



National Patient Reported Outcome Measures (PROMs) Programme Consultation Report

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1 Executive summary

Patient Reported Outcomes Measures (PROMs) measure health-related quality of life as reported by patients themselves. The use of PROMs before and after a clinical intervention can provide an understanding of the overall impact of that intervention and the associated health gain.

NHS England currently coordinates the national collection of PROMs for four elective surgical procedures: hip replacement, knee replacement, groin-hernia and varicose vein treatment. These collections were originally mandated in 2009 by the Department of Health.

NHS England carried out a consultation to understand how the National PROMs Programme is currently working, and how it should be developed in the future. The consultation ran on the NHS England website from 4 January to 28 March 2016. 119 responses were received in total from a range of types of stakeholder: researchers and academics, clinicians, patients, members of the public, and representatives of charities, professional bodies, CCGs, NHS trusts, independent sector care providers and private sector suppliers of PROMs data services.

The consultation recorded a wide range of views on PROMs, from those highlighting the burden of the current national collections, to those underlining their importance. This variation in opinion reflected both the different roles associated with the collection and application of PROMs data, and the range of potential uses of PROMs. It is clear from the consultation responses that the PROMs programme is performing better at some of these uses than others, and where PROMs are underutilised, the impact of their collection – in terms of both financial costs and staff time – is more keenly felt. And while many champion PROMs for ensuring that patients have a direct say in how the quality of their care is determined, some feel that PROMs do not go far enough in measuring what is most important to patients.

Respondents identified the main purposes of the National PROMs Programme as demonstrating the effectiveness of treatments by providing evidence of health gain, and providing information to reduce variation in care by highlighting where there are differences between organisations. It is at this population-level that the current manifestation of PROMs arguably provides most utility, although the extent to which it is used for these purposes by care providers, commissioners and patient representative groups varies greatly from organisation to organisation. The consultation gathered evidence of PROMs being used in innovative and effective ways to improve the delivery of services, to inform the allocation of commissioning resources, and by Patient Participation Groups to raise questions about care quality. Yet it is clear that in many cases the potential of PROMs is not being realised in these ways.

The availability and presentation of the data is seen as a particularly significant barrier to the wider use of PROMs results, with many finding the current published products difficult to access, interpret and act upon. Some feel that the results do not provide enough detail to identify the cause of any issues or how to solve them. The time taken to produce results – up to twenty-eight months from pre-operative collection to final publication – is also seen as a barrier to their use in service improvement, since some felt the published data no longer describe the present situation.

Respondents also identified the potential of PROMs to inform and support direct care by measuring individual patient's progress towards their goals, and thereby highlighting issues that might otherwise be missed. It is thought that such an application could help ensure the patients' needs are considered by the clinician, such that the care is tailored to the individual. However, the current National PROMs Programme, being an anonymous data collection, does not facilitate this direct clinical use of patient-reported measurements while care is being delivered. Although some view this as a missed opportunity, issues around patient expectations would need to be explored if a national collection was to be integrated with local clinical use in this way. Many identified the fact that PROMs are currently collected on paper as a barrier to this use. By making results available in real time, electronic collection could in principle facilitate many new uses of PROMs, while still ensuring that results can be reported at the national level. In addition to enabling the use of patient-reported measurement in the consultation process, electronic collection could also automatically link PROMs data to other related sets of patient information, thereby opening up potential for new research into the effectiveness of treatments.

Mixed views were expressed about the continuation of the existing PROMs programme, but the hip and knee replacement PROMs were broadly identified as providing useful data about different aspects of these treatments, with many examples of successful use. The value of these datasets is in part ascribed to the high prevalence of these surgical interventions, such that the hip and knee datasets are more commonly interrogated and applied than other PROMs. However, their value is also viewed as deriving from their specificity: the Oxford Hip and Knee score is viewed as providing information bearing directly on different clinical decisions. The varicose vein and groin-hernia collections, by contrast, are overall viewed as less well-utilised and as having less potential use. In part this is because their data is considered by some to be too generic to allow for detailed conclusion about treatment decisions. In particular, doubts were raised about the quality of the varicose vein condition-specific metric, while the groin-hernia collection was criticised as having no such metric. The EQ5D Health-Related Quality of Life measure is considered by clinicians in particular to be too dependent on other factors for it to be a sole measure of clinical success.

Beyond the existing national collections, there is interest in a broader utilisation of PROMs going forward, especially in the facilitation of local uses of PROMs data and of integrating PROMs feedback with other datasets. Some respondents called for more routine use of PROMs alongside patient experience measures, thus expanding how care quality is being measured, while others championed the development of individualised patient-reported outcome measurement for clinical use, so that patients can define what they hope to achieve from their course of treatment. Many respondents also expressed interest in conducting PROMs in other clinical areas. It is felt that routine electronic collection of PROMs could lower many of the existing barriers to these wider uses of PROMs. At the same time, however, respondents called for further research into the use and value of PROMs, with any further development of the programme to be tested rigorously.

NHS England's response to the consultation

Following this consultation, NHS England has taken the decision to discontinue the mandatory varicose vein surgery and groin-hernia surgery national PROM collections. Along with the evidence found in the consultation, the rationale for this decision is based on multiple factors:

- surgical treatment of varicose veins is currently much less frequent and the condition is usually not a major cause of patient debility;
- groin hernia surgery is offered mainly to reduce the risk of requiring emergency surgery, rather than to relieve symptoms, which are often relatively minimal. This, along with the fact that there is no condition-specific PROM for groin-hernia surgery, means that the existing PROM has limited value.

By doing this, the burden on organisations of continuing to collect this data should be reduced where it is felt these PROMs deliver limited value.

NHS England will continue with the hip and knee surgery PROM collections.

NHS England will work with NHS Digital to make the national PROMs data easier to use and to provide a range of automated outputs that are tailored to the needs of trusts, CCGs and other users.

Where possible, NHS England will seek to drive digital collection of PROMs data. This could help lower a number of barriers to unlocking the potential of PROMs, by increasing the timeliness of the data and by facilitating their use in direct care. This would also provide the benefit of allowing patients greater access to their own PROMs data.

Finally, NHS England is working with NHS Digital to establish an 'Accredited PROMs Supplier List' that would open the suppliers market to new ideas and innovations.

2 Background to the National PROMs Programme

PROMs measure health-related quality of life as reported by patients themselves. Measurements before and after a clinical intervention can be used to understand the overall impact of that intervention and the associated health gain.

In 2009, the Department of Health introduced the mandatory collection of PROMs for four surgical procedures: hip replacement, knee replacement, groin-hernia and varicose vein treatment. These four national PROMs collections made the NHS the first health system internationally to measure what it produces, in terms of health gain, rather than health care.¹ PROMs are one of many outcome measurements and should be considered as part of a suite of datasets that contribute to understanding what matters to citizens, when using the NHS.

There was no single aim for the PROMs programme when it was established by the Department of Health.²

PROMs were expected to be used for a number of purposes:

- to establish whether outcomes differed depending on whether patients were treated in the NHS or at an independent sector provider;
- to inform patient choice of which trust to go to for surgery/treatment;
- to set incentives for performance improvements, e.g. by linking payment of providers to their performance;
- to facilitate service improvements by clinicians and managers scrutinising the data, and acting upon them to improve their scores;
- testing the effectiveness of different interventions.

PROMs are part of the NHS Outcomes Framework and the NHS Standard Contract, and also the Clinical Commissioning Group Outcomes Indicator Set (CCG OIS). PROMs indicators are also presented on myNHS hospital pages, and are used in Right Care packs on musculoskeletal conditions and in CQC's Intelligent Monitoring of hospital trusts.

It is a requirement for organisations performing NHS-funded hip replacement, knee replacement, varicose vein or groin-hernia surgery to collect PROMs data and to submit this data to NHS Digital (formerly known as the Health & Social Care

¹ Devlin and Appleby 2010 - Getting the most out of PROMs- Putting health outcomes at the heart of NHS decision-making, The King's Fund

² Varaganam, Hutchings, Neuburger and Black 2014: Impact on hospital performance of introducing routine patient reported outcome measures in surgery, Journal of Health Services & Research 19 (77)

Information Centre - HSCIC). NHS Digital then publishes this PROMs data in quarterly and annual reports.

Predominantly, the data is collected using paper questionnaires. The total cost to the NHS for the collection of the four nationally mandated PROMs is approximately £825K annually,³ which is borne by provider trusts.

PROMs for a number of other treatment pathways are collected locally across the NHS.

For more information on PROMs, visit the [NHS Digital \(HSCIC\) website](#).

3 This consultation

The PROMs programme was a revolutionary programme when set up in 2009. The NHS in England was the first health system in the world to introduce the routine collection of PROMs data at the system level.⁴

Since NHS England inherited the National PROMs Programme in 2013, there has been a great deal of debate about PROMs and whether the data is delivering what the system and patients need. There are case studies that demonstrate how [PROMs are being used to good effect in places](#), but nationally the picture is mixed. There has also been criticism that the measures used do not adequately reflect what patients want from their care. A newer approach named Patient Centred Outcome Measures (PCOMs) has been explored in part to answer the latter challenge. The debate is ongoing and brings into focus the key questions of what we want from the data and how we should set up collections accordingly.

NHS England has carried out this consultation on the National PROMs Programme to understand how the programme is currently working, and how it should be developed in the future. In particular, we wished to understand:

- how all interested parties view the national collection of PROMs data – including patients and the public, clinicians, trust boards, academics, patient groups, professional bodies, charities, Clinical Commissioning Groups (and other commissioners);
- how, when and why national PROMs data is used, and what the benefits are to the NHS, both nationally and locally;

³ This is an annualised amount for 2014/15 calculated from spend management information received from PROMs framework suppliers.

⁴ OECD - Recommendations to OECD Ministers of Health from the High Level Reflection Group on the Future of Health Statistics - Strengthening the international comparison of health system performance through patient-reported indicators – January 2017
<https://www.oecd.org/els/health-systems/Recommendations-from-high-level-reflection-group-on-the-future-of-health-statistics.pdf>

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- what other potential uses PROMs might have; and
- how users and stakeholders think the PROMs should be developed in future.

The consultation ran from 4 January 2016 until 28 March 2016. Respondents could complete the questionnaire directly online via the NHS England website, or alternatively they could email their responses.

We received 105 online responses to the consultation questionnaire, plus another 14 responses which were emailed to us.

These came from a range of stakeholders from research & academia, clinicians, charities, professional bodies, CCGs, trusts, independent sector care providers, private sector suppliers of PROMs data services, and patients and the public.

	Online	Email	Total
CCGs	2		2
Charities	2	3	5
Clinicians	37		37
Independent Sector Provider	1	1	2
Patients and the Public	9		9
Private Sector Supplier	7	1	8
Professional Bodies	8	4	12
Research & Academia	14	2	16
Trust managers	20		20
Other	5	3	8
TOTAL	105	14	119

4 What are PROMs for?

In order to understand respondents' perceptions about the current PROMs programme, the consultation asked people to consider "What do you think are the most important purposes of PROMS, and why?" Participants interpreted the question as asking what the general objectives of PROMs are, rather than what PROMs are currently being used to achieve. As such, these comments pertain to the potential of the concept of PROMs, rather than to how specific PROMs collections are currently used.

It should be noted that the majority of respondents to the consultation were enthusiastic about the potential of PROMs, even if they had critical views about their current implementation and use. As such, they outlined a wide range of perceived purposes, uses and benefits of PROMs, including:

- demonstrating the effectiveness of treatments;
- assessing performance to reduce variation in care;
- allocating commissioning resources;
- hearing from patients about what matters to them;
- supporting person-centred care; and
- providing data for further research.

4.1 Demonstrating the effectiveness of treatments

Many respondents stated that a fundamental purpose of PROMs is to demonstrate the effectiveness or otherwise of a particular treatment intervention. While the immediate success, or otherwise, of surgery may be evident, the longer-term effects of treatment interventions are less easily understood. For any individual patient, any number of additional factors could affect their health and wellbeing following treatment, meaning that it is difficult to interpret the efficacy of the treatment itself. PROMs can perform a role similar to that of pharmaceutical clinical trials, collecting data at larger scale in order to provide evidence of whether or not treatments are making a positive difference to patients' health and wellbeing.

“[PROMs] show if health care taking place is making a real difference to patients or not. What could be more important? It is a factual quality measure of improvement in care.”

Trust manager

4.2 Assessing performance to reduce variation in care

Another common purpose raised by many respondents was that of performance assessment. PROMs provide a way of benchmarking performance standards in order to compare service provision and to detect variations in the standard of care delivered to patients. The ultimate goal of this activity is a reduction in variation of patient outcomes and an overall improvement in care quality. Different approaches to achieving these aims were cited, including:

- offering financial incentives for good performance;
- the identification and dissemination of good practice; and
- support for those exhibiting poorer outcomes.

“[PROMs allow you to] identify particularly good outcome units, to share practice [and] identify poor outcomes units, to earmark for urgent improvement.”

Clinician

4.3 Allocating commissioning resources

Several respondents argued that PROMs should support commissioners to allocate resources. PROMs can provide evidence about the relative effectiveness of different treatments, and thereby be used to demonstrate their value for money. This is particularly important where treatments do not have clearly observable clinical outcomes. In this way, PROMs data can inform decisions about recommissioning or decommissioning services, and can be used to help determine levels of spending across competing treatments.

“[PROMs] help to define the value of services that do not have clear clinical outcomes.”

Clinician

4.4 Hearing from patients about what matters to them

A commonly cited purpose of PROMs was to measure what matters to patients. Many responses highlighted the importance of PROMs in ensuring that care outcomes are defined in terms of the patient’s quality of life, and not only by clinically defined measures. A wide range of people shared this view, including clinicians, academics and service improvement managers. Some specifically argued that this is empowering for patients, insofar as it involves them in the assessment of the quality of their care.

“PROMs shift the focus of consultations and audit away from metrics that are important to clinicians (for example laboratory measures and attainment of standards) to take account of what is important to patients - quality of life and symptoms.”

Professional Body

4.5 Supporting person-centred care

Some respondents mentioned the potential for using PROMs within consultations in order to support the clinician-patient interaction and to help ensure that care is tailored to the individual. Some argued, for example, that individual PROMs responses could help to highlight issues that might otherwise be missed in a typical consultation. Others emphasised that a patient’s responses could be used to support shared decision making about ongoing treatment options.

“[PROMs provide a] comprehensive and standardised way of understanding [the] patient's situation - for [the] clinician's benefit, so they avoid 'missing' anything in [the] conversation or [making] any assumptions.

Private Sector Supplier

4.6 Providing data for further research

The potential uses of PROMs by the research community were also highlighted. The complexity of PROMs datasets, along with their potential for linkage with clinical measurements and other datasets, means that the opportunities for learning from them are significant. However, this size and complexity also means that dedicated expertise is required in order to unlock the value of the data. A number of respondents therefore identified academic researchers as having an important role to play in using PROMs data to drive innovation and improvement.

“There is a huge research and QIP [Quality Improvement Project] potential for PROMs in cardiovascular medicine especially if linked to National Audits and National Institute for Cardiovascular Outcomes Research.”

Professional Body & Clinician

5 Current use of the National PROMs Programme

In this section we move our attention to respondents' descriptions of how they are currently using data from the National PROMs Programme rather than the potential they may offer. There were a wide range of examples of existing uses of the data from the National PROMs Programme. These uses tended to differ between different user groups, hence we have chosen to categorise them below in terms of the different types of user.

5.1 Academics

The consultation identified a range of research uses of the national PROMs data by academics. Examples included:

- understanding drivers of variation in care, including access to care, experience of care, and health-related quality of life outcomes;
- understanding the recovery process after surgery in more detail; and
- understanding how the success of treatment impacts on the wider healthcare economy.

“I have been involved in a project to map national PROM data for hip and knee replacement to healthcare resource use in the NHS”

Research and Academia

5.2 Clinicians

It should be noted that many clinicians who responded said that they did not currently use PROMs data. However, the minority of clinicians who said they were users of the data reported a broad range of uses. Many of these focused on how PROMs can support improvements to clinical outcomes, for example by creating a feedback loop

through benchmarking and performance monitoring, or by using the data to determine which treatment option achieves the best health gain.

“[PROMs allow you to] identify particularly good outcome units, to share practice [and to] identify poor outcomes units, to earmark for urgent improvement.”

Clinician

However, other uses were also highlighted. Some used PROMs to support the clinician-patient relationship, by referring to the data in order to inform conversations about treatment options. Another use mentioned was using PROMs as a diagnostic tool for identifying support and care needs that may not always be picked up by traditional assessments, such as psychological and social support needs.

“I find it can open the door to conversations with relatives or carers about treatment choices”

Clinician

5.3 Healthcare managers

Among trust managers, PROMs were most commonly used for performance monitoring, particularly in terms of benchmarking against other organisations. In addition, some managers specifically used PROMs data as part of service improvement activity, benchmarking against national averages in order to identify areas for improvement.

“We use it to compare our outcomes with national results, to identify if there are any areas where improvements should or could be made.”

Trust manager

5.4 Patients and the public

Two main uses of PROMs data by patients and the public were highlighted by the consultation. The first was where members of the public have an official role involving representing patient views, such as being a lay member on the board of a CCG, or a member of a Patient Participation Group. Here the comparability of PROMs data across providers was felt to be empowering for individuals who have responsibility for holding the organisation to account on areas of poor performance.

“I use it on various PPP groups I sit on – to raise issues of service quality and performance”

Patients and the Public

A second use mentioned by one patient was where they wished to understand more about the treatment pathway that was being proposed for them, in terms of the recovery process, expected health gain and any side effects.

6 Views on the current National PROMs Programme

This section presents respondents' opinions concerning the National PROMs Programme, organised into different topic areas. These opinions cover the perceived strengths and weaknesses of the programme, and identifying ways in which the programme could potentially be improved.

6.1 Unfulfilled potential

Most respondents believed in the potential of PROMs to make a positive difference to services and to patient care. Some argued that the PROMs programme provides very rich datasets which have considerable potential for insight into what drives good and poor treatment outcomes.

“The UK is a world leader in patient data. Initiatives such as PROMs contribute to that and allow for health services research that can hardly be found elsewhere on the planet. They allow researchers to assess variability in surgical outcomes so we can learn more about what works best and what leads to poorer patient outcomes so that patient care can evolve.”

Research and Academia

On the other hand, some respondents, many of whom were clinicians, reported that they doubted the value of the programme itself. In particular, these respondents were sceptical about PROMs' potential for making a difference to clinical outcomes and patient care.

“When I have asked commissioners or senior medical managers, no-one is able to suggest one improvement to patient care that has arisen from the collection and reporting of PROMs.”

Clinician

However, a more common theme was that, while the national PROMs are of potential value, this potential is currently unfulfilled. Some respondents felt that the programme is not currently producing any real improvements in patient care.

“Whilst in principle the concept of PROMs promised to be helpful by having another means of monitoring outcome effectiveness, in reality PROMs delivers little if any benefit.”

Clinician

By far the most commonly cited reason for PROMs' failure to achieve its full potential was that the data goes relatively unused. Indeed, many respondents replied that they did not actually use the data at present. While in some cases this was simply because the treatments covered by the national PROMs collections were not relevant to their professional specialism, a number of other reasons were suggested.

Some respondents questioned whether, in their current form, PROMs actually produce data that can successfully identify true variation in care, so that lack of use is due to the data not being fully fit for purpose. Views on the quality of the PROMs data are discussed in more detail in the ['Data quality' section](#) below.

Another set of respondents argued that the issue with lack of usage was less to do with the data itself, than with barriers to accessing, understanding and applying insights from the data. Views on the presentation and dissemination of data are discussed in the ['Data presentation and dissemination' section](#) below.

“Data collection is good, but the outputs are simply not used to improve care or to deliver any measurable improvements.”

Clinician

Other respondents identified that where PROMs was used by managers and commissioners, this tended to be only on a reactive basis, in order to identify problems. Some suggested that the PROMs programme would be more effective if more resource was spent on their potential proactive uses, such as using them to develop and communicate best practice in order to reduce variation and improve overall care.

“As a CCG we do not at present use the PROMs data unless it is highlighted to us that there is a problem.”

CCG

A separate view, suggested by a minority, was that the real issue with the unfulfilled potential of the PROMs' programme was that more clinical areas were not benefitting from these data collections.

“The question is not if the current collections are useful but which conditions or populations have we missed.”

Research and Academia

6.2 Mandatory collection of PROMs

Looking at specific aspects of PROMs, respondents identified a number of positives associated with the fact that the national PROMs are mandatory:

- it has established an infrastructure for data collection, including funding processes;
- data collections are taken more seriously than under an optional scheme;
- the datasets are complete due to all providers being included;
- the data is of high quality since it is collected under standard methodological conditions;
- it provides an inclusive approach to feedback as every patient has an opportunity to be involved

These characteristics support the key aims of using PROMs data for benchmarking over time and for comparing against other trusts and against the national average.

However, several respondents viewed the mandatory nature of PROMs negatively, insofar as enforced participation does not guarantee buy-in into the potential benefits of PROMs. As such, there is a risk, for some, that the data collection has become a “tick-box exercise.”

Another relatively common criticism of mandating the PROMs programme was the burden on trusts of collecting the data, both in terms of the time taken to administer them and the cost of doing so.

Finally, some argued that the national mandate has stifled innovation in the development of PROMs. By requiring such significant resource of trusts, the national programme was viewed to have prevented the development of more dynamic, clinically useful, and better value data collection approaches.

6.3 Paper-based collection

Respondents had a number of views relating to the way that PROMs are collected on pre- and post-treatment paper questionnaires, with the final data published in a single batch after extensive data processing.

6.3.1 Timeliness

One repeatedly-cited issue with the current PROMs data collection method was the timeliness of the data, which some saw as an obstacle to bringing about change. With up to 28 months between initial collection and full reporting, many felt that this long gap often made the data feel less relevant, and more tempting to dismiss, than if it had been made available sooner. In particular, changes that had been made to services in the intervening period would not be reflected in the data, such that clinicians and managers sometimes felt that the results did not describe the current level of clinical care.

“Even for the operations that we do it for (hips / knees / VV and hernia) it takes months (or years) for the data to be fed back to the clinicians.”

Clinician

6.3.2 Cost

Another issue relating to the paper-based approach was the cost of the collections, which is borne by NHS trusts. A number of respondents suggested that an electronic-based approach could significantly reduce overall costs as well as simplifying and streamlining the process of data collection.

“Much of the cost related to PROMs is related to their collection and the associated time involved. NHS England should look at how this process could be improved by using electronic collection.”

Private Sector Supplier

6.3.3 Additional uses

Some believed that electronic data collection would more generally allow for more flexible use of the data, such as enabling results to be made available in real time, and to automatically link the results to other relevant clinical datasets, such as registry data, audit data, Hospital Episode Statistics (HES), and hospital electronic patient records (EPR). This could significantly support the use of PROMs by clinicians and patients – a potential use that is difficult to achieve in the paper-based system. Some believed that electronic collection could also improve the quality of the data, for example by potentially increasing the response rate, as well as making it easier and swifter to collect and to use.

Overall, a view shared by many was that the National PROMs Programme needed to be more modern in implementation.

“Direct linking with joint registry data, ability to upload outcome scores from other software platforms to avoid duplication, results available in real time to patient and clinician.”

Clinician

6.4 Data quality

A number of respondents questioned the quality of national PROMs data. Issues covered included the clinical validity of the data, its statistical reliability, and its granularity and content.

6.4.1 Clinical validity

Clinicians tended to display scepticism about the meaningfulness of PROMs data, more than any other group, with some questioning the clinical validity of the metrics. These respondents did not believe that the outcome measures produced by PROMs were accurate indicators of clinical quality, insofar as non-clinical factors may influence the results. As such, they shared a perception that negative outlying results were not necessarily proof of actual poor care, and that further investigation into the results would find no evidence of a service in need of improvement. A small number of trust managers likewise did not feel that PROMs could help identify poor organisations or individuals.

“Good results do not reflect good treatment, any more than ‘poor’ results reflect poor treatment.”

Clinician

6.4.2 Statistical reliability

Several respondents cited the statistical reliability of the data as a problem. For some, the key issue was the survey response rate. These respondents felt that the possibility of non-response bias meant that the data cannot be considered to be accurate.

“The biggest limiting factor is the response rates.”

Research and Academia

These concerns about the validity and reliability of the data often explain why some respondents were concerned that PROMs data could be used in negative ways against organisations or individual clinicians, for example that commissioners could financially penalise trusts for poor PROMs results without taking account of the wider context.

“CCGs should not use scores as a blinkered reason to refuse payment for surgery as the process of reaching the decision for surgery is never a simple one.”

Clinician

6.4.3 Level of detail

Another set of concerns focused on the level of detail in the data, which some clinicians and managers found unhelpful when trying to interpret the overall results in order to understand what was working well and what needed to be improved. As such, it could often be difficult to identify issues that could drive actual improvement in services, both at the organisation level or for individual clinical practice. In order to function successfully as a tool for service improvement, these respondents felt that PROMs data would need to be interpreted by way of a detailed understanding of the

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delivery of treatments, and the knowledge generated through this process would need to be communicated to clinicians and managers in an effective manner.

“It is difficult to drill down to use it for service level improvements, make it meaningful for consultants or use it for anything else.”

Trust manager

Some respondents suggested that ideally PROMs would provide data at a more granular level in order to understand the performance of individual surgeons and to assess different treatment methods or equipment within the same provider. Others were concerned that PROMs data could then be used penalise surgeons with poorer outcomes, and that this practice might encourage surgeons to avoid taking on the most difficult cases, thereby impacting negatively on patients.

Another more granular use of PROMs mentioned by some was that of using it to understand individual patient outcomes. While it can be instructive for a clinician or manager to compare their organisation with a peer, many feel that they can only really understand what is happening within their own trust and with their own patients. Some argued that the suppression of individual identities to protect patient anonymity represents a missed opportunity for learning and for the clinical care of patients.

“[We are] not allowed to know how individual patients have done, which is clearly crazy.”

Clinician

This is despite the fact that the data extracts from NHS Digital which the providers sign up to are identifiable, so they can be used to retrospectively review individual patient cases. However, not all organisations access this data, and there are restrictions as to who and how many people in the trust can access the data. This might explain the apparent lack of awareness among some clinicians about this possible use of the data.

Finally, some respondents suggested that PROMs should enable patients to define what matters to them rather than to the clinician, particularly in terms of working to achieve personal goals following surgery.

“Do not use the scores we are using currently. Allow the patients to determine what is success for them - this can be captured using the patient specific functional scoring.”

Clinician

6.5 The use of EQ-5D within the national PROMs collections

A common discussion point with regard to PROMs data related to the value of generic items that are common across different collections. In particular, EQ-5D, the health-related quality of life measure, polarised opinion, with some respondents arguing that its use in PROMs should end.

Amongst some respondents, there was a feeling that the data provided by generic components such as EQ-5D was less meaningful than treatment specific questionnaire items. One criticism was that the questions of EQ-5D were too generic to be used to evaluate the success of the specific intervention. EQ-5D's measurement of mobility, for example, was not seen as acute enough to identify the cause of any problems and their relation to the surgery in question. As such, these respondents generally favoured more specialised metrics.

“[M]ost of our patients have multiple issues and asking whether they have difficulties in walking does not differentiate between the benefits gained by the operation in question and any other issues the patient has such as foot and ankle or spinal problems.”

Trust manager

The perceived lack of usefulness of EQ-5D for some clinicians may in part be explained by their focus on individual patient outcomes and the factors that may affect these. On the other hand, researchers who utilised EQ-5D at a population level tended not to identify this weakness, since individual contexts become less of an issue when the data is interrogated at a statistical population level.

“EQ-5D is vague and other life factors will affect its score.”

Clinician

More positive opinions were voiced by other respondents. Some made the point that certain basic goals, such as wellbeing and activity, are common to all patients and that general outcome measures are therefore of universal interest. Others believed EQ-5D to be a useful measure of the success of treatment, in terms of the effect of the intervention on quality of life, and wished to see EQ-5D introduced as part of collections for other conditions.

“[R]outine data collection should focus on use of generic measures. [...] Almost all people want the same things, to feel better, to do more, to have a "good" death when it comes, to receive excellent care and service and to be fully engaged in what happens to them.”

Private Sector Supplier

However, a more common view of EQ-5D was that it demonstrated its greatest value when combined with condition-specific metrics, such as the Oxford Hip and Knee scores. This is because many felt that the general measure of health-related quality of life only becomes meaningful when interpreted through the lens of metrics concerned specifically with the condition and the treatment.

“For joint replacement, I think that use of Oxford scores and EQ-5D at baseline and six months works well.”

Research and Academia

6.6 Differences between the four national PROMs collections

The National PROMs Programme currently comprises data collections on four elective surgeries: hip replacement, knee replacement, groin-hernia surgery and varicose vein surgery. Respondents were able to make a number of distinctions between the current value of the four collections.

Many responses to the consultation argued that the hip and knee data are useful whilst there were significant question marks over the other two collections. For some this was because these are highly prevalent surgical interventions, and as a consequence of this prevalence, these datasets tended to be more commonly interrogated and applied. Others argued that the orthopaedic PROMs had proved their effectiveness since they have already been used to learn about a number of clinical issues.

“Hip and knee replacement [...] have been used very well. They have been used to answer a range of questions about prognosis, effectiveness and methods”.

Research and Academia

Some pointed to the fact that this data benefited from having successful condition-specific metrics, the Oxford Hip and Oxford Knee scores. These tailored measurements were seen to provide more useful information for service improvement than is produced by more generic health metrics.

“It may be that the national Joint Registry can make a case for the continued collection of Oxford Hip and Oxford Knee scores for patients undergoing joint replacement.”

Clinician

“Hip and knee seem hugely useful and cover a high prevalence of UK surgical treatments”

Professional body

This positive assessment of the hip and knee metrics was in contrast to views about the other two national PROMs, where the condition-specific score for varicose veins was criticised by some as lacking clinical evidence, and where the absence of a specific metric for groin-hernia was viewed by some as a particular weakness. In general, fewer respondents felt that groin-hernia and varicose vein datasets were useful, with some offering particularly negative views.

“Knees and hips seem valuable. Less so varicose veins and groin-hernia, especially the latter where only EQ-5D is used - this PROM is very un insightful”

Private Sector Supplier

6.7 Data presentation and dissemination

A number of respondents identified problems with how PROMs data is made available, and the impact this has on its use. These included awareness of the data, access to it, its presentation, and the impact this has on interpretation and use.

Firstly, some respondents felt that one basic reason that PROMs data is underutilised is simply that awareness of the datasets is low, due to PROMs publications not being promoted sufficiently.

“Many people aren't aware that the patient-level data from PROMs are freely available online: this could be better publicised”

Research and Academia

A more commonly identified problem, however, was the difficulty of accessing the data. Many found the current process time-consuming and challenging, and off-putting to the non-expert. This could be improved at least by providing information on how to access the data, although ideally the process itself would be simplified, with much clearer instructions and signposting along the way.

“The process of accessing this data is unwieldy to say the least and needs improving markedly”

Trust manager

A further key barrier to wider use of PROMs data was the format of the data outputs themselves, which many found unhelpful. The current presentation makes it challenging for casual users of the data to understand what it is telling them.

“I don't use it, because as a patient I find it inaccessible”

Patients and the Public

While there is a role for detailed datasets, it would help many users for there to be simpler presentations that help to interpret the results, particularly with a focus on what they mean for driving service improvement.

“The presentation of results does need improving, as it is not easy to identify which trusts are performing well”

Trust manager

It was also felt by some that along with improving the presentation of the data, more support was needed to help users interpret or understand the results. This could be in the form of tutorials and guides, or could be built into the presentation of the results themselves.

“Better support with trusts understanding results and presentation”

Clinician

7 The future of the National PROMs Programme

In keeping with other areas of the consultation, feedback on the future of the National PROMs Programme varied widely. To some extent, the nature of the feedback varied according to the respondent’s role and interests, although we did not observe any clear consensus among representatives of similar types of organisation.

7.1 The four existing national collections

Views varied widely about the future of the four existing national PROMs collections (hip, knee, groin-hernia and varicose vein), with little clear consensus among different types of respondent.

A few respondents unreservedly advocated the continuation of the four existing mandated PROMs. People with this view tended to be clinicians who had found a regular use for PROMs, or representatives of private sector suppliers of data collection. Some cited the incorporation of PROMs within their ongoing clinical practices, along with the belief that the full potential of the four existing PROMs is yet to be realised. These respondents tended to think that ending the current collections would mean that full return would not be made on the investment in PROMs up to this point, as well as a missed opportunity for understanding the extent to which they can be used to improve services.

“To stop now would diminish the progress the NHS is making on this important measure.”

Clinician

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Others were less specific in their explanation, simply arguing that the four existing PROMs should continue by virtue of their unique role in patient-centred quality measurement.

“It is important to collect data for surgical procedures in order to be able to monitor patient experience and then improve patient experience. Just because the procedures are common does not mean they are performed to the best standards to enhance patient outcomes. This measure should act as the method of ensuring that both high volume and high quality can be achieved.”

Private Sector Supplier

Some respondents argued that the four national PROM collections should probably continue, but only if certain conditions are met. They reported that they could only support the continuation of the existing programme if its benefits can be established, particularly with regard to improvement in clinical practice.

“It depends on whether the required knowledge has been gleaned and any changes in clinical practice effected.”

Other

Existing case studies of PROMs usage were not considered by some to sufficiently establish the value of PROMs, such that a specific evaluation of the programme should be considered.

Some respondents supported the continuation of PROMs in principle, but argued that methodological changes are required. For example, while the response rate for the PROMs programme compares well with other national patient-reported data collections, a few believed that it should be higher.

“[Yes, they should continue] only if a better return rate can be achieved.”

Research and Academia

Another academic advocated the trialling of a telephone-based collection approach in order to scrutinise the effectiveness of the current paper self-completion methodology.

Some suggested that PROMs should continue only if the data could be used to greater effect and that the data needs to be presented in a manner that is more relevant for users and which is simpler to use.

“No [they should not continue] unless made more meaningful, easier access, drill down.”

Trust manager

Some argued that commissioning policy should make greater use of system levers in order to drive use of the PROMs data to greater effect.

“[Yes, they should continue] but linked to healthcare organisational and system financial incentivisation.”

Clinician

Many respondents suggested that the hip and knee replacement collections should be continued, but that groin and varicose vein should be discontinued.

“It might possibly be worthwhile continuing to collect data on hip and knee, but not worth carrying on with hernia and varicose veins”

Research and Academia

Finally, a number of respondents advocated the complete pause or abolition of the four national PROM collections. With some exceptions, these respondents tended to be clinicians or trust managers who criticised the mandated PROMs as a burden on time and resources.

“None of the four PROMs add value since there is no discernible action taken as a result... the data and information is simply ignored by all”

Clinician

7.2 Implementing PROMs in other clinical areas

As we have seen, many respondents were against the continuation of PROMs. However, a number of others advocated the expansion of the PROMs programme to include conditions and treatments that were relevant to their speciality. These tended to be clinical researchers or managers who had identified ways that PROMs could serve a purpose in their area, although some clinicians and frontline staff also called for new PROMs. One suggested that new PROMs should include the generic EQ-5D measure in order to compare across different procedures, but that condition-specific metrics would also be required, particularly for more complex conditions.

The table below illustrates the clinical areas which our respondents identified as potentially benefiting from a PROM collection:

Additional collection	Frequency (by number of respondents)
Cancer	8
Long-Term Conditions	8

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Additional collection	Frequency (by number of respondents)
Trauma	7
Diabetes	6
Mental Health	6
Vascular/Coronary	6
Cardiac/Heart	5
Spinal/Back	4
Other areas mentioned were: Dementia/Alzheimer's, Disabilities, Elbow, Elective, Emergency/Unplanned, Epilepsy, Foot/Ankle, Musculoskeletal, Palliative, Renal, Shoulder and Stroke.	

A wide range of uses were suggested for the expansion of PROMs, including:

- to assess additional elective treatments (especially musculoskeletal treatments such as shoulder surgery, using the knee and hip PROMs as models);
- to inform research into the success of treatments (e.g. in cancer);
- to inform patient selection for surgery (e.g. in cardiology);
- to assess Quality Improvement Premiums;
- to assess the quality of care in the management of long-term conditions (e.g. diabetes);
- to assess the quality of clinical departments (e.g. paediatric services);
- to assess the quality of care pathways (e.g. unplanned care);
- to assess the quality of care where there may be no alternative outcome measurements (e.g. palliative care).

The call for new PROMs was not always a call for an increase in the number of PROMs: some respondents suggested any new PROMs should replace existing collections so as not to increase the cost and burden on trusts. Indeed, a number of respondents cited the cost and resource implications of PROMs as the chief reason why the current programme should not be expanded.

“Not additional, possibly alternatives although must be a well-designed project which would minimise cost and use of trust resources”

Trust manager

Some suggested the programme could be run on rotation so that each PROM would be run for a certain period of time to gather data for analysis before being replaced by another. In this way, a greater number of procedures and treatments of interest could be assessed.

Others underlined the need for caution and the need for further testing in order to establish feasibility and/or value of additional PROMs.

7.3 Nationally mandated collection versus local discretion

There was a wide range of views regarding whether PROMs should be nationally mandated.

A range of respondents advocated for nationally mandated collection, as only this approach can ensure the comparability of data across providers, and therefore support performance assessment, quality assurance, regulation and patient choice. Without a nationally-coordinated collection, it was believed that comparisons between trusts could be inaccurate and misleading and would therefore undermine our ability to understand geographic differences in the quality of care.

“Aggregating data nationally permits overall profession continuous improvement.”

Patients and the Public

Others advocated the local collection of PROMs, but in addition to a core national programme, rather than replacing it. A central national programme was viewed as necessary, both in order to ensure that providers can be directly compared on selected treatments, but also to set a template for best practice. Some suggested that a national PROMs infrastructure could be set up which makes it simpler for trusts and CCGs to run additional PROMs collections in their priority areas. Another suggestion was for local users of PROMs data to be given a more active role in the presentation and dissemination of PROMs data, therefore encouraging greater ownership and use of the results.

“A national PROMs should remain for major interventions but with an infrastructure that allows the development and use of local PROMs but using similar methodology / processes as a national PROM.”

Clinician

Another cohort of respondents also viewed PROMs as ideally a collaboration between national and local, but believed that the emphasis should be placed on local collections, with local interests driving the national programme. Some suggested this could take the form of greater local ownership of the collection process, such that local organisations have immediate access to their own data before allowing it to be collated nationally. It was thought that electronic collection of PROMs could facilitate this type of approach as it would simplify the data capture process.

Others felt that current local needs, in terms of provision and performance, should determine which PROMs are collected in each area. Local results for each type of PROM could still be compared at national level, but coverage would be determined by which treatments in each area are most in need of improvement.

Finally, some who were strongly critical of nationally-mandated collections argued that local organisations should have complete independence over which PROMs collections they should direct. These respondents felt that local ownership would increase clinical buy-in, and in this way it would also be likely to facilitate greater engagement from patients and increase the use and impact of the data.

“It should all be collected at local level - national collection is too faceless and so much more difficult to get patient engagement and trust”

Clinician

7.4 Relationship between PROMs and other patient-reported measures

The consultation also specifically asked about how PROMs might work alongside other patient-reported measures of care, such as Patient-Reported Experience Measures (PREMs) and Patient-Centred Outcome Measures (PCOMs).

Patient experience is already widely measured in the health system via a suite of national patient surveys, as well as local patient surveys in most areas, but PREMs is sometimes used to specifically refer to the more routine collection of a small number of measures of experience at the point of care or shortly thereafter. Patient Centred Outcome Measures (PCOMs), by contrast, have been proposed as a way of ensuring that outcomes being measured have been specifically chosen by the patient and represent their personal goals for the course of treatment. We received little feedback about PCOMs, so this analysis will focus on the relationship between PROMs and PREMs.

The majority of respondents who responded on the issue of PROMs and PREMs made the general point that patient-reported measures should be more closely linked or that they should complement each other, although opinions differed as to whether outcomes or experiences were more important. Experience measures were seen by managers and clinicians as generally more directly applicable to quality improvement initiatives, since they tend to provide more granular detail about aspects of care. PROMs had the potential to inform more significant changes to treatment but required greater analysis for these insights to be unlocked.

“PROMs are concerned with the objectives of treatment whereas PREMs relate to the process of that treatment as experienced by the patient. They are different but, probably, complementary.”

Patients and the Public

Many argued that PROMs and PREMs should be viewed together as part of a suite of patient feedback mechanisms. Some mentioned the need for ‘dashboards’ or single trust-level reports as a way of helping them to make sense of multiple kinds of patient-reported measurement.

The proliferation of different types of feedback mechanism was raised by some in terms of the increasing burden this is placing on patients. In particular, some clinicians and trust managers suggested combining or integrating PROMs and PREMs in order to ensure that patients are not asked to complete numerous questionnaires or feedback forms.

“Where possible burden to patients should be minimised - so incorporating as much as possible into just one questionnaire rather than patients being repeatedly contacted. They often can't tell the difference and may assume they are ‘filling in the same thing every 5 minutes’ as one once told me.”

Trust manager

Finally, it should be noted that there was a degree of pushback about the way that PROMs and PREMs are currently defined. Some saw the divisions as arbitrary and confusing. Others pointed out that these divisions meant nothing to the majority of patients and were unhelpful. Others still believed that divisions were necessary, but re-classification was needed.

“This really does need to be clarified as many people are deeply confused.”

Research and Academia

8 Overall summary

The consultation on PROMs encountered a range of views on how the National PROMs Programme is currently working, and how it should be developed in the future. Views ranged from those concerned with the financial burden and staff costs of the current national collections to those underlining their importance for learning from and improving care. This variation in opinion often reflected the diverse range of roles associated with the collection and different uses of PROMs data.

While a range of potential uses of PROMs were identified, the main finding of the consultation was a large degree of variation in the extent to which stakeholders are

actually benefitting from these uses. Where value was not being derived from PROMs, their burden on trusts was felt more keenly.

Consultation responses identified the main purposes of the National PROMs Programme as:

1. Demonstrating the effectiveness of treatments; and
2. Providing information to reduce variation in care.

It is at this population-level that the current manifestation of the National PROMs Programme arguably provides most utility, although the extent to which it is used for these purposes varies greatly from organisation to organisation. On the one hand, the consultation recorded a number of innovative and effective ways in which PROMs data are being used to improve services, but on the other, in many cases this potential of PROMs is not being realised.

The consultation broadly identified the hip and knee replacement PROMs as providing useful data that can bear on clinical decisions, but it encountered less compelling evidence about the value of the varicose vein and groin-hernia collections. These were viewed overall as less well-utilised and as having less potential use, in part because their data is viewed by many as too generic to inform decision-making about treatment.

Beyond the existing national collections, many expressed interest in wider application of PROMs data collection tools, especially in the facilitation of local collections. Many respondents also expressed interest in conducting PROMs in other clinical areas.

Access to PROMs data is viewed as a particular barrier to their wider use, with the currently-available outputs experienced as difficult to interpret and act on. The time lag between collection and publication of PROMs data is also viewed as a barrier to their use for improving services. More timely PROMs data could be routinely integrated with other datasets, including patient experience measures, so as to provide a more holistic measure of care quality.

In terms of potential further benefits of PROMs, some respondents called for their use in direct care, as a measure of an individual's progress towards their goals following a care intervention, thereby identifying issues that might otherwise be missed. PROMs could be further enhanced for their application in this role by including some personalised measures so that care can be tailored to the individual's needs.

It was thought that the development of more real-time PROMs, facilitated by electronic data capture, could help unlock many further potential applications of PROMs and make the data more accessible and easily used. Additionally, if appropriate consent models can be developed, the electronic collection of PROMs

could promote their use in direct care, as well as in new areas of research into clinical effectiveness via automatic linkage with other related sets of patient information

At the same time, however, respondents called for further research into the use and value of PROMs, with any further development of the programme to be tested rigorously.

9 NHS England Response

As a result of the findings of the above consultation, NHS England has taken the decision to discontinue the mandatory varicose vein surgery and groin-hernia surgery national PROM collections.

The rationale for this decision is based on multiple factors:

- surgical treatment of varicose veins is currently much less frequent and the condition is usually not a major cause of patient debility;
- groin hernia surgery is offered mainly to reduce the risk of requiring emergency surgery, rather than to relieve symptoms, which are often relatively minimal. This, along with the fact that there is no condition-specific PROM for groin-hernia surgery, means that the existing PROM has limited value.

The consultation provided little evidence of varicose vein surgery or groin-hernia surgery PROMs being used in practice to drive quality improvement or for benchmarking or performance management. By doing this, the burden on organisations of continuing to collect this data should be reduced where it is felt these PROMs deliver limited value.

NHS England will be continuing the hip and knee surgery PROM collections.

NHS England will ensure work is undertaken to address some of the issues with the National PROMs Programme that have been outlined in this consultation document in order to increase the impact of the hip and knee national PROMs data and has already published a [bitesize guide to PROMs for CCGs](#). In addition, NHS England will work with NHS Digital to make the national PROMs data easier to use and to provide a range of automated outputs that are tailored to the needs of trusts, CCGs and other users.

Where possible, NHS England will seek to drive digital collection of PROMs data. This could help lower a number of barriers to unlocking the potential of PROMs, by

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increasing the timeliness of the data and by facilitating their use in direct care. This would also provide the benefit of allowing patients greater access to their own PROMs data.

Finally, NHS England is working with NHS Digital to establish an 'Accredited PROMs Supplier List' which would open the suppliers market to new ideas and innovations, and would allow an NHS trust to collect its own national PROMs data, should it so wish. This is the new PROMs Supplier Accreditation Process would allow any supplier or healthcare organisation who can demonstrate that they meet the requirements for the collection and submission of PROMs data to NHS Digital to become accredited at any point in time.

APPENDIX: Consultation Questionnaire

National Patient Reported Outcome Measures (PROMs) Programme Consultation

(Publications Gateway Reference: 04478)

Overview

Patient Reported Outcome Measures (PROMs) measure health gain in patients, and have been collected nationally in England, since 2009. Patients are asked to complete questionnaires before and after their operations to assess the improvement in their health as they perceive it.

Four PROM data collections are currently specified in the NHS Outcomes Framework (3.1), the NHS Mandate and in the NHS standard contract. It is a requirement for organisations performing NHS funded hip replacement, knee replacement, varicose vein or groin-hernia surgery to collect PROMs data and submit that data to the Health & Social Care Information Centre (HSCIC). The HSCIC then publish that PROMs data in quarterly and annual reports. (see www.hscic.gov.uk/proms)

Predominantly, the data is collected using paper questionnaires. The total cost to the NHS for the collection of the four nationally mandated PROMs is approximately £825K annually (annualised amount for 2014/15 as per spend Management Information from framework suppliers) – borne by provider trusts.

PROMs for many other conditions are collected locally across the NHS.

Some examples of the benefits of collecting PROM data can be found on the [Health & Social Care Information Centre website](#).

Why We Are Consulting

We are now consulting, publicly, on the future content of the National PROMs Programme. We wish to consult regarding options around how to utilise our resources most effectively to understand the outcomes which matter to patients, to highlight areas with unwarranted variation in outcome and to consider indicators for service improvement.

We would like to understand more about how, when and why national PROMs data is used, and what benefits are provided to the NHS, both nationally and locally. We would like to understand how all interested parties view the national collection of PROMs data - including patients and the public, clinicians, trust boards, academics, patient groups, professional bodies, charities, Clinical Commissioning Groups (and other commissioners) and others.

Options for the future of the National PROMs Programme include dis-continuing some clinical areas of the current collection, where the data is not being used to improve services; keeping some clinical areas of the current collection where benefits

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do exist; and/or introducing new PROM data collections in areas we need to know more about.

The Five Year Forward View is clear that we can do more by measuring what matters, requiring comprehensive transparency of performance data and ensuring that data increasingly informs payment mechanisms and commissioning decisions.

Under the restrictions of the current financial climate, discontinuation of any of the current PROM data may free up resources to collect patient-reported information on other, higher priority conditions, in line with NHS England priorities.

PROMS are currently official statistics; potentially soon to be national statistics. Therefore any changes to the existing collections require a defined process, alongside communication and liaison with the Department of Health, providers, CCGs, patient groups, clinical communities, the relevant professional bodies (e.g. British Orthopaedic Association, the National Joint Registry), and survey suppliers, who would need to be issued with reasonable notice.

NHS England is seeking views on the current national PROMs collections and the future for PROMs. We have set out specific questions which we are keen to get your views on and we have also left a section open for you to feedback comments or ideas more generally. You can respond to all of the questions, some of the questions, or just one if you would like.

The consultation is open to anyone who has an interest in this area.

You can respond online using the consultation survey or you can submit your response by email at: england.PROMS@nhs.net or by post at: PROMS Consultation, NHS England Insight Team, Quarry House 7E57, Quarry Hill, Leeds, LS2 7UE.

Please use the questions below as a prompt and if there are other points you wish to make please let us know

The consultation will run from Monday 4th January 2016 until Monday 28th March 2016.

PROMS Consultation

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

- Academic
- CCG
- Charity
- Clinician
- Patient / Public
- Professional Body
- Trust Board Member
- Trust Service Improvement
- Local Authority / Healthwatch (or similar)?
- Other – please state

Q1b. If you are responding on behalf of an organisation, and only if you are happy to do so, please tell us the name of that organisation.

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

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

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?

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Q5. What are the benefits of nationally mandated PROMs?

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

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

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

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)

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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.)

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

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?

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

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

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