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Generating research questions from research priorities in early osteoarthritis of hip and knee

Report of a workshop held on the 26th February 2016

at the Botnar Research Centre Nuffield Orthopaedic Centre, Oxford

Prepared by Sally Crowe, James Lind Alliance (JLA), with contributions from Maryrose Tarpey and Tracey Howe (Facilitators) and Sandra Regan (Oxford Biomedical Research Centre)

March 2016

Report overview

This report comprises three sections; the first describes the James Lind Alliance Early Osteoarthritis of Hip and Knee Priority Setting Partnership, and process for developing the priorities and results, which was presented in the first part of the workshop; the second section describes the small and larger group discussions that developed these priorities into research questions, which was the main part of the workshop; the final section reflects on the process and the feedback from participants.

Workshop overview

Workshop objectives:

- To describe the Early Osteoarthritis in Hip and Knee research priorities, in context with the Priority Setting Partnership (PSP)
- To discuss and formulate research questions from the priorities and identify any potential overlaps

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Workshop participants

There were 30 participants in the workshop (including 3 facilitators, 2 support staff) an additional 2 joined later in the day to observe, a full list in Appendix 2. These were split roughly into a third patients and carers, a third health professionals, and a third researchers. These were drawn from partner organisations, and individuals that had mostly contributed to the PSP and prioritisation process. All participants received information about the workshop beforehand, including some background information and general notes about clinical research methods, and a research glossary.

A full programme is available in Appendix 1.

1. The Early Osteoarthritis of Hip and Knee Priority Setting Partnership (PSP)

The Priority Setting Partnership (PSP) was established in 2015, with funding from a variety of sources. The objectives of the PSP were to:

- work with patients and health professionals to identify the unanswered questions about early osteoarthritis of hip and knee patient, carer and clinical perspectives.
- agree 3 x prioritised list of those uncertainties, for research purposes.
- publicise the process and results of the PSP.
- take the results to research commissioning bodies to be considered for funding.

1.1 Partners and Steering Group

Funding partners include James Lind Alliance, the NIHR Oxford Musculoskeletal Biomedical Research Unit (BRU), The British Orthopaedic Association (BOA), The British Association of Surgeons of the Knee (BASK), and The British Hip Society (BHS). The NIHR Oxford Biomedical Research Centre (BRC) provided co-ordination through the James Lind Alliance PSP hub. The Steering Group consisted of representatives from some of these organisations plus people with osteoarthritis and a carer, specialist health professionals (surgeon, rheumatologist, GP, physiotherapist, extended nurse practitioner and acupuncturist). Some steering group members represented professional organisations who contributed 'in kind': the Chartered Society of Physiotherapy, British Acupuncture Council, British Association for Sport and Exercise Medicine, STEPS, and Arthroplasty Care Practitioner's Association.

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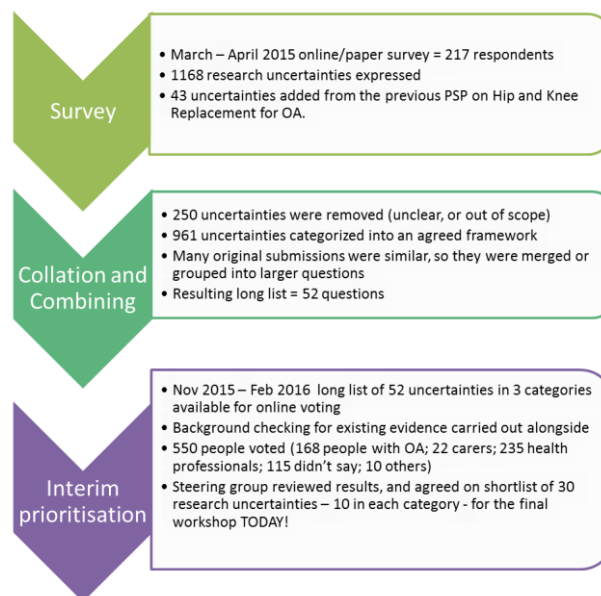
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1.2 Setting the scene – developing the priorities

An exercise that encouraged small groups of people to introduce themselves and discuss why they were participating and how they were feeling about the day was the starting point. Using a light hearted visual for colouring in helped to break the ice and signal that the day was designed to be informal and collaborative.

Team members described the evolution of the partnership (Andrew Price), the process of gathering and prioritising treatment uncertainties in early osteoarthritis of hip and knee (Sandra Regan for Elena Benedetto who was unable to take part on the day), and the Steering Group members were introduced.

The following were key steps in this process as described in the first part of the workshop:



1.3 Surgical priorities (where questions had an explicit surgical interventions)



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1	13. Taking cost into account, what is the most effective treatment between surgical and non-surgical?
2	12. What is the best way (content and structure) of delivering rehabilitation (physiotherapy) after surgery?
3	4. What pre-operative factors can predict the outcome of surgery in people with early osteoarthritis?
4	5. In people with early osteoarthritis, can we help the cartilage to repair itself (cartilage regeneration) through treatments such as stem cells, micro fracture, and cartilage transplant?
5	3. Assuming surgery for osteoarthritis is necessary, does its timing affect the outcome?
6	9. What are the best surgical treatments for younger people (< 55 years) with early osteoarthritis?
7	10. What is the best way of measuring and keeping track of the outcome of surgery in people with early osteoarthritis?
8	1. Is the progression of osteoarthritis to the point of requiring surgery inevitable?
9	11. What is the best way of following up people who have had surgery for early osteoarthritis?
10	7. In people with early osteoarthritis, is joint replacement treatment appropriate and effective?

1.4 Non Surgical Priorities (where questions have an explicit non surgical interventions)

Non surgical working group



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1	20. Is regular exercise and physical activity effective at reducing disease progression in early OA?
2	21. What is the best non-surgical treatment (e.g. physiotherapy, hydrotherapy) to improve outcomes in people with early OA?
3	19. For people with early OA, what are the best exercise requirements (frequency, intensity, type and duration) necessary for clinical improvement?
4	14. Is it possible to influence the progression of OA by changing identifiable risk factors?
5	15. What is the best way to self-manage and monitor my OA?
6	22. What are the most effective physiotherapy treatments for treating early OA?
7	29. For people with early OA going to their GP for painkillers what is the best pain relief strategy?
8	27. What drugs (including joint injections or new treatments) are effective in treating people with early OA?
9	30. What are the best treatments for people with early OA, who also have other musculoskeletal conditions (such as Rheumatoid Arthritis and back pain)?
10	16. At what point does Body Mass Index impact on the progression of early OA?

1.5 Other Important Priorities (where questions embraced both surgical and non surgical interventions, other types of interventions or were not intervention questions)

Other Important Priorities working group



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1	43. Are there treatments that can slow, arrest or reverse early OA?
2	46. What non-surgical services for early OA should be improved and how?
3	45. What is the best treatment or intervention to keep people with early OA working?
4	35. How can we predict disease progression in people with osteoarthritis of the knee/hip?
5	52. Is a multidisciplinary care model (physiotherapist, GPs, practice nurses, pharmacy) effective for managing OA in primary care?
6	40. What factors and patterns of disease are responsible for progression of OA?
7	34. In people with early symptoms of OA, how much does it matter WHEN people are diagnosed (using their signs and symptoms - i.e. clinical characteristics) and does this affect how they progress (i.e. the outcome of the disease)?
8	32. In people with early symptoms of OA, which diagnostic tests should be used?
9	41. What tests are useful to monitor the progress of OA?
10	37. Does the amount or type of joint abnormality seen in the early stages of OA have impact on outcome?

2 Turning priorities into research questions

Following presentations about the PSP, the process to achieve the three top tens and discussion and questions, participants broke into three smaller facilitated discussion and working groups. In these there was a balance of people with osteoarthritis, health professionals and researchers in each group, except in one group where a patient had left early (this was noted and the status quo maintained for consistency of decision making). Participants were allocated to their discussion group according to first or second preference. This ensured that groups had people with relevant interests and experiences,

Each priority was introduced by the facilitator, and some time was spent sharing related experience and expertise from either a patient/carer or health professional/research perspective. Each group had cards to work with that contained important contextual information about the priority under discussion, such as patterns of voting that it had attracted. An additional facilitator had access to the original database of submitted uncertainties so that these could be accessed to add to the discussion if needed.

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Groups 'scoped' the priority taking into account all the issues that any good research question would need to address, and then finessed a research question (s) out of this. A form was provided to try and ensure structure and consistency in capturing the decisions from each group. Where groups identified overlaps between the priorities these were discussed within small groups, and in one case a substitution made following a proposal and discussion in the large group.



Surgical Working Group

All group facilitators reported good patient input in the early stages of the discussion, as well as clinical and research input. As groups moved on to actually formatting the research questions from the priorities there seemed to be more input from the clinicians and researchers, but the facilitators thought this was appropriate. Areas that patients/carers contributed included experience relating to the priority, risks and concerns, clarification of the priority and suggestions for outcomes to be measured where appropriate. The workshop team's expectations were moderate, the development of well formed research questions is often an iterative process that can take time; despite this 28 of the 30 priorities were discussed.

The tables below show the outcomes of discussion on the 28 research priority topics. These research questions are intended to be a broad reflection on how the priority topics might be usefully interpreted and addressed, as viewed by the workshop participants on the day. They are not intended to be exhaustive in their scope, or to be fully developed in terms of detail and breadth. Each question has an rank order number, the number in brackets is the question identification from the original survey.



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2.1 Surgical Priorities (where questions had an explicit surgical intervention)

Rank order	Priority	Context information
1 ID 13	Taking cost into account what is the most effective treatment for early OA between surgical and non surgical treatments?	Outcomes; Measures for surgical priorities should reflect changes in tissue, and patient outcomes Merits or otherwise of doing research comparing different sorts of surgery rather than comparing surgery with no surgery?
2 ID 12	What is the best way (content and structure) of delivering rehabilitation (physiotherapy) after surgery for early OA <i>(Slight rewording)</i>	Outcomes; Measures for surgical priorities should reflect changes in tissue, patient and cost effectiveness
3 ID 4	What pre operative factors can predict the outcome of surgery in people with early OA?	Outcomes; Measures for surgical priorities should reflect changes in tissue, patient and cost effectiveness
4 ID 5	In people with early OA are surgical treatments designed to repair, not replace the joint (such as stem cells, micro fracture and cartilage transplant) effective? <i>(Reworded)</i>	Outcomes; Measures for surgical priorities should reflect changes in tissue, patient and cost effectiveness The results of this study would have great application to patient and clinical decision making.
5 ID 3	In people with early OA does timing affect the outcome for non joint replacement surgery e.g. osteotomy, athroplasty? <i>(Reworded)</i>	Original question: "Assuming surgery for osteoarthritis is necessary, does its timing affect the outcome?" 'necessary' was considered inappropriate so removed in the reworded question Outcomes; Measures for surgical priorities should reflect changes in tissue, patient and cost effectiveness
6 ID 9	What are the most effective surgical treatments e.g. arthroscopic, biological, realignment, osteotomy in people with early OA?	Population; any age not just under 55 years Outcomes; Measures for surgical priorities should reflect changes in tissue, patient and cost effectiveness
7 ID 10	What is the best way of measuring outcomes (pain, function, quality of life, joint preservation) of non arthroplasty surgery with people with early OA? <i>(Reworded)</i>	Outcomes; Measures for surgical priorities should reflect changes in tissue, patient and cost effectiveness
8	What is the best way of delivering	Lots of discussion about what is meant by follow up post surgery.

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ID 11	care short and long term post surgery for early OA? <i>(Slight rewording)</i> <i>Moved up from No 9</i>	Intervention; Technological assistance (using smart phones?) hospital visits and self care? Outcome; Long term progression? Measures for surgical priorities should reflect changes in tissue, patient and cost effectiveness
9 ID 7	In people with early OA is joint replacement appropriate and affective? <i>Moved up from No 10</i>	Outcomes; Measures for surgical priorities should reflect changes in tissue, patient and cost effectiveness
10 ID 6	New priority In people with early OA do surgical procedures that involve cutting and re shaping bone (inc. realignment and osteotomy) work? <i>(Slight rewording)</i>	Outcomes; Measures for surgical priorities should reflect changes in tissue, patient and cost effectiveness

Moved out of the Surgical Top Ten

No 8 ID 1 Is the progression of OA to the point of joint surgery inevitable? <i>(Slight rewording)</i>	Assumption that joint replacement is the surgery implicated but actually this is about more non surgical or other important priority suggest it is considered with 35 No 4 in Other Important Priorities Outcomes; Measures for surgical priorities should reflect changes in tissue, patient and cost effectiveness
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2.2. Non Surgical Priorities (where questions had explicit non surgical interventions)

Rank order	Priority	Context information
1 ID 20	Is regular exercise and physical activity effective at reducing disease progression?	Very real dilemma for many with early OA with differing advice received from health professionals. Intervention; cardiovascular exercise and specific joint exercise Type of research; start off with systematic review (Cochrane review is for hip only at present) study needs to be longer term to capture disease progression, cohort and there is a registry of people with OA (non replacement) that could be used? Population; all people with early OA Outcomes; difficult to measure disease progression? Important to measure harms
2	What are the most effective and cost	Important that this question addresses combinations of non surgical





<p>ID 21</p>	<p>effective non surgical management options, including combinations of treatments to improve outcomes in people with early OA <i>(Slight rewording)</i></p>	<p>options as this replicates real life. Type of research; Clinical trials Intervention; to include complementary and alternative options especially acupuncture, debate about whether to include physiotherapy and hydro therapy. Population; older people with OA and with co-morbidities, we discussed whether this was also relevant for younger people Outcomes; Pain and function (life limiting and impact on daily activities Health related quality of life measures</p>
<p>3 ID 19</p>	<p>For people with early OA, what are the most effective and cost effective exercise programmes for clinical improvement? <i>(Slight rewording)</i></p>	<p>Intervention; cardiovascular exercise and specific joint exercise e.g. muscle strengthening Population; all people with OA especially obese and overweight Outcomes; clinical outcomes and OA specific measures Patient focussed if able</p>
<p>4 ID 14</p>	<p>Is it possible to influence the progression of OA by modifying identifiable risk factors? <i>(Slight rewording)</i></p>	<p>Links to No 6 in Other Important Priorities, what are risk factors and are they modifiable? Progression needs clearer definition? Progression to be measured by X Ray deterioration, symptoms getting worse and function and activity level Risk Factors; genetic, BMI, psychosocial, sport, manual work (farmers and carpet fitters), weather, immobility, diet, muscle strength and injuries</p>
<p>5 ID 15</p>	<p>What options are available for OA self management and how effective are they? <i>(Significant rewording)</i></p>	<p>Definition of self management needed, a course, guidance? It's about ownership of self management once established with effective options presented. Role of enthusiasm of practitioner as well. Intervention; self efficacy, empowerment and agency all concepts that apply here. Outcomes; reduction in hospital or primary care visits, measures of self empowerment, improved quality of life, stable or reduced pain and stable or improved function</p>
<p>6 ID 22</p>	<p>What is the most effective and cost effective physiotherapy for treating people with early OA? <i>(Slight rewording)</i></p>	<p>Important question as majority of people will be signposted to physio (or a subset) in the NHS Interested in these questions; variation, intensity, frequency and specificity Intervention; distinct from exercise and activity - prescribed exercise and manual therapy Outcomes; patient focussed and quality of life</p>
<p>7 ID 29</p>	<p>For people with early OA going to primary care what is the best and most cost effective and appropriate pain relief strategy <i>(Slight rewording)</i></p>	<p>Many people want to avoid taking lots of pain killers and explore alternatives and need a combination of approaches that are personal to their stage of OA, lifestyle etc. This question could be considered as a sub set of Q 2 Intervention; packages of care (so not just analgesia), include</p>





		frequency of treatment. Population; people with identifiable pain symptoms presenting in primary care (not necessarily just GP) Outcomes; relief of or improvement in pain, adherence to strategy
8 ID 27	What new drug treatments are effective in treating people with early OA? <i>(Significant rewording)</i>	Changed the focus of this question on new drug treatments as existing ones not very effective and not suitable for everyone (e.g. NSAIDs). Also remove joint injections as specific question about these (no 11). Intervention; Topical and oral drugs new (or repurposed), use in flares, activity related pain and chronic and enduring pain Type of research; this would be good for a systematic review to begin with Population; Outcomes; benefits (pain reduction) and side and adverse effects (especially cardiovascular and peptic ulcer related)
9 ID 30	What are the best treatments for people with early OA, who also have other musculoskeletal conditions (such as Rheumatoid Arthritis and back pain)?	Not discussed due to lack of time
10 ID 16	When does Body Mass Index (BMI) impact on the progression of early OA? <i>(Slight rewording)</i>	This was discussed in context with No 4 but felt that it was important to keep separate as it is modifiable and worth attention on its own. Group wanted to acknowledge the complex nature of why people have high BMI and especially the mental health, and public health aspects. Removed 'point' and prefer concept of a scale and/or range within which BMI impacts on progression. Type of research; Epidemiology research and probably a cohort approach. Existing data sets in OA and high BMI?

2.3 Other Important Priorities (where questions embraced both surgical and non surgical interventions, other types of interventions or were not intervention questions.)

Rank order	(Reworded) priority	Context information
1 ID 43	Can early OA be slowed down, reversed or cured? <i>(Significant rewording)</i>	Uncertainties about effect of existing or new treatments somewhat open to interpretation regarding potential medical, surgical contexts for use. Type of research; longer term and/or clinical trial (self management adding on to existing treatment) e.g. 1. drug trial 2. surgical e.g. alignment surgery 3. non-pharmacological e.g. weight loss





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		<p>Intervention; Surgical – corrective alignment surgery, Drugs / injection, Brace/ orthotics/ non-pharma e.g. acupuncture, Weight loss</p> <p>Population; early disease: all patients, but may be younger, people who are at risk, early trauma/ sport, overweight, family risk, congenital</p> <p>Outcomes; Validated knee measure or hip e.g. KOOS (Knee Injury and Osteoarthritis Outcome Score), OKS-APQ (Oxford Knee Score - Activity & Participation Questionnaire), Occupational / activity EQ-5D index and VAS PROMS measures (Index = health-related quality of life - mobility, self-care, usual activities, pain/discomfort and anxiety/depression VAS = a self-rating of health-related quality of life, Pain, Imaging (MRI)/ X-Ray – but neither are definitive</p>
2 ID 46	<p>‘What standardised non-surgical integrated pathways for early OA improve patient outcomes and experience?’ (Slight rewording)</p>	<p>Currently no clear pathways or agreed treatment interventions. Diagnosis and treatments vary by Clinical Commissioning Groups from one service (e.g. physiotherapy) through to many services which may or may not be based in a single site/ multidisciplinary team.</p> <p>Type of research; Health care services research/ delivery, Quality of care, Integrated services, Qualitative research</p> <p>Outcomes; PROMS / PIOMS, Qualitative patient experiences and outcomes</p>
3 ID 45	<p>What are the best interventions to keep people with early OA working? (Slight rewording)</p>	<p>Timing is important for clinical diagnosis regarding treatment i.e. stage of disease. Balancing benefit of intervention v failure needs to be on an individual basis. Need to put not one treatment but multiple treatments in context.</p> <p>Type of research; Cohort, Qualitative, Clinical Trial</p> <p>Intervention; Identifying multiple interventions, Education, Complex interventions v no intervention</p> <p>Population; Young people, Working people, People in physical jobs</p> <p>Outcomes; EQ – 5D (Quality of Life survey), Binary work outcomes (in work/ out of work), Sick days, Change of employment/ behaviour / activities</p>
4 ID 35	<p>How can we predict disease progression in people with early OA of the knee/hip?</p>	<p>Type of research; Longitudinal, Cohort, Retrospective/Prospective studies</p> <p>Population; High risk groups e.g. knee injury, occupational groups, Young v older people</p> <p>Outcomes; PROMS/ PIOMS e.g. pain, Imaging depending on study</p>
5 ID 52	<p>What is the best multidisciplinary care model for effective management of OA in primary care? (Slightly reworded)</p>	<p>This question overlaps with Q 2 and Q 7 in non surgical and they could be considered together</p> <p>Types of research; RCT of complex interventions, Systematic review of models, economic analysis of this question could be very useful</p> <p>Population; People presently with OA symptoms in primary care</p> <p>Outcomes; PROMS</p>

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<p>6 ID 40</p>	<p>What factors and patterns of disease are responsible for progression of OA?</p>	<p>Some knowledge but needs to be better, need to personalise approaches. Need development of predictive tool Type of research; Longitudinal, Retrospective, Cohort, Epidemiological EP databases, Big data, Developing a predictive tool – risk factors (e.g. of family history) Population; large! Outcomes; PROMS/PIOMS, X-Ray/MRI</p>
<p>7 ID 34</p>	<p>Is timing of OA diagnosis important for disease progression and applying interventions/treatments? <i>(Slight rewording)</i></p>	<p>Implied need for exploration of intervention v non-intervention in this question. Type of research; Cohort, Clinical practice, Clinical trial (if intervention) Population; Obese, Early symptoms, Those at high risk Intervention; Would this be part of an education programme aimed at individuals/ high risk groups i.e. what to do / self-management/ awareness</p>
<p>8 ID 32</p>	<p>In people with early symptoms of OA, which diagnostic tests should be used?</p>	<p>Lack of standardised diagnostic tests or interpretation / reporting of tests (e.g. X-Rays). GPs not currently able to diagnose accurately. Type of research; Evidence synthesis of diagnostic tests Population; Range of health professionals from primary to secondary care Outcomes; Sensitivity and specificity of imaging (X-Rays/ MRI), X – Ray & MRI reporting</p>
<p>9 ID 41</p>	<p>What tests are useful to monitor the progress of OA?</p>	<p>Lack of standardisation e.g. radiograph, GPs don't have ability to request skyline view of knee X-Rays which tracks changing clinical symptoms Type of research; Longitudinal study, Quantitative Population; Range of health professionals primary – secondary care including radiologists/imaging Intervention; Standardisation of imaging Outcomes; PROM scores, Inflammation markers, Reduction of pain/swelling, Oxford Hip and Knee scores, X-Ray – accuracy</p>
<p>10 ID 37</p>	<p>Does the amount or type of joint abnormality seen in the early stages of OA have impact on outcome</p>	<p>Not discussed as lack of time</p>





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2.4 Appeal and reflection on group work



An important part of any research priority setting process is a consistent process and appeal mechanism, whereby people can challenge the decision making. The three working groups joined together in the afternoon to review each other's work and hear about any proposed changes to the Top Tens as a result of discussion. The Surgical group proposed 1 merger which gave them one extra space in their top ten list so No. 11 was brought into the list. All groups brought forward research priorities that they felt had been significantly changed in wording but not meaning and discussed and voted on these. Energy was flagging in the room but there was still spirited debate about the merits of rewording and emphasis.



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3. What next for the priorities?

Participants finally shared their ideas and networks for getting the priorities to the attention of relevant research funders and stimulating interest in the priorities in the research community. The following ideas were contributed:

- Report from the workshop with the process, original priorities and changes made
- Steering Group to reflect on (telephone or email) the final Top Ten for each area and in relation to each other
- Suggestions made for research funders to be alerted to the process and outcomes (Arthritis Research UK, NETSCC etc) via a co-ordinated and timed press release and associated material - so an **embargo agreed within the group until this time is agreed.**
- Champions for each set of priorities so that they can be shared with relevant networks (SG members primarily)
- Consider a broad landscape for press release; Saga magazine, relevant industry organisations, Cochrane (for priorities that need an evidence review), Professional Football Association, BBC Radio 4 Inside Health (Philip Conaghan was talking about OA recently, maybe follow up?), Chris Witty (new head of National Institute of Health Research), George Freeman DOH etc
- Approach social media bloggers for example MSK Elf (Tracey Howe)
<http://www.nationalelfservice.net/musculoskeletal/>
- Don't forget the devolved stakeholders, in Wales, Scotland and Northern Ireland
- Consider a launch (funders) event, Andrew Price suggested ARUK might want to host this - Sally to find out from JLA how much other PSPs spend on launch events and feed back to SG
- Work with Oxford BRC and Oxford University Press and Medical Sciences Division may help
- A paper for a journal that incorporates the two PSP results

4. Workshop evaluation and reflection

14 participants completed an evaluation form directly or very soon after the workshop. Respondents were equally split between patients and carers and health professionals. The ratings of the elements of the workshop were high, with people either satisfied or very satisfied with administrative aspects of the workshop, facilitation and workshop content.

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There was a section of the evaluation form for people to express their own views about the day and the following were noted:

Generally positive:

- It is very good to find a patient voice heard and taken account of in this work (patient)
- Excellent well structured format that allowed for participants from a variety of stakeholders (patient)

More negative:

- The only downside was the temperature in the room far too hot (patient)
- The lack of patient representation in one small group (health professional)

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Appendix 1

WORKSHOP PROGRAMME

09.45	Registration and refreshments
10.00	Introductory exercise and overview of workshop
10.20	Background to the Early OA Hip and Knee Priority Setting Partnership
10.45	Questions and discussion - setting up small groups to work on research priorities
11.20	Small group work
12.45	Lunch break
13.30	Small groups re convene
14.15	Group presentations
15.15	Tea break
15.40	Next steps and how to raise the profile of the research questions – discussion
16.00	Workshop ends

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Appendix 2

WORKSHOP PARTICIPANTS LIST

Supporters	Sandra Regan	Jiyang Li	
Facilitators	Sally Crowe	Tracey Howe	Maryrose Tarpey
Observers	Sam Larkin, NETSCC	Kathy Tier, NETSCC	
Participants	Tracey Barton	Andrew Price	Tony Andrade
	Margaret Booth	David Beard	Jacqueline Buckle
	Mark Bovey	Bob Green	John Dickson
	Chris Downey	Will Jackson	Colin Esler
	Jennie Kramer	Paul Landon	Elspeth Wise
	Jan Lawrence	Hilary Noakes	Emma Morley
	Fraser Old	Ross Pritchard	Lesley Pattenden
	Fiona Watt	Jenny Watson	

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