

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

NIHR Clinician Scientist awarded study - Using NHS data for musculoskeletal epidemiology: the risk/benefit of total knee and hip arthroplasty in patients with rheumatoid arthritis, and the potential effects of biologics on reducing the need for surgery.

Provided by:

Daniel Prieto-Alhambra, Associate Professor and NIHR Clinician Scientist, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Science

How patients and the public were/ are involved

PPI representatives have been involved in our projects since the design stage. Two patients involved in local patient groups (National Rheumatoid Arthritis Society and Arthritis Care) were contacted and asked for advice regarding the design of patient components of the application, and their inputs were included in the grant proposal.

Several activities have been organised with PPI representatives since the beginning of the study:

1. PPI meeting: Two rheumatoid arthritis patients, including an NRAS (National Rheumatoid Arthritis Society) local representative, were invited to discuss the appropriateness, validity, and structure of the research programme. The feedback received was very positive, showing a special interest in the usage of previously-collected data as a safe, more representative source of data. **Very useful suggestions arose during the meeting which have been included as additional analyses in the study.**
2. Steering committee meetings. A patient and local representative of NRAS is part of the steering committee of the project. These meetings provide an opportunity to regularly discuss the progress, methodology, and the relevance of the study findings from a patient as well as from a scientific perspective. **Our PPI representative has proved to be essential to the programme, providing a different point of view to all our discussions. She has agreed to help us to further disseminate results when available to the lay audience.**
3. PROMs pilot test. Three rheumatoid arthritis patients (contacted using the local National Rheumatoid Arthritis Society patient groups) were offered to undertake a pilot test of the validated Patient Reported Outcomes (PROMs) questionnaires to be used in the study (Oxford Hip/Knee Scores), and the EuroQoL-5D. Although these have been widely used in the population of patients undergoing lower limb joint replacement for osteoarthritis, there is less data on their use for people suffering from Rheumatoid Arthritis. After an introduction to the project, the patients had some time to read the questions and try to answer the form, followed by a discussion on the relevance of both the test and the paper form itself for rheumatoid arthritis patients. **They strongly supported the use of these PROMs to measure relevant patient outcomes, and suggested that some of the sections should be considered especially relevant for rheumatoid arthritis patients. This will be included in our analysis.**
4. NRAS local group meeting. The PI of the study (Daniel Prieto-Alhambra) attended a NRAS Oxford meeting with about 15 rheumatoid arthritis patients. The study proposal was discussed in detail,

and patients had an opportunity to express any particular concerns or additional ideas that might help this research. **They were very enthusiastic about the proposed research programme, as well as on the proposed outcomes and methods, including the use of anonymised routinely collected clinical data for research on the effects of drugs in real NHS practice (and in actual NHS patients).** There are plans to communicate study findings to this same group when available in the coming few months.

#### The impact of involving patients and public in the study

First of all, having the support of patients and public in the research project has been encouraging. Although they have approved of our choice of topics, outcomes and methodology for this study, they have also contributed with new thought and ideas, which makes us feel confident about the significance of our research.

Secondly, some changes/additions to the original plans have been included according to suggestions made by PPI representatives in different meetings. Therefore, the relevance of our study has improved by including the interests of the public and not only of clinicians and scientists.

In addition, these activities have allowed us to communicate with the public instead of just disseminating our results – we are not only speaking, but also listening to the public and letting them be part of the design of the different stages by not considering their views like static opinions but like part of a dialogue that leads to decisions.

Finally, we envisage their involvement as key in the dissemination of our findings to the lay audience and to patient and public representatives.

#### The importance of involving patients and the public in research

Involving patients and the public is essential for research groups to connect with societal perspectives and needs.

It also has an impact on the relevance of the studies designed. Interests of scientific research come from the interests of society, and therefore the scientific community cannot work as an isolated entity that creates and covers its own needs. Taking into account patients and public will create more meaningful studies leading –hopefully- to a greater impact.

Another point to consider is the best use of research resources. Researchers have the obligation to make an efficient use of their funds, and patients and the public can help to decide or prioritise what is really important and what could produce a higher benefit.

Research groups could benefit from patients and public involvement in several ways:

- Receiving their support when needed for research proposals that will –most likely- need their contribution, either at the recruitment/participation or at the dissemination and implementation stage.
- Getting used to the inclusion of topics/methodologies/outcomes evidenced/suggested by the

public as a *sine qua non*<sup>i</sup> for new research projects.

- Developing efficient communication procedures leading to a better way of expressing ideas in non-scientific environments, gathering information from the public to make the most of it and converting public ideas into successful applications.

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

Some important issues to bear in mind are:

- It can seem difficult to find patients that can and are willing to be involved: charities are a good starting point to look for patients and carers for PPI participation. Transparency about the role is essential, and patients should obviously not feel under pressure to take part on a study as representatives.
- Information available for patients could not be clear enough: an extra effort should be made to let patients and public representatives understand the topics that are being discussed.
- Methodological discussions must not be avoided in the presence of patients. Although scientists tend to think that such ‘complicated’ matters are for specialist discussions only, we have learnt that patients can be extremely useful when it comes to formulating relevant questions and choosing research methods. The effort of ‘translating’ methodological and clinical jargon into plain English is definitely worth it, but it should not be underestimated.

---

<sup>i</sup> Essential condition