James Lind Alliance

Priority Setting Partnerships

Description of a process and workshop to set research priorities in Hip and Knee Replacement for Osteoarthritis

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Enabling translational research through partnership

NHS National Institute for Health Research

1. Introduction and context for this report

This report describes the prioritisation process leading up to the final prioritisation workshop of the James Lind Alliance Priority Setting Partnership for Hip and Knee Replacement for Osteoarthritis, both in terms of process and outcomes. Additional reports are being prepared for publication in peer review journals and for wider dissemination by partner organisations.

This report will be available on the James Lind Alliance website http://www.lindalliance.org/index.asp as well as on the dedicated Priority Setting Partnership website, which is hosted by The Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Science at The University of Oxford (http://www.ndorms.ox.ac.uk/hipkneepriorities.php).

2. Background to the Priority Setting Partnership (PSP)

Setting up the partnership

Every year, about 150,000 hip and knee replacements are carried out in the UK because of osteoarthritis. But we still do not know enough about which patients with osteoarthritis benefit most, when is the best time for surgery, and how to ensure that patients recover quickly and well. The aim of this PSP was to help focus future research funding on the questions that matter to people experiencing hip and knee replacement for osteoarthritis and those that treat and care for them. The JLA, funded by the National Institute of Health Research, provides an infrastructure and process to help patients and clinicians work together to agree on the most important treatment research questions, or uncertainties, in their area of interest.

During 2012, Andrew Price, Professor of Orthopaedic Surgery at The University of Oxford and a Consultant Knee Surgeon at The Nuffield Orthopaedic Centre, and David Beard, Professor of Musculoskeletal Sciences and Co-Director of RCS Surgical Trials Unit (SITU) expressed interest in the JLA approach and met Sally Crowe of the JLA. A subsequent teleconference with members of the Oxford Biomedical Research Unit and the Oxford Biomedical Research Centre established funding for the PSP.

The initial Steering Group was established in October 2012 and consisted of patient and carer representatives, surgeons, physiotherapists, a nurse, a rheumatologist and an anaesthetist. The JLA provided independent chairing of this group.

Partnership objectives

- Work with patients and clinicians to identify uncertainties about the effects of hip and knee replacement for osteoarthritis treatment;
- agree by consensus a prioritised list of those uncertainties, for research;
- publicise the results and process;
- take the results to research funders.

Partners

Partner groups are essential to the success of a Priority Setting Partnership. They offer a link to their members, many of whom have an interest in Hip and Knee Replacement for Osteoarthritis, as contributors to the process, or /also as potential research funders and research generators. Their members took part in discussion groups to highlight unanswered questions, and in the final prioritisation process to select the top ten research questions. The partners that assisted this process include:

- Arthritis Care
- Arthritis Care Scotland
- Arthritis Research UK
- Arthritis Research UK Primary Care Centre, Keele University
- Arthroplasty Care Practitioners Association (ACPA)
- British Association for Surgery of the Knee (BASK)
- British Society for Rheumatology
- Chartered Society of Physiotherapy
- College of Occupational Therapists' Specialist Section on Trauma and Orthopaedics
- Cochrane Musculoskeletal Group
- Comprehensive Local Research Network Musculoskeletal Specialty Group
- Growing Recruitment for Interventional and Surgical Trials (GRIST)
- Nuffield Orthopaedic Centre Patient and Public Involvement Network
- Oxfordshire Clinical Commissioning Group
- Pain Concern
- Royal College of Anaesthetists
- Royal College of Nursing Society of Orthopaedic and Trauma Nursing

3. Developing the shortlist of research questions, for discussion and prioritisation at the workshop

The partnership followed an established route for gathering and prioritising treatment uncertainties (we called them research questions) in hip and knee replacement for osteoarthritis as described in the James Lind Alliance Guidebook http://www.jlaguidebook.org/ and consisted of the following key steps:

Gathering research questions

To gather the questions the partnership chose three different methods:

(i) separate discussion groups for patients/carers and healthcare professionals held in July, August and September 2013

(ii) a short survey, which was available online and by post and available between July - September 2013;

(iii) analysis of interview records from people with hip problems, conducted by the Health Experience Research Group at the University of Oxford.

Existing research and guidelines were initially searched for unanswered research questions. The partnership reviewed this task, and decided not to include these in the dataset due to resource limitations.

Analysing the research questions gathered

Two research staff from the Botnar Research Centre analysed the research questions suggested in the survey (there were 266 surveys returned), the discussion group reports and the extracted questions from the interview records. The research questions suggested were evenly balanced between health professionals, patients and carers and there were 647 questions overall.

The research questions were allocated to themes; similar questions were identified, (there were many of these) merged and reworded into a more research-friendly format. Some questions were removed as they were not within the scope of the exercise (e.g. questions about specific clinics) and some were removed that did address hip and knee osteoarthritis, but not hip and knee replacement.

An independent information specialist (with help from the steering group) checked and removed research questions that were fully answered by up to date and relevant reviews of research.

This reduced the number of questions significantly to 123 (compriseing 49 combined questions and 74 unique questions).

The steering group members were then asked to undertake an interim prioritisation exercise which consisted of individual voting and a group discussion, resulting in a final 30 questions to take the final workshop.

4. Workshop overview

Workshop objectives

1. To give an overview of work so far by the Hip and Knee Replacement for Osteoarthritis Priority Setting Partnership
2. To discuss and vote on a shortlist of research uncertainties
3. Together, agree the 10 most important of these
4. Consider next steps, to ensure that the priorities are taken forward for research funding

Workshop participants

Fifteen patients and carers participated in the workshop, including people who had experienced successful and not so successful hip or knee replacements, those waiting for an operation and some for whom a replacement wasn't suitable treatment. Four of these participants were members of the PSP Steering Group.

There were also 15 health professional workshop participants, including surgeons, nurses, physiotherapists, an anaesthetist, GP, rheumatologist public health and acupuncture specialist. Six of these were members of the PSP Steering Group.

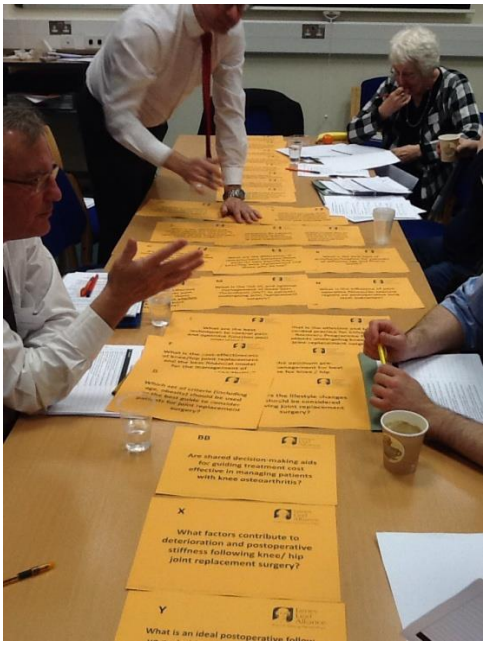
Workshop methods

Prior to the workshop, all participants were asked to provide short biographical information about themselves, complete a declaration of competing interests for hip and knee replacement for osteoarthritis research, and review and rank the shortlist of questions under consideration.

First Phase

The background to the James Lind Alliance Hip and Knee Replacement for Osteoarthritis Priority Setting Partnership was described by Andrew Price, David Beard, and Sally Crowe and participants invited to make comments about the process, and seek clarification.

The priority setting process was described by Sally Crowe and participants encouraged to interact and discuss the 30 questions under consideration at the workshop.



Second Phase

Participants were assigned to small groups, each of which had a mixture of patients, carers and health professionals and an impartial facilitator.

Within each group, time was spent discussing, exploring and comparing each participant's individual rankings of 30 uncertainties. After some time considering these individual comparisons, the groups refocused on the shortlist as a whole, and started to identify shared priorities. Each group had a set of cards with each of the 30 questions (and voting information and examples of the question as originally worded on the flip side) and these

were placed according to group agreement in a rank order of 1 - 30 (1 = the most important).

The facilitators for each group had the task of ensuring that no one person dominated the discussion or exerted undue influence on the group, and that all group members participated in the discussion.

As the workshop approached the lunchtime break, groups were encouraged to finally agree the final ranking. Over the lunch period, data from the three groups were entered into an Excel spreadsheet to aggregate the scores across the groups.

The whole group then reconvened and discussed aggregate scores after the first round of ranking. The purpose of this was not to reorder the list but to clarify where there was existing consensus between groups, and where there was difference.

The three small groups from the morning were rearranged to create new combinations of participants. This time the groups appraised and discussed the new aggregate ranking order from the first round of priority setting. Similar processes were used as in the first round, but the focus here was on having clear agreement of the top ten, as well as a complete 1-30 rank of questions.

Final Phase

During the refreshment break the JLA team again collated the results from this second round of ranking, and the revised order of 30 was laid out on the floor for the whole group to see. The debate was then opened up for everyone to contribute, with two of the JLA facilitators managing the discussions.

This is always a challenging and potentially less inclusive session due to the nature of the room layout, the numbers of people involved, the pressure to achieve consensus, and some participants' interests and bias coming into play. The top ten was debated in detail with suggestions for some merging of questions, substitutions were made (proposers had to make clear their rationale) and an outlier question concerning thrombosis brought into the top 10, albeit with some rewording - to the general satisfaction of the group. Suggestions for improved wording of questions were also noted.

The top ten were agreed just before the formal end of the workshop. It was further agreed that these would be finalised/refined in light of all of the feedback from the workshop and that the Steering Group would oversee this process.

Professor Price then outlined the next steps for the priorities and the next partnership process that will focus on the earlier phase of osteoarthritis of the knee and hips. He invited interested parties to register their interest in getting involved.

5. What next for the priorities?

- The Steering Group will oversee the final wording of the top ten, and provide some additional notes for research funders;
- A publication in a medical journal will alert health professionals to the priorities;
- A feature in the Daily Telegraph will draw the work to the attention of the wider public;
- Potential research funders will be approached ;
- The results will be shared through patient group newsletters etc.

6. The final Top Ten priorities

1	What are the most important patient and clinical outcomes in hip and knee replacement surgery, for people with OA, and what is the best way to measure them?
2	What is the optimal timing for hip and knee replacement surgery, in people with OA, for best post-operative outcomes?
3	In people with OA, what are the pre-operative predictors of post-operative success (and risk factors of poor outcomes)?
4	What (health service) pre-operative, intra-operative, and post-operative factors can be modified to influence outcome following hip and knee replacement?
5	What is the best pain control regime pre-operatively, peri-operatively and immediately post-operatively for hip and knee joint replacement surgery for people with OA?
6	What are the best techniques to control longer term chronic pain and improve long term function following hip and knee replacement?

7	What are the long-term outcomes of non surgical treatments compared with operative treatment for patients with advanced knee/hip OA?
8	What is the most effective pre- and post-operative patient education support and advice for improving outcomes and satisfaction for people with OA following hip/ knee replacement?
9	What is an ideal post-operative follow up period and the best long term care model for people with OA who have had hip/knee replacement?
10	What is the best way to protect patients from the risk of thrombotic (blood clots, bleeding) events associated with hip/knee replacement?

7. Summary of themes from the workshop evaluation

- Many enjoyed the experience and felt welcome as contributors.
- Some felt that something more sophisticated than cards could be used - perhaps on screen?
- People generally felt the day was well-organised.
- Some observed that health professionals' research interests were shared forcefully at times, but the quality of debate was good, considering the range of participants.
- Some didn't enjoy the final large session as much as the smaller groups due to reduced levels of participation.
- The process of compressing many similar research questions may have suppressed the subtleties and nuances of the original questions.
- For some it felt quite unique to have such close involvement of patients, professionals and carers.
- There were mixed views about the facilitators' role, but it was generally positive.

8. Participants

We would like to take this opportunity to thank everyone who took part on the day – your time and contributions are all very much appreciated.

Name	**Role**
Harriet Allison	Observer
Gordon Bannister	Participant
David Beard	Participant
Jennie Beattie	Participant
Anne Clarkson-Webb	Participant
Cushla Cooper	Participant
Alison Crail	Participant
David Crowe	Observer
Hilary Cullen	Supporter
John Dickson	Participant
Sharon Dixon	Participant
Vida Field	Participant

Name	**Role**
Lester Firkins	Facilitator
Bob Green	Participant
Tracey Howe	Participant
Carol Ingram	Participant
Richard Kelsall	Participant
Jennie Kramer	Participant
Paul Landon	Participant
Richard Morley	Facilitator
Sue Musson	Participant
Rosemary Newbery	Participant
Fraser Old	Participant
Nick Pahl	Participant
Martyn Porter	Participant
Natalie Shearwood-Porter	Observer
Andrew Price	Participant
Jane Price	Participant
Carol Rhodes	Observer
Gregor Ross	Participant
Polly Rubery	Participant
Jill Tappin	Participant
Adrian Taylor	Participant
Tessa Thomas	Participant
Geoff Watson	Participant
Jenny Watson	Participant
Sandra Watson	Participant
David Wright	Observer
Sophie Petit-Zeman	Supporter