CASE REPORT

When to operate: online patient-reported outcome measures (PROMs) can help decide

William John Edward Reeve,¹ Daniel H Williams²

¹Department of Trauma and Orthopaedics, Royal Cornwall Hospitals NHS Trust, Truro, UK
²Department of Orthopaedics, Royal Cornwall Hospitals NHS Trust, Truro, UK

Correspondence to
 William John Edward Reeve,
 willreeve@doctors.org.uk

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SUMMARY

We present a report on use of a web-based electronic patient-reported outcome measures (ePROMs) system to support decision-making for a patient with an osteoarthritic knee. After being placed on a waiting list for knee arthroplasty, the use of preoperative PROMs allowed the patient and surgical team to review ongoing disability, and, as a result, alter the management plan by deferring surgery. Ongoing clinical review and symptom management has been centred on ePROMs and has been tailored to the specific needs of the individual. PROMs data are increasingly becoming a necessary component of outcome measurement in many surgical areas. Often, these data are available to neither patient nor clinician in a way that prospectively allows meaningful management. This case highlights how ePROMs can directly influence patient care in real time.

BACKGROUND

National Health Service (NHS) England, the renamed NHS Commissioning Board, published *Everyone Counts: Planning for Patients 2013/2014*,¹ to help local clinicians deliver a more responsive health service, focus on improving outcomes for patients, address local priorities and meet the rights people have under the NHS Constitution. NHS England "...expect secondary care providers to be able to account for the outcomes of all patients... by 2014–2015" (this year). Advances in information technology present opportunities to deliver these goals alongside efficiencies in NHS service delivery, but it is unclear how to practically deliver this goal. While studies that make use of large aggregated data sets, including those that collect patient-reported outcome measures (PROMs), have delivered powerful insights, there are few reports of how technology and real-time reporting of these data can improve care on a day-to-day basis at an individual patient level.^{2–5}

CASE PRESENTATION

A 64-year-old woman presented with a 12-month history of a severe, constant, sharp pain affecting the medial aspect of the left knee. The pain required regular daily analgesia, was present at rest and limited her mobility to walking 200 yards on the flat.

Examination revealed medial joint line tenderness, a range of motion measuring 0–110° of flexion and no ligament instability. Plain film radiographs confirmed significant medial joint space narrowing consistent with osteoarthritis of the knee (figure 1A, B). The benefits and risks of operative

management were discussed and due to the severity of symptoms affecting her quality of life the patient was listed for unicompartmental knee replacement.

TREATMENT

As part of the preoperative work up, the patient registered on the web-based PROMs system in use at this hospital, and completed a set of ePROM scores and answered preoperative questions.⁶ The Oxford Knee score was 10/48 (0–48 scale, a higher score being better) with a general well-being HowRU score of 2/12 (0–12 scale, a higher score being better). These two scoring systems were selected to give a measurement specific to the knee and a global overview of well-being of the patient as a whole. Following completion of these quality of life measures, the system provides condition-specific information about non-operative and operative treatment, including video testimonials from previous patients, provided by NHS Choices. Following the advice of the surgical team and the information on the website, the patient began a weight loss programme, resulting in weight loss of 13 kg over the subsequent 2-month period.

OUTCOME AND FOLLOW-UP

The patient recorded a repeat Oxford knee score of 22/48 with a further improvement to 33/48 over the coming weeks and an improvement in her general well-being HowRU score to 8/12 (figure 2). As a result, the patient requested deferral of surgery and a clinical review in a few months. Having consented to share her PROMs with the surgical team during registration on the system, the online system allows the patient and surgical team to view the trends in scores at any time. The surgical team, following the patient's score improvement online, deferred surgery and continued to actively monitor the scores. After the initial improvement, subsequent ePROMs scores fluctuated over the follow-up period from 33/48 to 13/48 for a short time, and then back up to 30/48 (figure 2A). The patient has controlled her follow-up appointments and continues to manage her symptoms with both managing fluctuation in her weight and lifestyle, and using alternative pain management therapies. Subsequently, the Oxford Knee score has decreased to 21/48 and 13/48. However, having an understanding of how the scores fluctuate with time and a good grasp of techniques to manage her symptoms, the patient wants to avoid surgical intervention at the present time. Future face-to-face follow-up will continue to be guided by the trend in the PROM scores.

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Figure 1 (A) Anteroposterior radiograph of the knee demonstrating medial compartment osteoarthritis. (B) Lateral radiograph of the knee.

DISCUSSION

Successive Department of Health papers have signalled a shift away from a target driven culture in the NHS to one focused on quality clinical outcomes.^{7–9} PROMs are validated condition-specific and generic measures that quantify patient symptoms, function, social stigma and quality of life, and have been utilised for research purposes—as outcomes in clinical trials and economic evaluations—for many years.^{10–15} Recent policy interest in the use of PROMs springs from a recognition that traditional activity-based measures of health service productivity do not measure the contribution of healthcare to the health and well-being of people.^{11 12 15} Arguably, patients themselves are best placed to judge their own health and well-being. The National PROMs Programme (NPP), created in April 2009, is an important development in the use of PROMs and has revealed some interesting early findings.^{3 4} The programme mandates routine PROMs collection for all NHS patients in England, before and after receiving

surgery.¹⁶ The requirement to collect PROMs data applies to only four surgical procedures at present, including hip and knee replacement, but work is under way to develop or evolve the programme further. As yet, patients do not have direct access to their own PROMs data and the results of the NPP are only made available to hospitals and clinicians after a delay of some 6–9 months, arguably after the real-time clinical usefulness of these data has expired. Incremental remodelling of NHS services will increasingly make use of innovative opportunities presented by technical advances in information technology to provide real-time access to individual patient data. Web-based systems, such as that used here, could potentially enable patients and clinicians to make use of real-time PROMs in everyday clinical practice while simultaneously feeding these data directly into a future NPP framework. The benefits of both real-time access at an individual patient level and real-time access to appropriately anonymised, aggregated population data can then be realised. Expanded use of such systems could also potentially assist both, commissioners and providers in meeting the goals set out by NHS England.¹ Further work is required to study how such web-based technologies can be applied and used across whole patient populations.

Figure 2 (A) Graph of Oxford Knee scores over time. (B) Graph of HowRU general well-being scores over time.

Learning points

This case demonstrates that PROM scores recorded and reported in real-time on a web-based system have a number of potential benefits for the patient:

- Informed patients are able to play a greater part in their own treatment decisions.
- Related non-operative treatment information, for example, lifestyle modifications, presented alongside the symptom scores potentially acts as a powerful motivator to change.
- The ability to readily repeat and clearly see trends in symptom scores can provide feedback to positively reinforce changes in behaviour and positively influence clinical outcome.

Twitter Follow Daniel Williams at @danhwilliams

Contributors WJER was the primary author and DHW the lead clinician and secondary author.

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