

Priority Setting Partnerships

## UNIVERSITY OF OXFORD

# James Lind Alliance Priority Setting Partnership on Hip and Knee Replacement for Osteoarthritis

Newsletter January 2014

#### News flash:

Funding now in place for a new Priority Setting Partnership to look at treatment uncertainties around early stage osteoarthritis of hips and knees

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#### Progress so far

We would like to offer a big **thank you** to everyone who has supported this Priority Setting Partnership (PSP) since it started in late 2012. Without the support of all our partners and the people who took part in contributing their unanswered questions on the issue of hip and knee replacement for osteoarthritis, we would not be able to write this Newsletter pay.

We had a total of 266 respondents to our online survey, and held two discussion groups with patients/ carers and one with healthcare professionals. We also received questions extracted from the Health Experiences

Research Group interviews with people who had had hip replacements.

We have now collected all the questions, categorised them

using the Health Research Classification System, and used special software to sort them. The result is an amazing total of 647 questions.

We are currently working to check which of these questions have already been answered by research. We will then remove a small number of questions that are more relevant to early stage osteoarthritis as we now have funding to start a new Priority Setting Partnership in this area. See below for the story on this exciting new development.

Next we are going to look for questions that are similar and merge them, which will reduce the list further still. The remaining long list of questions will be reduced to about 30 through a prioritisation exercise involving patients/ carers and healthcare

professionals on January 23rd. This shortlist will then be reduced to the top ten at the final workshop on March 27th. Again, both patients/ carers and healthcare professionals will take part.



We have some places at this final workshop—please contact us if you are interested in taking part.

### New Priority Setting Partnership to look at treatment uncertainties around early stage osteoarthritis in hips and knees

Andrew Price, Professor of Orthopaedic Surgery at the The University of Oxford's Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Science said: "Having initiated the PSP on hip and knee replacement for late stage osteoarthritis I am very happy to report our success in bringing together the necessary resources to build on this work. Early stage osteoarthritis in hips and knees provides different challenges for patients and clinicians alike, and the James Lind Alliance (JLA) method provides a transparent and inclusive approach to understanding and developing the priorities for research funding agreed by all involved."

**Dr. Sophie Petit-Zeman, Director** of Patient Involvement in Re-

search, National Institute for Health Research (NIHR) Oxford Biomedical Research Centre said: "We were delighted when this PSP began, as the first funded by the Oxford Biomedical Research Centre (OxBRC). The JLA method is key to our commitment to patient involvement in research, ensuring that what is done "for" patients is developed with them. As we started to gather uncertainties, it became clear that there was real interest in this work among patients, carers and clinicians, and that capitalising on this PSP by carrying out a similar exercise for people with early stage osteoarthritis would help to complete an important picture of research gaps. The OxBRC is delighted that Andy Price and his team have secured significant external funding for this work,

that Sally Crowe will continue leading it, and that Hilary Cullen, our new JLA Adviser at the Ox-BRC will co-ordinate and support the work and its associated website. The JLA method is gaining real momentum in Oxford: more PSPs are getting underway and organisations that fund research are increasingly looking to PSP outcomes to determine where they spend their money. We are confident that this marriage of research deemed important by those at the sharp end of ill health with those who allocate the funds to address it, will reap rewards for patients."

For more information on this new PSP, please contact:

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A final priority setting exercise

#### Comment from the Chair

It is a real pleasure to work with such an enthusiastic and committed group of people who are either personally affected by osteoarthritis or providing care and treatment for people affected by it. My job as Chair of this process is to make sure that we get from start to finish in a way that is open and transparent in its process and decision making, includes a wide range of people's perspectives, and uses research evidence to guide and support our decisions. If you are interested in how the partnership is making decisions about the process, all of the minutes from meetings are available on the PSP website.

In this partnership the focus is on hip and knee replacement surgery, from the decision making process leading up to surgery and all that is entailed in a major operation and successful recovery, and we rely so much on the people that have a story to tell or a clinical perspective to share, so thanks to anyone reading this who has made a contribution – it really does count!

Whilst we are using the <u>James Lind Alliance Guidebook</u> to steer our progress, we have approached things slightly differently. The three discussion groups held in the summer of 2013 were enjoyable and productive sessions that enabled people with osteoarthritis of the hip or knees, and carers, and health professionals to talk about uncertainties in replacement surgery from a broad perspective and try out research questions and ideas. As we have been collecting these uncertainties from different sources (online and postal survey, discussion groups and <u>Healthtalkonline</u>) we will of course be interested in how different or similar they turn out to be, and there is a parallel project ongoing to describe this process, and comment on the results. It is very encouraging that we can continue the partnership to address research uncertainties in the earlier phases of osteoarthritis, following the completion of our current work in March 2014. **Sally Crowe** 

#### Views from patient/ carer members of the Steering Group

Having had arthritis for 40 years, I attended the first PSP Steering Group Meeting with a keen interest. I was intrigued as to what research questions there could possibly be that remained 'unanswered': surely after all these years of medical advancement there would not be many and, therefore, my involvement would not bring much added value to the team? I was therefore greatly surprised by the volume of questions that have been raised by the Survey and Group Sessions. The Patient Group session was a particular eye-opener – there were certainly some questions specific to individuals, but the great majority of questions were common to all: we all shared the same concerns and had a personal interest in research providing answers. It was a fascinating, reassuring and rewarding process to be part of. I am therefore looking forward with great anticipation to the next stage of the PSP. Sandra Watson

I feel very positive about my experience with the Steering Group for this PSP. The care my wife and I have received from the NHS has always been excellent, and I have very much enjoyed participating in the debate. I have been keen to highlight the complexity of medical and social issues confronted by the patient in coming to a decision about hip and knee replacement, and the possible effects of anaesthetics on memory in older patients. I have also been keen to see communications with patients simplified and clarified because there is an inevitable tendency for information sheets to be complex and reflect the medical detail, whereas many patients would like the information to be very straightforward and accessible. My point of view has been listened to and acted on, and I have learned a lot about the technical aspects, and as a former researcher, that has been well worthwhile. I feel that the more I understand, the more support I can give my wife (and the better deal with my own OA problems). Fraser Old

#### Some members of the Steering Group

Standing, Left to Right: Sally Crowe; Sophie Petit-Zeman; Andrew Price; David Beard; Karen Barker; Kristina Harris; Jill Tappin; Fraser Old

**Seated, Left to Right:** Cushla Cooper, Adrian Taylor, Sandra Regan, Geoff Watson

