

Patient and Public Involvement (PPI) in Research – Case Study

Provided by:

Professor Jonathan Rees
Professor of Orthopaedic Surgery and Musculoskeletal Science, NDORMS, Botnar, BRU

How patients and the public were/ are involved

In 2013 I initiated and ran a James Lind Alliance (JLA) Priority Setting Partnership (PSP) for ‘Surgery for Common Shoulder Problems’. We set this PSP up as a national model for orthopaedics by obtaining funding from national professional organisations, namely the British Elbow and Shoulder Society (BESS) and the British Orthopaedic Association (BOA) and NIHR via the NIHR Oxford Musculoskeletal Biomedical Research Unit and the NIHR Oxford Biomedical Research Centre.

The process took 18 months to complete with 371 participants. We had 404 important questions which were eventually shortlisted to the final top 10. Patients, carers and clinicians were involved at all stages of this process. We had patients as part of the steering group for the whole 18 months and patients also contributed from around the country via online surveys and some also attended the final prioritisation meeting.

The impact of involving patients and public in the study/ your work overall

The aim of the ‘Surgery for Common Shoulder Problems’ PSP was to identify the unanswered questions about surgical treatments for Common Shoulder Problems’ that are important to patients carers and clinicians. By working with patients, clinicians and allied health professionals, we were able to follow a process that has identified treatment uncertainties about different types of shoulder surgery including when to operate and which patients are best treated with surgery.

BESS has endorsed the Top Ten priorities, which will be published as follows:

bmjopen-2015-010412. Research Priorities for Shoulder Surgery: results of the 2015 James Lind Alliance patient and clinician priority setting partnership. Rangan, Amar; The James Cook University Hospital, Trauma and Orthopaedics; Upadhyaya, Sheela; Regan, Sandra; Oxford University Hospitals NHS Trust, Biomedical Research Centre; Toye, Francine; Oxford University Hospitals NHS Trust, Nuffield Orthopaedic Centre Physiotherapy Research Unit; Rees, Jonathan; University of Oxford.

Researchers from the National Institute for Health Research (NIHR) observed the final workshop and are aware of the priorities.

Both Amar Rangan and myself have plans to address the priorities through our research programmes, and are planning to submit an application for funding to the NIHR for a trial that would

address the question “In patients with shoulder arthritis is a hemiarthroplasty or a total shoulder replacement or a reverse replacement most effective?” [NB. Since writing, the NIHR HTA Programme published a commissioning brief to address this question].

The importance of involving patients and the public in research

Overall, a JLA PSP is a very positive and worthwhile experience. Our patient representatives found it thoroughly rewarding. The top 10 results of our shoulder surgery PSP were announced and presented by Professor Jonny Rees in June 2015 at the BESS annual conference. These top 10 results can now be disseminated and published knowing that they have been obtained through a patient engagement process that involved patients at all stages of their development and selection.

Top 10 questions

- For the main shoulder conditions of arthritis, frozen shoulder, impingement, rotator cuff tears and instability, can you predict which patients will do well with surgery to help them decide on whether to have surgery or not?
- In patients with 3 and 4 part proximal humeral fractures what is the long term outcome of reverse total shoulder replacement compared to hemiarthroplasty?
- Does arthroscopic subacromial decompression surgery in patients with degenerative rotator cuff tendon problems improve outcome and prevent further tendon degeneration and tears compared to patients with no surgical intervention?
- Does early mobilisation and physiotherapy after shoulder surgery improve patient outcome compared to standard immobilisation and physiotherapy?
- In patients with shoulder arthritis is a hemiarthroplasty or a total shoulder replacement or a reverse replacement most effective?
- Are patients (including older age groups) with rotator cuff tendon tears in their shoulder best treated with surgery or physiotherapy?
- How can we ensure that patients see the right doctors and clinicians promptly and correctly, and does this lead to better outcomes?
- In patients with Frozen Shoulder, does early surgery improve outcome compared to non-surgery treatments such as injection and dilatation?
- In patients with newly diagnosed calcific tendinitis (calcium in a shoulder tendon), is early surgical intervention more clinically effective than non-operative treatments?
- Do patients with partial thickness rotator cuff tendon tears benefit more from a surgical repair compared to a decompression and debridement alone?

The biggest challenges in PPI and what might help to overcome them

Developing and maintaining a good resource of engaged patients in various specialities.