsibility for the PROMs programme shifting from the Department of Health to NHS England...The problem seems to be that, as with many other NHS activities, the 2012 reorganisation led to a loss of focus for the PROMs programme."

[\(Devlin, Appleby, Parkin 2014\)](#)

We welcome this opportunity to comment on the NHS PROMs programme. In 2006/7, OHE initiated an *OHE Commission on NHS Outputs, Productivity and Performance*, where we noted:

"A large body of data is available on health care inputs and expenditures; far less is known about the outcomes that the resources and activities produce. Yet, knowing the outcomes achieved by health services is essential to being able to achieve the greatest benefit, the best patient care, from the resources used. The effectiveness, efficiency and accountability of the NHS all depend on knowing the outcomes it is achieving"

[\(OHE 2008\)](#)

We continue to hold that view. The NHS PROMs programme represented an important step forward - and deserves the full support of government and the NHS.

About OHE:

OHE is the oldest health economics research centre in the world, having been established in 1962. We are owned by the Association of the British Pharmaceutical Industry and receive a research grant from them but operate at arm's length, as a not-for-profit organisation, based in London, undertaking innovative methodological and applied research of global reach and impact under three key themes: the economics of health care systems, the economics of health technology appraisal, and the economics of the life sciences industry. OHE receives funding for its research and

dissemination activities from a range of sources, including the NIHR, MRC, Bill and Melinda Gates Foundation; EuroQol Group; health care charities, the NHS; the Pharmaceutical Oncology Initiative, and individual pharmaceutical companies.

OHE's key recommendations:

- The PROMs programme represented a bold, world-leading initiative in 2009. It has the potential to be the centre-piece of an outcomes-led NHS. It deserves strong leadership and a renewed commitment to putting patients' health outcomes at the heart of health care decision making.
- More effort should be made to ensure the data are presented in ways that are informative and accessible for the (multiple) decision makers to whom they are relevant: patients; clinicians; providers; commissioners; regulators.
- The remit of the PROMs programme should be extended beyond the routine collection of PRO data in 4 elective procedures introduced in 2009. 'Real world' data from patients should be the cornerstone of a modern health care system.
- PROMs data are vital to understanding the effectiveness and cost effectiveness of NHS services. For this reason, we strongly urge NHS England to continue to field both a brief, generic PRO questionnaire in combination with a detailed, condition-specific measure, where available. Generic PRO data provide the crucial, common denominator with which to measure outcomes *across* treatments and diseases.
- NHS England should strive for excellence in its use of PROs, both in seeking to minimise the costs of data collection (e.g shifting to electronic data capture; considering adopting sampling rather than routine data collection in some cases); and maximising the relevance of the data to the patients providing it; and the impact of the data as a driver of quality improvement.



Professor Nancy Devlin
Director of Research
Office of Health Economics

28th March 2016

1. Responses to questions

Q1a. Please let us know what your interest is in PROMs. I am responding as a/on behalf of:

Other

Q1b.

The Office of Health Economics (OHE), London

Q2. What do you think are the most important purposes of PROMS, and why?

“The PROMs initiative is a truly remarkable development for the NHS – and a first internationally: the NHS is the first health care system in the world to measure what it produces in terms of health, rather than in terms of the production of health care” (Appleby, Devlin, Parkin 2016).

The routine collection of PRO data has the potential to put the patients’ views about their own health at the heart of decision making. NHS PROMs data enable patients’ views to be used in important ways, by multiple decision makers:

- Informing the choices made by patients (and their doctors) about what treatment to choose, and what providers to receive it from;
- Measuring and benchmarking the performance of health care providers – both to identify good performance to disseminate more widely, and to identify poor performance requiring management;
- Linking the payment received by providers to their performance in improving patient health;
- Understanding and managing referral from primary to secondary care;
- Facilitating cooperation between clinicians and managers in the delivery of care;
- Enabling health care professionals to monitor and improve health care practices;
- Regulating for safety and quality in health care services;
- Establishing the effectiveness and value for money of NHS health care services.

Q3. How do you use national PROM data? What do you use it for? Why do you use it?

OHE has used these data to:

- Investigate methods of case mix adjustment ([Nuttall et al 2013](#)) of PROMs data;
- Demonstrate methods for analysing patients’ data that do not require the use of ‘utilities’ ([Devlin et al 2010](#));
- Show important differences between hospitals’ performance in terms of the dimensions of health in the EQ-5D ([Gutacker et al 2013](#)); and the relationship between outcomes and cost ([Gutacker et al 2013](#)).
- Explore whether there is a relationship between the levels of concentration in hospital markets and performance in terms of improving patients’ self-reported health ([Feng et al 2015](#))
- Look at the extent to which patients’ self-reported ‘overall’ health on the 0-100 scale (EQ-VAS) relates to specific problems they report on other questions ([Feng et al 2013](#))

- Examine the reasons why EQ-5D data from patients have multi-modal characteristics (Parkin et al 2016 – forthcoming in *Medical Decision Making*) and implications of that for interpreting patients' data.
- Show how PROMs data can be used in cost effectiveness analysis of NHS services – ([Poteliakhoff et al 2013](#))
-

Q4. Thinking beyond your own personal usage, how well used do you think the current national PROMS data are? What are they used for? By whom?

While the PROMs data are used by providers and commissioners, it is our view that the evidence they provide on the relationship between service delivery and patients' outcomes could be used to a much greater extent to drive quality improvement. To do so requires that the data are used to provide relevant information targeted to different decision makers, and presented in ways that are informative and accessible for them. Although PROMs data have been collected from patients since 2009, it is notable that these data have only been included in 'my NHS' and 'NHS Choices' since 2015.

Further, the current approaches to data collection seem to preclude the data provided by patients being used by patients and clinicians to inform treatment decisions – for example, so the clinician is aware of the patients' experience of health problems, their expectations about treatment. This misses an important opportunity for the data to benefit the people to whom it is most immediately relevant: the individual patients providing it.

The future use of PROs in health care systems could involve a radically different way of approaching things: "Patients could use their own PRO data: completing the PRO questionnaires online, enabling them to monitor their own health over time and to compare it with the health of others in the population of their own age and sex and other background characteristics, and those with similar conditions. PRO data can be shared with clinicians and appointments, and provide a basis for conversations about health and treatment options. The data, in anonymised form, can be pooled and linked to administrative data sets, to serve the needs of other decision makers, such as providers, commissioners and regulators" (Appleby, Devlin, Parkin 2016).

Q5. What are the benefits of nationally mandated PROMs?

Outwith the scope of the "PROMs programme", as defined in this consultation to comprise the four elective procedures for which data are collected before and after surgery, there are a wide range of exciting initiatives in the use of PRO data, both in pilot studies coordinated by NHS England, and also by local NHS organisations, proactively pushing ahead with their own initiatives to make service delivery outcomes-focussed (e.g., Cambridgeshire Community Services NHS Trust).

However, relying on local initiatives, without any central coordination or guidance about the use of PRO data, risks the use of different instruments across different parts of the NHS, limiting the insights that can come from comparing data. Further, different practises in the way data are collected locally (e.g., with respect to the timing of follow-up questionnaires) can also compromise the comparative use of data.

A nationally-led PROMs programme has the important advantage of ensuring consistency of approach and measurement. This facilitates an understanding of regional variations; comparisons of provider performance; and the effectiveness and value for money of health care services.

This does not *necessarily* mean mandating the use of PROs as part of routine data collection. However, mandatory data collection is important in targeting effort on certain service areas identified as being priorities. These priority areas could be determined using agreed criteria, e.g. prior evidence of variation in referral or treatment rates; evidence of variation in treatment patterns; concerns about quality of care; concerns about effectiveness or cost effectiveness of treatments; evidence on feasibility of data collection; demonstrated relevance of evidence generated from that data to decision makers. In the absence of such criteria, it is not clear, at present, what the basis is for what is *included* in the mandated national PROMs programme and what is left out of it; or how decisions will be made to add to or drop procedures from the mandatory PROMs programme.

However, the PROMs programme should not be restricted to a handful of mandated elective surgical procedures. NHS England could serve an important leadership role in encouraging NHS organisations to routinely collect and use PRO data - by providing clear guidance and recommendations on what instruments to use (for example, recommending the use of both a disease specific and generic PRO instrument); how to collect data; and how to analyse, report and disseminate it for maximum impact on quality improvement. This sort of 'best practise' framework would assist local NHS organisations wishing to become more outcomes driven in commissioning and service delivery, and would also generate valuable data to inform future nationally-mandated PROMs.

Q6. What are the drawbacks of the nationally mandated PROMs?

An important lesson from the English NHS PROMs programme is that "it is possible to collect PRO data from patients as part of the routine delivery of care and also to obtain follow up data from patients so that changes in health can be tracked. The logistical, ethical and other challenges in collecting data can be managed, and the response rates that have been achieved are impressive". (Appleby, Devlin and Parkin 2016).

The reliance on paper and pencil administration should be revisited – shifting to electronic data capture could offer a number of advantages both in terms of cost and flexibility in use of the data.

Q7. Do you think all of the current four national PROM collections are useful, and why?

As noted, above, that there should be a clearer basis for including (or removing) specific treatments in the nationally mandated PROMs programme.

Q8. Do you think all of the current four national PROM collections should continue, and why?

Given the data from the PROMs programme have only just begun to be embedded in reporting tools (such as NHS Choices) it would be premature to discontinue data collection for these four

procedures. Renewed effort should be made to making the evidence generated from PROMs data is useable by and relevant to decision makers.

Q9. What changes would you make to the current national PROMs collections? (Questionnaire, usage of condition specific and EQ5D, time between Q1 and Q2, time between collection and results being available, presentation of results)

The reliance on paper and pencil administration should be revisited – shifting to electronic data capture could offer a number of advantages both in terms of cost and use of the data ([Calvert et al 2015](#)).

Q10. Do you think additional PROM collections should be mandated and collected nationally, and why? (Please bear in mind the current financial climate and the limitations on resources in your answer.)

See our response to Q.5 (above).

It is OHE's view that the remit of the PROMs programme should be extended beyond the routine collection of PRO data in 4 elective procedures introduced in 2009. 'Real world' data from patients should be the cornerstone of a modern, patient-centred health care system ([Calvert et al 2015](#)).

With respect to the current financial climate, and limitations on resources, we would argue that this makes it even more important to ensure that health services are produced efficiently; and that resources are allocated to those services which produce the greatest improvements in health. Routinely collected PRO data creates an important opportunity to link costs, activity and outcomes to offer the NHS a powerful tool for assessing performance and productivity. As OHE noted in its 2008 Commission on NHS Productivity and Performance, "knowing the outcomes achieved by health services is essential to being able to achieve the greatest benefit, the best patient care, from the resources used. The effectiveness, efficiency and accountability of the NHS all depend on knowing the outcomes it is achieving" ([OHE 2008](#)).

Q11. What should the balance be between national and local PROMs collections? Why?

See our response to Q.5 (above)

Q12. Would the NHS benefit from collecting nationally mandated PROMs in specific clinical areas or along care pathways. Please explain your answer. Which clinical areas would most benefit from a nationally mandated PROM collection, and why?

See our response to Q 5 (above).

Routine PRO data collection is now being adopted in other countries, in a range of procedures other than the 4 elective surgical procedures which are the focus of the NHS PROMs programme. The use of PROMs data by (for example) Alberta Health Services, the Swedish health care system, and New Zealand's private health care insurer, Southern Cross, may provide useful evidence for NHS England on the feasibility and merit of extending the PROMs programme. A further important development

is the planned routine collection of PROMs in the UK's private health care sector, coordinated and published by the Private Healthcare Information Network (PHIN).

Q13. What would be the main purpose(s) / benefit(s) of these additional national PROM collections?

See our response to Q2 (above).

Q14. How should PROMs work alongside other patient reported collections (i.e. Patient Centred Outcome Measures (PCOMs), Patient Reported Experience Measures (PREMs) etc.)?

A patient reported outcome (PRO) questionnaire comprises a series of questions that patients are asked in order to gauge their views on their own health. The purpose of a PRO questionnaire is get the patient's own assessment of their health and health related quality of life. PRO instruments include both generic instruments (relevant across a wide range of conditions); and condition-specific instruments (which provide detailed questions specific to the health problem for which treatment is being considered). Most PRO instruments comprise standardised sets of questions and scoring approaches, carefully developed and tested for validity and reliability in patient populations. Such instruments are vital to the use of these data to compare health between patients and between providers and between treatments.

Some PRO instruments take an individualised approach, seeking to measure an individual's experience of their ill health. The distinguishing feature of these instruments is that the domains of health that are measured, and the way they are 'scored', is driven by what matters to that individual patient. These individualised instruments can be useful – but do not allow data to be aggregated.

All PRO instruments are arguably 'patient centred' – they just have different purposes. While clinicians may not always see the point of collecting generic PRO data (eg EQ-5D), preferring disease specific PRO instruments relevant to their speciality, generic data have an absolutely critical role to play in comparing outcomes across disease areas, and in identifying ways of ensuring that resources can be better allocated to achieve the greatest improvements in patient health. Furthermore, generic PROs also allow patients to report symptoms not specific to the particular condition under consideration, and which are therefore sometimes missed in condition specific PROs, but which may be highly relevant to understanding the patients' experience of their (multiple) health problems and treatment needs.

PRO questionnaires do not ask about the patients' satisfaction with or experience of health care, or seek their opinions about how successful their treatment was. Thus there is also an important role for patient experience and patient satisfaction measures alongside PROs.

Q15. Please let us have any further thoughts or comments you have about PROMs

The PROMs programme represented a bold, world-leading initiative in 2009. It has the potential to be the centre-piece of an outcomes-led NHS. It deserves strong leadership and a renewed commitment to putting patients' health outcomes at the heart of health care decision making.