

## Priority Setting Partnership - Hip and knee replacement for osteoarthritis

PROTOCOL May 2013<sup>1</sup>

### Purpose

The purpose of this protocol is to set out the aims, objectives and commitments of the **Hip and knee replacement for osteoarthritis Priority Setting Partnership (PSP)** and the basic roles and responsibilities of the partners therein.

### Steering Group

The Hip and knee replacement for osteoarthritis PSP will be led and managed by the following:

Patient representatives:

- Nuffield Orthopaedic Centre Patient and Public Involvement Network – Fraser Old
- Arthritis Care – Sandra Watson
- Jill Tappin

Clinical representatives:

- Nuffield Orthopaedic Centre, Oxford University Hospitals Trust; Andrew Price, David Beard, Sion Glyn Jones, Adrian Taylor, Karen Barker
- Community Specialist in Rheumatology & Clinical Manager for the NICE OA Management Guidelines; John Dickson

This PSP is funded by the Oxford Biomedical Research Centre and is represented on the Steering Group by Sophie Petit Zeman.

The Partnership and the priority setting process will be supported and guided by:

- The James Lind Alliance (JLA) and UK DUETs (NHS Evidence)
  - Sally Crowe (JLA)
  - Mark Fenton (UK DUETs Editor)

The Steering Group includes representation of patient/carer groups and clinicians<sup>2</sup> a full list of members is at the end of this protocol.

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<sup>1</sup> This is a generic protocol which should be updated to include the names and details of the Steering Group members. The document may be modified with agreement from the JLA to reflect the make-up of different PSPs and the organisations driving them.

<sup>2</sup> In some cases, it has been suggested that researchers are represented at this level, to advise on the shaping of research questions. However, non clinically active researchers cannot participate in the prioritisation exercise. This is to ensure that the final prioritised research questions are those agreed by patients, carers and clinicians only, in line with the JLA's mission.

The Steering Group will agree the resources, including time and expertise that they will be able to contribute to each stage of the process. The JLA will advise on this.

### **Background to the Hip and Knee replacement for osteoarthritis PSP**

The JLA is funded by the National Institute of Health Research and is part of NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC). Its' aim is to provide an infrastructure and process to help patients and clinicians work together to agree which are the most important treatment uncertainties affecting their particular interest, in order to influence the prioritisation of future research in that area. The JLA defines an uncertainty as a "known unknown" – in this case relating to the effects of treatment.

During 2012, Andrew Price expressed interest in the JLA approach and met with Sally Crowe, a subsequent teleconference with members of the Botnar Research Centre and the Oxford Biomedical Research Centre established funding for the PSP.

### **Aims and objectives**

The aim of the Hip and knee replacement for osteoarthritis PSP is to identify the unanswered questions about hip and knee replacement for osteoarthritis treatments from patient and clinical perspectives and then prioritise those that patients and clinicians agree are the most important.

The objectives of the Hip and knee replacement for osteoarthritis PSP are to:

- work with patients and clinicians to identify uncertainties about the effects of hip and knee replacement for osteoarthritis treatments
- agree by consensus a prioritised list of those uncertainties, for research
- publicise the results of the PSP and process
- take the results to research commissioning bodies to be considered for funding

### **Partners**

Organisations and individuals will be invited to take part in the PSP, which represent the following groups:

- people who have had recent or longer term hip or knee replacement surgery or are waiting for treatment
- carers of people from the categories above
- medical doctors, nurses and professionals allied to medicine with clinical experience of hip and knee replacement surgery and osteoarthritis

It is important that all organisations which can reach and advocate for these groups should be invited to become involved in the PSP. The JLA will take responsibility for ensuring the various stakeholder groups are able to participate equally in the process.

**Organisations wishing to participate in the PSP will be required to affiliate to the JLA** in order to demonstrate their commitment to the aims and values of the JLA. Details on the affiliation procedure can be found at [www.lindalliance.org](http://www.lindalliance.org).

### **Exclusion criteria**

Some organisations may be judged by the JLA or the Steering Group to have conflicts of interest. These may be perceived to adversely affect those organisations' views, causing unacceptable bias. As this is likely to affect the ultimate findings of the PSP, those organisations will not be invited to participate. It is possible, however, that interested parties may participate in a purely observational capacity when the Steering Group considers it may be helpful.

## **METHODS**

This section describes a schedule of proposed stages through which the PSP aims to fulfil its objectives. The process is iterative and dependent on the active participation and contribution of different groups. The methods adopted in any stage will be agreed through consultation between the partners, guided by the PSP's aims and objectives. More details and examples can be found at [www.JLAGuidebook.org](http://www.JLAGuidebook.org).

### **1. Identification and invitation of potential partners**

Potential partner organisations will be identified through a process of peer knowledge and consultation, through the Steering Group members' networks and through the JLA's existing register of affiliates. Potential partners will be contacted and informed of the establishment and aims of the Hip and knee replacement for osteoarthritis PSP and invited to attend and participate in an initial meeting.

The JLA can draft the invitation, and an agreement should be reached as to the best organisation to distribute it.

### **2. Initial meeting**

The initial meeting will have several key objectives:

- to welcome and introduce potential members of the Hip and knee replacement for osteoarthritis PSP
- to present the proposed plan for the PSP
- to initiate discussion, answer questions and address concerns
- to identify those potential partner organisations which will commit to the PSP and identify individuals who will be those organisations' representatives and the PSP's principal contacts
- to establish principles upon which an open, inclusive and transparent mechanism can be based for contributing to, reporting and recording the work and progress of the PSP

The administrative process for convening this meeting will be managed by the Steering Group, supported by Sandra Regan and in coordination with the JLA.

Following the meeting, organisations which have decided to participate in the PSP will be asked to complete a declaration of interests, including disclosing relationships with the pharmaceutical industry.

### **3. Identifying treatment uncertainties**

Each partner will identify a method for soliciting from its members' questions and uncertainties about hip and knee replacement for osteoarthritis and practical clinical importance relating to the treatment and management of hip and knee replacement for osteoarthritis. A period of up to 2 - 3 months will be given to complete this exercise.



The methods may be designed according to the nature and membership of each organisation, but must be as transparent, inclusive and representative as practicable. Methods include a postal and web-based questionnaire, and discussion groups.

Existing sources of information about treatment uncertainties for patients and clinicians will be searched. These can include question-answering services for patients and carers and for clinicians; research recommendations in systematic reviews and clinical guidelines; protocols for systematic reviews being prepared and registers of ongoing research and in particular with this PSP an existing set of 16 interviews conducted for 'Healthtalkonline' with patients who have experienced hip replacement.

The starting point for identifying sources of uncertainties and research recommendations is NHS Evidence: [www.evidence.nhs.uk](http://www.evidence.nhs.uk).

#### **4. Refining questions and uncertainties**

The JLA will participate in this process as an observer, to ensure accountability and transparency.

The consultation process will produce "raw" unanswered questions about diagnosis and the effects of treatments. These raw questions will be assembled and categorised and refined by Inez Rombach (Statistician) and Kristina Knezevic (D Phil) into "collated indicative questions" which are clear, addressable by research and understandable to all. Similar or duplicate questions will be combined where appropriate.

The existing literature will be researched by Kristina Knezevic with some guidance from the Cochrane Review Group (Tracey Howe) to see to what extent these refined questions have, or have not, been answered by previous research.

Sometimes, uncertainties are expressed that can in fact be resolved with reference to existing research evidence – i.e. they are "unrecognised knowns" and not uncertainties. If a question about treatment effects can be answered with existing information but this is not known, it suggests that information is not being communicated effectively to those who need it. Accordingly, the JLA recommends strongly that PSPs keep a record of these 'answerable questions' and deal with them separately from the 'true uncertainties' considered during the research priority setting process.<sup>3</sup>

Uncertainties which are not adequately addressed by previous research will be collated and entered into a musculoskeletal section within the UK Database of Uncertainties about the Effects of Treatments (UK DUETs - [www.library.nhs.uk/duets](http://www.library.nhs.uk/duets)). This will ensure that the uncertainties have been actually checked to be uncertainties. This is the responsibility of the Steering Group, which will need to have agreed personnel and resources to carry this accountability. **This is a key component of the JLA process, and the next stage of prioritisation can only proceed upon its completion.**

#### **5. Prioritisation – interim and final stages**

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<sup>3</sup> Steering Group members should insert information on how they intend to do this.

The aim of the final stage of the priority setting process is to prioritise through consensus the identified uncertainties relating to the treatment or management of Hip and knee replacement for osteoarthritis. This will be carried out by members of the Steering Group and the wider partnership that represents patients and clinicians.

The interim stage, to proceed from a long list of uncertainties to a shorter list (e.g. up to 20 - 30), may be carried out over email, whereby organisations consult their membership and ask for a (number TBC) most important uncertainties, ranked or unranked.

The final stage, to reach, for example, 10 prioritised uncertainties, is likely to be conducted in a face-to-face meeting, using group discussions and plenary sessions.

The methods used for this prioritisation process will be determined by consultation with the partner organisations and with the advice of the JLA. Methods which have been identified as potentially useful in this process include: adapted Delphi techniques; expert panels or nominal group techniques; consensus development conference; electronic nominal group and online voting; interactive research agenda setting and focus groups.

The JLA will facilitate this process and ensure transparency, accountability and fairness.

#### **Findings and research**

It is anticipated that the findings of the Hip and knee replacement for osteoarthritis PSP will be reported to funding and research agenda setting organisations such as the NIHR HTA Programme and the MRC, as well as the major research funding charities. Steering Group members and partners are encouraged to develop the prioritised uncertainties into research questions, and to work to establish the research needs of those unanswered questions to use when approaching potential funders, or when allocating funding for research themselves, if applicable.


#### **Publicity**

As well as alerting funders, partners and Steering Group members are encouraged to publish the findings of the Hip and knee replacement for osteoarthritis **PSP** using both internal and external communication mechanisms. The PSP may also capture and publicise the results, through descriptive reports of the process itself. This exercise will be distinct from the production of an academic paper, which the partners are also encouraged to do. However, production of an academic paper should not take precedence over publicising of the final results.

#### **Signed by the Steering Group**

The undersigned agree to follow the **Hip and knee replacement for osteoarthritis PSP** Priority Setting Protocol.

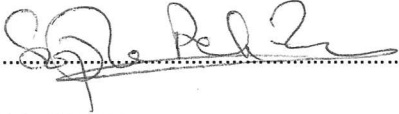
**Nuffield Orthopaedic Centre, Oxford University Hospitals Trust**

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Karen Barker

Date: .....

**Oxford Biomedical Research Centre**

  
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Sophie Petit Zeman

Date: 2/7/2013 .....

**The James Lind Alliance**

  
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Sally Crowe

Date: 3/7/13 .....

**Full membership of the PSP steering group**

- Sally Crowe (SC), James Lind Alliance **Chair**
- Andrew Price (AP), Professor of Orthopaedic Surgery, NDORMS, University of Oxford
- David Beard (DB), Professor of Musculoskeletal Science, NDORMS, University of Oxford
- Fraser Old, Carer and member of NOC Patient and Public Involvement Network
- Tracy Howe (TH), Professor of Rehabilitation Sciences, Glasgow Caledonian University
- Sophie Petit Zeman (SPZ), Director, SPZ Associates Ltd
- Sian Rees (SR), Clinical Health Policy Lead, Health Experiences Research Group, Dept. of Primary Care, University of Oxford
- Kristina Knezevic (KK), DPhil Candidate, NDORMS, University of Oxford
- Sandra Regan (SaR), PA to Professor Price, NDORMS, University of Oxford (Co-ordinator)
- Karen Barker (KB), Clinical Director, Orthopaedics, Nuffield Orthopaedic Centre, Oxford University Hospitals Trust
- Sion Glyn-Jones (SGJ), Consultant Hip Surgeon and HEFCE Senior Clinical Lecturer, NDORMS, University of Oxford
- Louise Locock (LL), Deputy Research Director, Health Experiences Research Group, Dept. of Primary Care, University of Oxford
- Adrian Taylor (AT), Consultant Orthopaedic Surgeon - Hip and Knee Surgery, Nuffield Orthopaedic Centre, Oxford University Hospitals Trust
- Sandra Watson (SW), Patient representative and member of Arthritis Care
- Geoff Watson (GW), Consultant Anaesthetist with an Interest in Critical Care Medicine
- Jill Tappin (JT), Patient Representative
- John Dickson (JD), Community Specialist in Rheumatology & Clinical Manager for NICE OA Management Guidelines
- Cushla Cooper (CC), Specialist Research Nurse/Trials Manager, NDORMS, University of Oxford