

James Lind Alliance Priority Setting Partnership on Early Osteoarthritis of

Introduction

The James Lind Alliance (JLA) brings together patients, carers and health and social care professionals in Priority Setting Partnerships to agree what research matters most in given disease areas.

Osteoarthritis (OA) is a condition that causes the joints to become painful and stiff. It is the most common type of arthritis in the UK. The severity of symptoms can vary greatly from person to person, and between different affected joints.

This partnership is addressing research needs for any stage of the disease or treatment, except hip and knee replacement surgery which was addressed in a previous partnership.

By taking part you will help to identify unanswered questions about diagnosing and treating osteoarthritis of the hip and knee at a time when new technologies and approaches are becoming available.

The first survey to collect questions was open in March/ April 2015. We had 217 responses, which gave us 1168 questions. We have reviewed all the questions, combined those that are similar, and removed those that are out of scope and those that have already been answered. We are left with 52 questions which we have grouped according to whether they are about surgical treatment, non-surgical treatment, or are other important questions.

This survey asks you to consider how important these questions are to you. We will then review the results in order to identify the top 30 most important questions. A Final Workshop will then work with these to ensure that the questions are as research-friendly as possible.

More information is available on the partnership website (see end of survey for link).

This is your chance to make your views known so please complete this survey if you: have been diagnosed with hip or knee osteoarthritis, think you might have it, or might be at risk of having it; are a carer of someone with it; or are a health, social care, alternative practitioner or professional caring for people with hip and knee osteoarthritis.

By participating in this survey you are agreeing to allow us to publish the questions you identify in the UK Database of Uncertainties about the Effects of Treatments (UK DUETs – www.library.nhs.uk/duets).

Your name and details will not be published.

Please complete the survey on the following pages.

James Lind Alliance Priority Setting Partnership on Early Osteoarthritis of

Section 1 - Surgical Questions

There are 13 questions relating to surgical treatment. Please look at each in turn and select your answer. It will be most useful if you can choose a level of importance to you; however, we have provided the "no opinion" option in case you need it.

* Here are the first 7 questions:

	Not a priority	Low priority	Medium priority	High priority	Very high priority	No opinion
1. Is the progression of osteoarthritis to the point of requiring surgery inevitable?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Can surgical treatment prevent osteoarthritis or affect its progression?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Assuming surgery for osteoarthritis is necessary, does its timing affect the outcome?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. What pre-operative factors can predict the outcome of surgery in people with early osteoarthritis?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. In people with early osteoarthritis do surgical procedures that involve cutting and reshaping the bone (i.e. realignment and osteotomy) work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. In people with early osteoarthritis, is joint replacement treatment appropriate and effective?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* Here are the final 6 surgical questions:

	Not a priority	Low priority	Medium priority	High priority	Very high priority	No opinion
8. In people with early osteoarthritis, does keyhole surgery to clean out the joint (arthroscopy) work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. What are the best surgical treatments for younger people (< 55 years) with early osteoarthritis?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. What is the best way of measuring and keeping track of the outcome of surgery in people with early osteoarthritis?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. What is the best way of following up people who have had surgery for early osteoarthritis?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. What is the best way (content and structure) of delivering rehabilitation (physiotherapy) after surgery?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Taking cost into account, what is the most effective treatment between surgical and non-surgical?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

James Lind Alliance Priority Setting Partnership on Early Osteoarthritis of

Section 2 - Non-surgical questions

There are 18 questions relating to non-surgical treatment. Please look at each in turn and select your answer. As before, it will be most useful if you can choose a level of importance to you; however, we have provided the "no opinion" option in case you need it.

* Here are the first 9 non-surgical questions:

	Not a priority	Low priority	Medium priority	High priority	Very high priority	No opinion
14. Is it possible to influence the progression of OA by changing identifiable risk factors?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. What is the best way to self-manage and monitor my OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. At what point does Body Mass Index impact on the progression of early OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. What is the best dietary advice to reduce symptoms/progression of early OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Are commonly available over the counter (otc) supplements (such as glucosamine or fish oil) effective for relieving symptoms of early OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. For people with early OA, what are the best exercise requirements (frequency, intensity, type and duration) necessary for clinical improvement?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Is regular exercise and physical activity effective at reducing disease progression in early OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. What is the best non-surgical treatment (e.g. physiotherapy, hydrotherapy) to improve outcomes in people with early OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. What are the most effective physiotherapy treatments for treating early OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

James Lind Alliance Priority Setting Partnership on Early Osteoarthritis of

* Here are the final 9 non-surgical questions:

	Not a priority	Low priority	Medium priority	High priority	Very high priority	No opinion
23. What orthoses/supports will help early OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Is acupuncture effective in relation to conventional medical treatments for early OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Which alternative therapies provide most benefit for people with OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Can alternative therapies improve clinical outcomes for OA when used together with conventional approaches, and who would benefit most?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. What drugs (including joint injections or new treatments) are effective in treating people with early OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. When and how should joint injections be used in early OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. For people with early OA going to their GP for painkillers what is the best pain relief strategy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. What are the best treatments for people with early OA, who also have other musculoskeletal conditions (such as Rheumatoid Arthritis and back pain)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. What is the best way of making sure that people correctly follow non-surgical treatment advice (compliance)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section 3 - Other important questions

There are 21 other important questions. Please look at each in turn and select your answer. As before, it will be most useful if you can choose a level of importance to you; however, we have provided the "no opinion" option in case you need it.

James Lind Alliance Priority Setting Partnership on Early Osteoarthritis of

*** Here are the first 10 other important questions:**

	Not a priority	Low priority	Medium priority	High priority	Very high priority	No opinion
32. In people with early symptoms of OA, which diagnostic tests should be used?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. In people with early symptoms of OA, what is the sensitivity and/or specificity of the tests used to detect OA (i.e. how certain can we be)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35. How can we predict disease progression in people with osteoarthritis of the knee/hip?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36. What is the relationship between women experiencing their menopause (and treatment for it e.g. HRT) and early OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37. Does the amount or type of joint abnormality seen in the early stages of OA have impact on outcome?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38. How do factors such as general wear and tear and injuries affect the development of OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
39. Is it possible to quantify the individual risk of developing OA at any particular joint site?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
40. What factors and patterns of disease are responsible for progression of OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
41. What tests are useful to monitor the progress of OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

James Lind Alliance Priority Setting Partnership on Early Osteoarthritis of

Not a priority

Low priority

Medium priority

High priority

Very high priority

No opinion

*** Here are the final 11 other important questions:**

	Not a priority	Low priority	Medium priority	High priority	Very high priority	No opinion
42. In people with signs of early OA, how can we predict (including tests) severity of pain, disability and structural progression?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43. Are there treatments that can slow, arrest or reverse early OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44. What is the likelihood of the disease spreading to other joints?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
45. What is the best treatment or intervention to keep people with early OA working?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46. What non-surgical services for early OA should be improved and how?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47. Is OA an inherited condition and what are the risks to my children/family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
48. What is the best way to deliver information and advice on surgical and non-surgical treatments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
49. How effective is information and advice about surgical and non-surgical treatments for early OA?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
50. Are NICE (National Institute for Health and Care Excellence) guidelines for management of OA accessed and followed sufficiently in primary care and in secondary care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
51. What are the best decision making processes for people with early OA (e.g. using the Patient Pathway, Shared Decision Making tool), especially when the decision involves surgery?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52. Is a multidisciplinary care model (physiotherapist, GPs, practice nurses, pharmacy) effective for managing OA in primary care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section 4 - About you

Thank you for answering all the questions so far. We just have a few more, to help us to understand who you are.

*Which of these best describes you?

- I have been diagnosed with early osteoarthritis (of hip/knee)
- I think I might have/ be at risk of osteoarthritis (of hip/knee)
- I am a carer, parent, or relative, of a person with osteoarthritis (of hip/knee)
- I am a carer, parent, or relative, of someone who might have/ be at risk of osteoarthritis (of hip/knee)
- I am a health care professional
- I am part of an organisation representing and/ or supporting people with osteoarthritis

You only need to answer this question if you are answering as a person with osteoarthritis (hip/knee) or a carer, parent or relative. Are you [or the person you support] being treated:

- In the community (e.g. by your GP, alternative practitioner)
- At a hospital
- Are you/they managing your/their own condition?
- Or a combination of the above (please specify in the box below):
- Prefer not to say

If a combination, please specify

You only need to answer this question if you are answering as a person with osteoarthritis (hip/knee) or a carer, parent or relative. At what age did you [or the person you support] first experience symptoms of osteoarthritis of hip or knee?

You only need to answer this question if you are answering as a health care professional or support worker. In which area do you primarily work?

- Community
- Hospital
- Intermediate Care
- Support group/ charity

You only need to answer this question if you are answering as a health care professional or support worker. What is your profession?

- Acupuncturist
- Chiropractor
- General Practitioner
- Health Service Manager
- Health Support Worker
- Health Visitor
- Nurse
- Occupational Health practitioner
- Occupational Therapist
- Orthopaedic Surgeon
- Massage therapist
- Prosthetist or Orthotist
- Osteopath
- Paediatric Surgeon
- Paediatric Nurse
- Personal Trainer
- Physiotherapist
- Pharmacist
- Podiatrist
- Primary Care Practice Nurse with OA specialism or Health & Exercise remit
- Radiographer
- Radiologist
- Rheumatologist
- Social Worker
- Sports therapist
- Sport and Exercise Medicine consultant

Other (please specify)

*** What is your gender?**

- Male
- Female
- Prefer not to say

*** What is your ethnic group?**

- Asian/ Asian British
- Black/ African/ Caribbean/ Black British
- Mixed/ multiple ethnicity
- White
- Prefer not to say

Other (please specify)

How old are you? Please enter your age in numbers (e.g. 43):

Please tell us the first half of your home postcode (e.g. OX11)

And finally....

Next steps

If you would like to be kept informed about the next stages and final results, please provide details for your preferred method of contact - email or postal address - together with your name, which will be kept confidential and securely, in accordance with the Data Protection Act.

James Lind Alliance Priority Setting Partnership on Early Osteoarthritis of

Thank you for completing this survey - please click **DONE** to exit

Here are our contact details:

James Lind Alliance Project Manager
NIHR Oxford Biomedical Research Centre,
Churchill Hospital, Joint Research Office,
Block 60, Headington, Oxford, OX3 7LE.

Tel/ voicemail: 01865 223298

Email: sandra.regan@ouh.nhs.uk

Website: <http://www.ouh.nhs.uk/research/patients/prioritysettingpartnerships/earlyosteoarthritis/default.aspx>