



National Joint Registry

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NHS England's national PROMs programme consultation:

Response from the British Orthopaedic Association (BOA), British Hip Society (BHS), British Association for Surgery of the Knee (BASK), British Elbow and Shoulder Society (BESS), British Orthopaedic Foot and Ankle Society (BOFAS) and the National Joint Registry for England, Wales, Northern Ireland and the Isle of Man (NJR)

Introduction

1. The British Orthopaedic Association (BOA) is the Surgical Specialty Association for Trauma and Orthopaedics in the UK, and works closely with societies representing specialist areas within trauma and orthopaedics, including the British Hip Society (BHS), British Association for Surgery of the Knee (BASK), British Elbow and Shoulder Society (BESS) and British Orthopaedic Foot and Ankle Society (BOFAS). Together, these groups total over 4300 members, the vast majority of whom are practicing surgeons in the UK and Ireland. These are pivotal organisations within the British surgical scene, representing the views of surgeons and with a strong focus on ensuring patients are at the heart of all their work.
2. The National Joint Registry for England, Wales, Northern Ireland and the Isle of Man (NJR) collects information on joint replacement surgery and monitors the performance of joint replacement implants. It was set up in 2002 by the Department of Health and Welsh Government, Northern Ireland joined in 2013 and the Isle of Man in July 2015. The registry helps to monitor the performance of these implants and the effectiveness of different types of surgery, improving clinical standards and benefiting patients, clinicians and the orthopaedic sector as a whole. The NJR currently collects data on all hip, knee, ankle, elbow and shoulder joint replacements across the NHS and independent healthcare sector.
3. This submission responds to the questions posed by NHS England in the National Patient Reported Outcome Measures (PROMs) Programme Consultation (*Publications Gateway Reference: 04478*). The response is also fully supported by the Getting it Right First Time Programme and Prof Tim Briggs in his capacity as National Director for Clinical Quality and Efficiency.

4. Additional consultation responses have been submitted from the British Elbow and Shoulder Society and the British Hip Society, with greater detail on sub-specialty issues which are complementary to the response here.

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

5. Professional Bodies and Other (National Registry).

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.

6. British Orthopaedic Association (BOA), British Hip Society (BHS), British Association for Surgery of the Knee (BASK), British Elbow and Shoulder Society (BESS), British Orthopaedic Foot and Ankle Society (BOFAS) and the National Joint Registry for England, Wales, Northern Ireland and the Isle of Man (NJR).

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

7. Our collective view is that the national PROMs data for hip and knee procedures are incredibly important and have a wide range of purposes. Many of these uses and purposes are discussed in the following paragraphs, but we particularly highlight the enormous value these data provide firstly in comparative data to support quality improvement and secondly for research purposes. As a principle, PROMs data in orthopaedics puts the patient perspective as central to our definition and measurement of a 'good outcome'. This allows us to go beyond the traditional means of measuring outcomes based on revision rates or a clinician's view of function/improvement, which are not always good measures of success, to ensure we understand the patient's perspective. For a patient-centred NHS we believe this is essential. Orthopaedic surgery represents a major area of healthcare spend, given the high prevalence of relevant musculoskeletal conditions, and so this is an area where PROMs can have a particularly significant impact, including in monitoring outcomes, decision making and stratifying care pathways.
8. Some of the particular uses of PROMs data include:
 - i. PROMs data allow clinicians and units to review their outcomes and benchmark themselves against others, leading to a wide range of benefits such as the ability to evaluate their current approach and outcomes, to inform improvements to their practices, and to monitor the impacts of changes to care pathways. This form of data-based review and reflection is something we see as an important part of the professional responsibility of clinicians and trusts, and this is central to the Getting it Right First Time approach that is currently being rolled out led by Prof Tim Briggs. Ultimately this data review process has important benefits for patients in seeking to improve their outcomes. We note that the PROMs programme itself highlights online various case study examples of where such approaches have been taken by individual hospitals and led to improvements.¹

¹ <http://www.hscic.gov.uk/benefitscasestudies/proms>

- ii. PROMs data provide an outstanding data resource for research regarding outcomes. The PROMs programme data are particularly valuable given the existence of the well-established National Joint Registry (NJR), as well as HES data, allowing data to be used in combination to provide a rich dataset for analysis – a unique resource internationally. Without hip and knee PROMs data, this could seriously undermine research utility of the NJR data. Research using NJR and PROMs data is undertaken both by the NJR itself and by external researchers, and has been widely published in peer-reviewed journals and presented at high-profile national and international conferences.
 - iii. PROMs data at unit-level is now part of the routine publication of data on both NHS Choices and the NJR Surgeon and Hospital profile site. These sites are aimed at patients and provide them with valuable information, for example on the outcomes for the potential units where they could be treated and on the typical outcomes of a procedure.
 - iv. PROMs data are used to inform national guidance on surgical procedures; for example, NICE referred to evidence regarding PROMs in its guideline “Arthritis of the hip (end stage) - hip replacement (total) and resurfacing arthroplasty (TA304)” in 2014² and Commissioning Guidance produced by the BOA/RCS in partnership with the specialist societies has also referred to PROMs.³
 - v. There is some evidence that PROMs can highlight potential implant failure, providing a further patient benefit from the programme.⁴
9. We also highlight the relevance of PROMs collection in light of the position of DH and NHS England on collection of outcomes information:
- i. Darzi report ‘High Quality Care For All’ 2008⁵ in a section on improving quality of care: “We will systematically measure and publish information about the quality of care from the frontline up. Measures will include patients’ own views on the success of their treatment and the quality of their experiences.”
 - ii. Francis report (2013)⁶: “There is an urgent need in many areas for measures to be developed to allow the effectiveness of a service to be understood. [...] It should no longer be acceptable for treatment to be offered to patients without information being available on how effective it is and what it is reasonable to expect as an outcome. The rate at which such outcomes are in fact achieved by units and individuals can then be better understood, and, where necessary, corrective measures taken. The more such information is available to the staff providing treatment, the more likely is a culture of striving for evidence-based excellence to be adopted.”
 - vi. PROMs are also a critical part of the quality framework that fit into ‘Getting it right first time’, the 5 Year Forward View and the recent Monitor report.
- Within orthopaedics, the PROMs programme is a major route for our profession to achieve this important measurement and analysis of outcomes.

² <https://www.nice.org.uk/guidance/ta304/resources/total-hip-replacement-and-resurfacing-arthroplasty-for-endstage-arthritis-of-the-hip-review-of-technology-appraisal-guidance-2-and-44-82602365977285>

³ <http://www.boa.ac.uk/pro-practice/commissioning-guide-painful-osteoarthritis-knee/>,
<http://www.boa.ac.uk/pro-practice/pain-arising-from-the-hip-in-adults-commissioning-guide/>

⁴ Howie (2014) PROMs: How was it for you? Journal of Trauma and Orthopaedics, 1(1), p49-51.
<https://www.boa.ac.uk/wp-content/uploads/2014/05/BOA-JTO-PROMs.pdf>

⁵ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/228836/7432.pdf

⁶ <http://www.midstaffspublicinquiry.com/>

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

10. This question has been largely answered in the response to Q2. Overall, the reason we use PROMs data is because we see that the patients' perspective on their outcome is central to determining and defining the success of a procedure and seeking to make improvements.
11. Some further specific examples of ways that the BOA has used or is using PROMs data include the following:
 - i. PROMs data was used in Prof Tim Briggs' 'Getting it right first time' data dashboard and visit programme across England to feedback to trusts their PROMs information. The resulting report, 'A national review of adult elective orthopaedic services in England', has a section on PROMs.⁷
 - ii. PROMs data are highlighted as important indicators of quality in the commissioning guidance produced by the RCS, BOA and specialist societies in 2013.⁸
 - iii. We also regularly feature coverage of PROMs in both our annual congress and our journal, the *Journal of Trauma and Orthopaedics*.
12. The NJR uses PROMs information in a variety of specific ways, which include:
 - a. In its annual reports and summaries since 2013 (although please note that this has not been possible in years when no data from the NHS England PROMs programme was available to the NJR from the HSCIC);
 - b. In research activities;
 - c. In the online NJR Surgeon & Hospital Profiles, which are intended to allow patients to learn about the typical PROMs outcomes for the hospitals in their area.⁹

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?

13. We believe that the national PROMs data for orthopaedics are widely used and highly valuable for a range of purposes including:
 - i. Decision Making - by usage in consultations with patients to discuss the potential improvement in their outcomes from a given procedure and the typical outcomes for units at which they will be or could be treated;
 - ii. Allowing units to reflect on the outcomes they are achieving for patients and acting on these where appropriate – many trusts already do this, and those that do not are being encouraged to do so through the 'Getting it right first time' programme;
 - iii. Allowing changes to care pathways to be monitored for their impact on patient outcomes;
 - iv. Providing valuable research data to investigate issues that impact patient outcomes in future such as the different outcomes for different population groups or those with comorbidities;
 - v. Highlighting potential implant failure – in conjunction with the NJR.

⁷ <http://www.hscic.gov.uk/benefitscasestudies/proms>

⁸ <http://www.boa.ac.uk/pro-practice/commissioning-guide-painful-osteoarthritis-knee/>,

<http://www.boa.ac.uk/pro-practice/pain-arising-from-the-hip-in-adults-commissioning-guide>

⁹ <http://njrsurgeonhospitalprofile.org.uk/>

14. As discussed later in paragraph 25, we believe that the PROMs data could be even better used if there were improved mechanisms for consultant to access their data, as at present consultants encounter great difficulties in obtaining the data.

Q5. What are the benefits of nationally mandated PROMs?

15. Since PROMs are nationally mandated this provides a large dataset for interrogation for all the above purposes. Without mandation, we would envisage that many trusts may not participate fully in the initiative, which would have a highly detrimental effect on the value of the data produced. The importance of this is highlighted by the fact that hip and knee PROMs (mandated) have much higher completion rates than shoulder PROMs (not mandated).

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

16. None. See above.

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

17. We can only comment on the hip and knee replacement collections, and we believe these are extremely valuable, for all the reasons outlined above.
18. We note that of the case studies described on your website of benefits of PROMs, all are from the two orthopaedic PROMs. We believe this indicates that there are significant benefits being derived from these collections. Considerable use is being made of the data, and we believe this justifies the importance and value of the data.
19. We would particularly like to highlight that for T&O, national PROMs data has now reached a stage where it is beginning to make a significant contribution to evidence based medicine, as sufficient data has been collected over a period of time and can be used meaningfully. It is clear that significant time, resources and public money have been used to reach this stage. In our view, any cessation would be a retrograde step that would significantly impinge on all current Quality Improvement initiatives aimed at enhancing patient care; indeed such is our belief in and commitment to the national programme that we are actively proposing its extension to other joint replacement procedures (discussed later).

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

20. We can only comment on the hip and knee replacement collections, and we certainly feel these should continue.

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)

21. Having taken advice from the British Association of Surgery of the Knee (BASK), we suggest the knee replacement Q2 should be undertaken at 12 months post-surgery rather than 6 months. This is because knee replacement patients at 6 months are continuing their recovery and a PROMs assessment at this stage would underestimate the success of the procedure.

22. We believe that both condition-specific and EQ5D PROMs collections should be maintained, as both contribute to the overall picture of patient improvement.
23. The Getting it Right First Time report has highlighted that the PROMs programme would be enhanced if additional metrics relating to a number of specifically orthopaedic complications could be added to the case mix adjustment criteria, and the case-mix methodology should be reviewed. The BOA believes that BMI and ASA grade are particularly relevant factors for case-mix adjustment that are not currently collected for the PROMs programme (but which are collected within the NJR).
24. We have previously highlighted a number of coding issues within PROMs which we understand are already being looked at but note them for completeness here also:
 - i. Closed reduction for dislocated THR should not be considered as a revision joint replacement procedure;
 - ii. Hemiarthroplasty is a procedure undertaken following fracture and PROMs information for this procedure should not be included with the data for the 'routine' joint replacement procedures;
 - iii. For both hip and knee replacement, revision surgery should always be considered separately to primary surgery;
 - iv. For knee replacement, there should be distinctions made between the following groups of procedures: Patello-Femoral Replacement, Total knee replacement and Unicondylar Knee Replacement, even though all three of these can also legitimately be referred to as a 'resurfacing procedure of the knee.' There is therefore a great opportunity for mistakes in coding. Even if mistakes are not made the three groups of procedure must not be lumped together as their outcomes are different. In addition, resurfacing of the patella as a secondary operation after TKR is a form of revision and should not be lumped in with the primaries.
25. It should be made easy for the surgeon (and his unit) to obtain PROMs data on their patients. We have mentioned above the data-based review and reflection is to us a central aspect of the value of having this data, but at present obtaining the data itself does not seem possible or if it is the process appears opaque.

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.)

26. Under Q12 we propose that PROM collections should be mandated for the other procedures covered by the NJR: shoulder replacement, ankle replacement and elbow replacement – further detail is provided there.

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

27. We are supportive of local PROMs collection to supplement the national collections, for example in areas these do not cover. However, we believe that nationally mandated data offers the significant advantages of the collection of a substantial dataset and providing nationwide coverage that allows widespread comparison across different units and different population groups.

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?

28. We consider that PROMs are critical for all joint replacement operations. Previous research has shown that when pain is used as an endpoint for implant survival, the outcomes of joint replacement surgery are much less favourable than if revision surgery is used as the survival endpoint. This is true for shoulder, elbow and ankle arthroplasty, and since the NJR now collects data on all of these procedures, to do so without PROMs is a wasted opportunity that also puts patients at potential risk if failing implants types are not identified early enough. The numbers of these procedures are much smaller than for hips and knees, and therefore this would not seem to be a significant threat to national programme costs and would directly support the NHS adopted Getting it Right First Time report.
29. Of these three procedures, shoulder and ankle arthroplasty would be the most valuable as they are the next most prevalent; the number of primaries submitted to the NJR in 2014 were: shoulder, 4,756; ankle, 509. Both procedures have a higher rate of revision than hips and knees, providing an important reason for focusing on patient outcomes. Furthermore, as these are lower volume procedures in which typically small volumes are performed by many surgeons, it is imperative that we understand the national picture on outcomes and use this to inform practice.
30. Regarding shoulder replacement, this is undergoing expansion year on year at present and implant survival is felt to be an extremely poor measure of shoulder implant performance. Because of this, a pilot study was funded by BESS and the NJR in order to obtain a clearer picture about outcomes after shoulder replacement. A well-established PROMs tool exists, in the Oxford Shoulder Score and the Pilot has demonstrated the feasibility of collecting this PROM nationally even with the hindrance of it not being mandated. As a result, BESS and the BOA feel there is compelling case for shoulders to become part of a mandated national PROMs programme.
31. Regarding ankle replacement, the collection of PROMs is currently being tested through a study funded by Arthritis Research UK, which is currently ongoing and which would provide valuable insights to support the collection of PROMs through a national programme in future.¹⁰ BOFAS and the BOA again believe there is a compelling case for ankle replacement to become part of a mandated national PROMs programme.
32. Finally, we would like to highlight that aside from joint replacement, there are numerous other procedures across trauma and orthopaedics where collection of PROMs has the potential to be beneficial. Several emerging registries are already seeking to collect PROMs in a range of procedures, and mandating entry of data into these registries would be welcomed (listed at www.boa.ac.uk/pro-practice/boa-quality-outcomes-project/). One further specific

¹⁰ <http://www.arthritisresearchuk.org/research/grant-tracker-items/2013/the-outcomes-in-ankle-replacement-study-oars.aspx>;

area where PROMs collection could be particularly valuable would be knee arthroscopy – certain knee arthroscopy procedures are captured by the National Ligament Registry, but PROMs collection more widely would be another consideration for the national PROMs programme.

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

33. In just the same way as for the hip and knee replacement PROMs benefits outlined above, these additional collections would allow more trusts to review and improve their practice based on PROMs, would provide valuable data for research and provide information for patients.
34. In relation to shoulder surgery, we would also like to highlight that BESS and the BOA supported a James Lind Alliance priority setting partnership run by BESS members which found that patients consistently expressed the view that outcomes of interventions including joint replacement should be based on PROMs, suggesting this is of great importance to patients.

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

35. The BOA believes that PREMs also are valuable sources of information about the services and care provided to patients. At present, we understand that for the current 'Friends and family test', it is not usually possible to tie this back to the department which treated the patient or the procedure or treatment type that they received because these are collected anonymously. We would encourage further exploration of these issues to see if it would be possible to do so, as we feel these provide valuable insights for the treating clinicians and wider team.

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

36. We are very happy to provide any further information or context to our responses provided here, if the PROMs team wish to contact us.