Young Adults with Hip Pain (YAHP) Priority Setting Partnership

PROTOCOL 18/07/2025 Version 1

1. Purpose of the PSP and background

The purpose of this protocol is to clearly set out the aims, objectives and commitments of the Young Adults with Hip Pain (YAHP) Priority Setting Partnership (PSP) in line with James Lind Alliance (JLA) principles. The Protocol is a JLA requirement and will be published on the PSP's page of the JLA website. The Steering Group will review the Protocol regularly and any updated version will be sent to the JLA.

The JLA is a non-profit making initiative, established in 2004. It brings patients, carers and clinicians together in PSPs. These PSPs identify and prioritise the evidence uncertainties, or 'unanswered questions', that they agree are the most important for research in their topic area. Traditionally PSPs have focused on uncertainties about the effects of treatments, but some PSPs have chosen to broaden their scope beyond that. The aim of a PSP is to help ensure that those who fund health research are aware of what really matters to patients, carers and clinicians. The National Institute for Health and Care Research (NIHR – www.nihr.ac.uk) coordinates the infrastructure of the JLA to oversee the processes for PSPs, based at the NIHR Coordinating Centre (NIHRCC), University of Southampton.

Hip pain in young adults is a common presentation estimated to affect between 12-25% of the general population (1,2) with an estimated annual incidence of 0.44% in individuals aged 15-60 (3). Unlike the widely recognised hip problems in older adults (osteoarthritis), or in children (slipped upper femoral epiphysis or Perthes disease), the pathologies causing hip pain in young adults often fall into a diagnostic and/or treatment dilemma which remains a cause for concern (4). Patients are often misdiagnosed, have delays in their treatment, but this can also have a significant effect on their quality of life and can pose an enormous economic burden on the NHS and the wider UK economy (5).

Furthermore, some of these pathologies in young adults, if left untreated can lead to degenerative change in the hip joint adding to the already significant burden (6–8). Hip preservation which deals with these pathologies has therefore grown rapidly as a sub-speciality of hip surgery over the last three decades and most countries around the world including the UK have developed tertiary units looking after these patients to ensure a prompt diagnosis and appropriate management for this cohort (9,10). The progression of this subspecialty has been significantly enhanced by the adoption of modern minimally invasive techniques, particularly hip arthroscopy (11–13) for impingement and periacetabular osteotomy for hip dysplasia. These advancements have allowed for more precise management of various intra and extra-articular hip pathologies, including femoroacetabular impingement, acetabular dysplasia, Perthe's disease, sequelae of slipped capital femoral epiphysis, external snapping hip, subspinous impingement and many more with reduced morbidity compared to traditional open surgery.

YAHP encompass a wide range of differentials, often making accurate diagnosis challenging (4). These pathologies can be categorised in various ways, such as by anatomical location in terms of the layers of the hip, or site of pathology (anterior, lateral, or posterior) or by distinguishing between intra and extra-articular pathologies. (14–16).

YAHP have a unique set of challenges compared with older adults with osteoarthritis. Pain/chronic pain in this cohort not only serves as a significant health burden but also exacerbates the negative effects on their lives. This includes an impact on physical and mental well-being, work and career, leisure activities, caring/parental responsibilities, as well as their ability to perform activities of daily living (ADLs).

Misdiagnosis within the NHS has significant financial implications. On average, YAHP saw four different healthcare providers, underwent 3.4 imaging tests, and had 3.1 treatments before receiving a correct diagnosis, with an average delay of 32 months (5). In another study it reported how in primary care 78.7% of referrals of hip pain to a secondary unit had no diagnosis but once reviewed at the secondary unit, 97.3% were able to be diagnosed (9).With better education and research in this field it will be possible to improve these inefficiencies and ultimately improve patients' lives.

This proposal is well aligned to the **National Health Service (NHS) Long Term Plan** which emphasises prevention to reduce the impact of disease, including musculoskeletal disorders, which account for 10.5% of all workplace sickness in the UK (17,18). Furthermore, it is also highlighted that there is a need to increase visibility of diseases for those with unmet health needs and to expand innovation to improve productivity and patient outcomes. The upcoming NHS ten-year plan additionally has a focus on hospital to community care, analogue to digital and sickness to prevention. Hip Preservation Surgery as a subspecialty is well aligned to address these issues with innovative techniques being developed (11,19). Further funding and research in this arena especially with a focus on prevention can lead to a healthy lifestyle in young adults and reduction in the number of patients requiring surgical intervention thereby reducing the economic impact on the NHS.

2. Aims, objectives and scope of the PSP

The aim of the YAHP PSP is to identify the unanswered questions about young adults with hip pain from a patient, carer and clinical perspectives and then prioritise those that patients, carers and clinicians agree are the most important for research to address.

The objectives of the PSP are to:

- work with patients, carers and clinicians to identify uncertainties about but not limited to:
    - Early Diagnosis - Establishing clear pathways for patients with hip pain to ensure consistent and comprehensive investigations. This would include clinical findings, imaging and other diagnostic tests with the aim to diagnose these pathologies earlier.
    - Conservative Management – Researching evidence-based physiotherapy protocols and/or role of intra and extra-articular injection therapy for each pathology
    - Prehabilitation prior to surgery – A recent protocol for PREHAB in FAI has been designed recently with the senior author (20)
    - Investigations – What imaging would be most beneficial taking into account the rotational profile of the lower limb and safest such as high-resolution CT and MRI. CT imaging may not be safe especially in a younger cohort due to the risk of radiation.
    - Intervention in appropriate cases – Establishing a comprehensive guideline for the non-surgical and surgical management for each pathology
    - Postop management pathways – Establishing evidence-based post operative rehabilitation protocols similar to PREHAB

- Outcomes of relevance – Assessing the relevance of validated outcome scores as for example the iHOT-12, HoS and HAGOS.
- Impact of YAHP on careers – specifically military or athletic careers
- Education of YAHP pathologies – to both clinicians and patients as little is known outside of orthopaedics about these conditions
- Inequalities of healthcare – Understanding if there are other reasons for delayed presentation for example by limited resources in parts of the country for a YAHP specialist
- The impact of technology – Will AI interventions help with decision making, precision surgery with robotics, faster more accurate interpretation of radiological scans.

- to agree by consensus a prioritised list of those uncertainties for research.
- to publicise the results of the PSP and process.
- to take the results to research commissioning bodies to be considered for funding.

The scope of the Young Adults with Hip Pain PSP is defined as:

Patient Population:

- This PSP will be designed to address young adults with musculoskeletal hip pathology, specifically targeting individuals between the ages of ages 16 to 55 years. The PSP will focus on all the musculoskeletal causes of hip pain.

Inclusion Criteria:

All non-acute musculoskeletal pathologies related to hip/groin pain which is not limited to the below:

1. Extra-Articular Pathologies:
   a. Muscles: Gluteus minimus and medius tendinopathy and/or tears, hamstring tendonitis and tears, adductor tendonitis and tears.
   b. Nerves: Deep gluteal syndrome, Obturator nerve entrapment, lateral femoral cutaneous nerve (LFCN) entrapment
   c. Tendons: Snapping hip (iliotibial band or iliopsoas)
   d. Bursa: Trochanteric bursitis
   e. Ligaments: Inguinal ligament strain or tear

2. Intra-Articular Pathologies:
   - Bones: Femoroacetabular Impingement (FAI), avascular necrosis (AVN), developmental dysplasia of the hip (DDH), Perthes disease, slipped capital femoral epiphysis, early degenerative changes.
   - Soft Tissues: Labral tears, chondral defects, ligamentum teres tears

The PSP will exclude from its scope questions about:

- Acute musculoskeletal hip pathology (fractures, inflammatory or infective arthropathies)
- Septic Arthritis
- Tumours

- First time presentation of osteoarthritis / moderate to severe osteoarthritic
- Referred pain from the spine
- Non musculoskeletal pathology
- Age less than 16 and above 55

These exclusions are based around the fact that acute arthropathies and tumours have a different treatment guideline with a different goal. This is in keeping generally with the consensus of the International Hip Related Pain Research Network. Osteoarthritis is typically a pathology that affects the elderly patients is well documented about its pathological nature.

The Steering Group is responsible for discussing what implications the scope of the PSP will have for the evidence-checking stage of the process. Resources and expertise will be put in place to do this evidence checking.

3. The Steering Group

The Steering Group includes membership of patients and carers and clinicians[1], as individuals or representatives from a relevant group.

The YAHP PSP will be led and managed by a Steering Group involving the following:

Project leads:
Prof Vikas Khanduja, Consultant Trauma & Orthopaedic & Affiliate Associate Professor, Addenbrooke's -Cambridge University Hospital NHS Foundation Trust, University of Cambridge & University of Ghent

Prof Ajay Malviya, Consultant Trauma & Orthopaedic, Northumbria Healthcare NHS Foundation Trust and University of Sunderland

Project Co-ordinator & Information Specialist:
Mr Ibrahim Haq, Trauma & Orthopaedic Specialist Registrar East Midlands and MPhil at University of Cambridge

James Lind Alliance Adviser and Chair of the Steering Group:
Dr Nahid Ahmed, James Lind Alliance

Clinical Representatives:
Prof Tim Board, Consultant Orthopaedic Surgeon, Wrightington Hospital- Visiting Professor at University of Leeds, Honorary Senior Lecturer at University of Manchester and Honorary Professor at Salford University.

Prof Rowena Johnson, Consultant Musculoskeletal Radiologist

Mr Wael Dandachli, Consultant Trauma & Orthopaedic, University Hospitals Coventry & Warwickshire

Mr Anuj Punnoose, Clinical Specialist Physiotherapist & NIHR Doctoral fellow, Addenbrookes Hospital, Cambridge

Ms Holly Soper-Doyle, Clinical Lead Young Adult Hip Advanced Practice Physio-NHS Honorary Clinical Lecturer UCL

[1] In some cases, it has been suggested that researchers are represented on the Steering Group, to advise on the shaping of research questions. However, 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.

Ms Dora Papadopoulou, Consultant Sports and Exercise Medicine & Orthopaedic Surgeon

Ms Malgorzata Garner, Surgical Care Practitioner, Addenbrooke's - Cambridge University Hospital NHS Foundation Trust.

Dr Kulothungan Suntharalingam, Consultant Sports & General Practitioner

Mr Barry Davison, Senior Specialist Physiotherapist, Northumbria Healthcare NHS Foundation Trust

Mr Ignatius Liew, Trauma and Orthopaedic Registrar

Patient and carer representatives:
Sneh Shah (GP registrar)

Wioleta Jonecko (Physiotherapist)

The Steering Group will agree the resources, including time and expertise that they will be able to contribute to each stage of the process, with input and advice from the JLA.

4. Partners

Organisations and individuals will be invited to be involved with the PSP as partners. Partners are organisations or groups who will commit to supporting the PSP, promoting the process and encouraging their represented groups or members to participate. Organisations which can reach and advocate for these groups will be invited to become involved in the PSP. Partners represent the following groups:

- Young adults who have had experienced musculoskeletal hip pain
- Carers of young adults who have had musculoskeletal hip pain
- Health and social care professionals - with experience of young adults with hip pain
- Representative from British Hip Society
- Organisations such as Non Arthroplasty Hip Register (NAHR), National Institute of Health Research (NIHR), Versus Arthritis, Connect Health, UK Physiotherapy Network, UK Hip Dysplasia Network.

Exclusion criteria

Some organisations may be judged by the JLA or the Steering Group to have conflicts of interest. These may be perceived to potentially cause unacceptable bias as a member of the Steering Group. 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.

5. The methods the PSP will use

This section describes a schedule of proposed steps through which the PSP aims to meet its objectives. The process is iterative and dependent on the active participation and contribution of different groups. The methods used in any step will be agreed through consultation between the Steering Group members, guided by the PSP's aims and objectives. More details of the method are in the Guidebook section of the JLA website at www.jla.nihr.ac.uk where examples of the work of other JLA PSPs can be seen.

Step 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. Potential partners will be contacted and informed of the establishment and aims of the YAHP PSP.

Step 2: Awareness raising

PSPs will need to raise awareness of their proposed activity among their patient, carer and clinician communities, in order to secure support and participation. Depending on budget, this may be done by a face-to-face meeting, or there may be other ways in which the process can be launched, e.g. via social media. It may be carried out as part of steps 1 and/or 3. The Steering Group should advise on when to do this. Awareness raising has several key objectives:

- to present the proposed plan for the PSP
- to generate support for the process
- to encourage participation in the process
- to initiate discussion, answer questions and address concerns.

Step 3: Identifying evidence uncertainties

The YAHP PSP will carry out a consultation to gather uncertainties from patients, carers and clinicians. A period of 1 year (June 2025 – June 2026) will be given to complete this exercise (which may be revised by the Steering Group if required).

The YAHP PSP recognises that the following groups may require additional consideration.

The Steering Group will use the following methods to reach the target groups

- Online surveys - available on social media, via email and specialty websites
- Paper surveys - clinics / scientific meetings
- Target audiences via BHS and BOA national meetings to include adult and paediatric surgeons
- Target audiences via social media e.g. X, LinkedIn and Instagram
- Dedicated Website - YAHP PSP

Existing sources of evidence uncertainties may also be searched. 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.

Step 4: Refining questions and uncertainties

The consultation process will produce 'raw' questions and comments indicating patients', carers' and clinicians' areas of uncertainty. These raw questions will be categorised and refined by Ibrahim Haq into summary questions which are clear, addressable by research, and understandable to all. Similar or duplicate questions will be combined where appropriate. Out-of-scope and 'answered' submissions will be compiled separately. The Steering Group will have oversight of this process to ensure that the raw data is being interpreted appropriately and that the summary questions are being worded in a way that is understandable to all audiences. The JLA Adviser will observe to ensure accountability and transparency.

This will result in a long list of in-scope summary questions. These are not research questions and to try and word them as such may make them too technical for a non-research audience. They will be framed as researchable questions that capture the themes and topics that people have suggested.

The summary questions will then be checked against evidence to determine whether they have already been answered by research. This will be done by Ibrahiim Haq. The PSP will complete the JLA Question Verification Form, which clearly describes the process used to verify the uncertainty of the questions, before starting prioritisation. The Question Verification Form includes details of the types and sources of evidence used to check uncertainty. The Question Verification Form should be published on the JLA website as soon as it has been agreed to enable researchers and other stakeholders to understand how the PSP has decided that its questions are unanswered, and any limitations of this.

Questions that are not adequately addressed by previous research will be collated and recorded on a standard JLA template by Ibrahim Haq. This will show the checking undertaken to make sure that the uncertainties have not already been answered. The data should be submitted to the JLA for publication on its website on completion of the priority setting exercise, taking into account any changes made at the final workshop, in order to ensure that PSP results are publicly available.

The Steering Group will also consider how it will deal with submitted questions that have been answered, and questions that are out of scope.

Step 5: Prioritisation – interim and final stages

The aim of the final stage of the priority setting process is to prioritise through consensus the identified uncertainties about YAHP. This will involve input from patients, carers and clinicians. The JLA encourages PSPs to involve as wide a range of people as possible, including those who did and did not contribute to the first consultation. There are usually two stages of prioritisation.

1. Interim prioritisation is the stage where the long list of questions is reduced to a shorter list that can be taken to the final priority setting workshop. This is aimed at a wide audience and is done using similar methods to the first consultation. With the JLA's guidance, the Steering Group will agree the method and consider how best to reach and engage patients, carers and clinicians in the process. The most highly ranked questions (around 25) will be taken to a final priority setting workshop. Where the interim prioritisation does not produce a clear ranking or cut off point, the Steering Group will decide which questions are taken forwards to the final prioritisation.

2. The final priority setting stage is generally a one-day workshop facilitated by the JLA. With guidance from the JLA and input from the Steering Group, up to 30 patients, carers and clinicians will be recruited to participate in a day of discussion and ranking, to determine the top 10 questions for research. All participants will declare their interests. The Steering Group will advise on any adaptations needed to ensure that the process is inclusive and accessible.

6. Dissemination of results

The Steering Group will identify audiences with which it wants to engage when disseminating the results of the priority setting process, such as researchers, funders and the patient and clinical communities. They will need to determine how best to communicate the results and who will take responsibility for this. Previous PSPs' outputs have included academic papers, lay reports, infographics, conference presentations and videos for social media.

It should be noted that the priorities are not worded as research questions. The Steering Group should discuss how they will work with researchers and funders to establish how to address the priorities and to work out what the research questions are that will address the issues that people have prioritised. The dissemination of the results of the PSP will be led by Ibrahim Haq.

The JLA encourages PSPs to report back about any activities that have come about because of the PSP, including funded research. Please send any details to jla@soton.ac.uk.

7. Agreement of the Steering Group

The YAHP PSP Steering Group agreed the content and direction of this Protocol on the 18th July 2025.

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