Features



James Lind Alliance Priority Setting Partnership - 'Top 10' research priorities in foot and ankle surgery

Jitendra Mangwani on behalf of the Foot and Ankle JLA PSP Steering Group



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JM thanks members of the steering group, survey and workshop participants.

esearch prioritisation necessitates involving both patient and clinical stakeholders, as well as considering questions of feasibility. Traditionally, research on the effects of various treatments has overlooked the shared priorities of patients, carers and clinicians1. One approach successfully deployed in healthcare is that of the James Lind Alliance (JLA), a non-profit-making initiative partly funded by the National Institute for Health Research (NIHR). JLA Priority Setting Partnerships (PSPs) enable clinicians, patients and carers to work together to identify and prioritise the questions they would like to address through research2.

PSPs are typically supported by multiple stakeholders, often including funders, patient advocacy groups and research charities with an aim to address the mismatch between what researchers choose to research, and what patients, carers and healthcare professionals actually want to know. PSPs thus ensure that those most affected by a condition are involved in prioritising research³. There is evidence that PSPs can have a great benefit on patient care, clinical practice of clinicians and organisational culture2.

History

The JLA is named after James Lind, the Scottish naval surgeon who discovered the cure for scurvy by employing early trial design theories. The James Lind Alliance (JLA) was established in 2004 by Sir Iain Chalmers (co-founder of the Cochrane Collaboration), Dr John Scadding (then Dean of the Royal Society of

Foot and Ankle JLA PSP Steering Group

Patient and carer representatives:

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Clinical representatives: Brigitte Scammell, Patricia Allen, Mark B Davies, Noelene Davey, Rebecca Kearney, Lyndon Mason, Stephen Lines, Nick Gallogly, Veena Patel

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Medicine) and Sir Nick Partridge (former Chair of INVOLVE). The original launch and aims of the PSPs were described in an article in The Lancet⁴. The JLA's evolution during the years 2003-2013 (as part of the James Lind Initiative) is described in an article in the Journal of the Royal Society of Medicine.

The first PSP was conducted in Asthma in 2007⁵ and since then the initiative has gone from strength to strength; with over 100 PSPs registered on the JLA website www.jla.nihr. ac.uk/priority-setting-partnerships.

Principles

The JLA have a well-established process (www. jla.nihr.ac.uk/jla-guidebook) which is founded on uncertainties. "Patients and the public have a right to expect that research funders, researchers and health professionals will identify uncertainties about whether treatments or other interventions are doing more harm than good or whether one treatment is better than another, and should expect them to organise the research needed to reduce the most important of these uncertainties." More details can be found in the

JLA Handbook⁶. The JLA PSP process sets out to establish all relevant research questions in a disease area and narrows these down to a 'Top 10 List' used to prioritise research questions for future work/funding.

In order to start a PSP, the JLA should be contacted centrally in the first instance at **jla@southampton.ac.uk** to complete a readiness questionnaire. Gathering the right team is one of the first tasks; a guide to the roles is shown in Table 1.

Methodology

James Lind Alliance methodology is a well-defined process and usually follows a pathway which includes; establishing a steering group with face to face or online meetings; an online/paper survey to gather uncertainties; organisation of responses and checking against up to date published evidence; interim priority setting to shorten the list of questions; a final workshop with a mixture of small and whole group discussions where all participants are present in person or online. The workshop brings together representatives from both the professional and lay communities who jointly refine the final top ten priorities. The JLA PSP process is outlined in Figure 1.

A PSP usually takes between 12-18 months to complete; however abbreviated processes have been published in the literature to condense this time, whilst adhering to JLA principles⁷. In recent years, the face to face elements of the PSP have been adapted to allow for remote options; keeping participants safe during the pandemic⁷ and in those with high infection risk⁸.

Following on from the process in Figure 1, the key is to disseminate and publish results of the priority setting exercise. This increases exposure of the priorities to potential funders and research teams; as well as feeding back to patients, carers, charities and health care professionals.

Establish steering group and roles	
Recruit partners/ stake holders	
Distribute survey to collect questions/ uncertainities	
Data analysis and checking	
Prioritisation Interim shortlisting Final workshop	
Figure 1: JLA PSP process.	

Role	Example Tasks
JLA Advisor	Chair meetings. Provide ad hoc support in use of the Guidebook.
	 Provide support for data management process and interim priority setting exercise. Chair final priority setting workshop, with at least 2 other JLA Advisers to facilitate small group work.
PSP Lead	Champion the PSP.
	Ensure it is successfully promoted, completed and disseminated to funders.
PSP Co-ordinator	 Write and follow-up on action notes. Manage communications with the Steering Group, stakeholders and the community. Prepare a website. Communicate via Twitter. Develop the questions/survey and post online. Organise the priority setting workshop.
Information Specialist	 Organise the raw data from the initial PSP survey. Examine each submitted 'uncertainty' and allocate into categories with guidance from Steering Group. Liaise with the PSP Steering Group on work to identify relevant systematic reviews and guidelines, and any other relevant sources of evidence. Check the in-scope formatted questions against the evidence base. Prepare a long list of verified uncertainties for interim prioritisation.

Table 1: Guide to JLA PSP roles.

JLA PSPs in Trauma and Orthopaedics

In trauma and orthopaedics, there have been 13 registered PSPs so far; documented in Table 2.

British Orthopaedic Foot and Ankle Society (BOFAS) JLA PSP

BOFAS JLA PSP was conducted as part of the British Orthopaedic Association (BOA) research committee initiative. Foot and ankle conditions pose a particular challenge to the patients and their treating professionals due to a wide variety of conditions and

the lack of high quality published evidence. This, in turn, introduces variation in clinical practice and indeed patient outcomes.

The PSP was conducted in accordance with guidance issued by the JLA and overseen by an independent JLA adviser. BOFAS JLA started in September 2019. The initial survey was launched at the BOFAS annual meeting in November 2019.

The scope of the BOFAS JLA PSP was defined as:

- Surgical treatments and injections for the treatment of foot and ankle conditions and injuries in adults (over 18yrs).
- 2. Post-surgical rehabilitation or injection aftercare. >>

Broken Bones in Older People		
Broken Bones of the Upper Limb in People over 50		
Common Conditions Affecting the Hand and Wrist		
Complex Fractures		
Early Hip and Knee Osteoarthritis		
Elbow Conditions		
Foot and Ankle Surgery		
Hip & Knee Replacement for Osteoarthritis		
Surgery for Common Shoulder Problems		
Revision Hip Replacement		
Revision Knee Replacement		
Paediatric Lower Limb Surgery		
Juvenile Idiopathic Arthritis		
Table 2: Registered PSPs in Trauma and Orthopaedics.		

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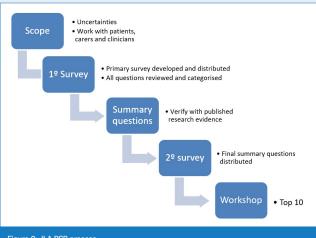
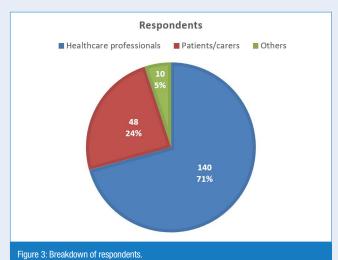


Figure 2: JLA PSP process.



The PSP was conducted in line with the well-established JLA process (Figure 2).

A total of 198 people responded with 472 questions. The breakdown of patients, carers and healthcare professionals is shown in Figure 3.

Out of scope questions were eliminated. The remaining questions (330) were categorised and summary questions were generated which were verified against the published evidence. The interim survey was launched. There were 291 respondents to the Interim Survey. The final workshop was carried out online on 13th July 2021. At the final prioritisation workshop, patients, carers and clinicians, using an inclusive facilitated approach developed by the JLA, agreed the final order of the 16 presented research questions in a series of three rounds of discussion and decision-making. The final top ten research priorities for foot and ankle surgery PSP focus on important aspects of interventions and rehabilitation in foot and ankle surgery (Figure 4). There were some inadvertent delays and changes in the process due to the COVID-19 pandemic, in particular use of online technology for steering group meetings and final workshop. This process was validated by the JLA team.

Declaration

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References

References can be found online at: www.boa.ac.uk/publications/JTO.

