The James Lind Alliance

Patients, carers and clinicians setting research priorities together
What does the JLA do?

• Provides a long-established method that brings patients, carers and health and social care professionals together in Priority Setting Partnerships (PSPs).

• Supports the identification and prioritisation of unanswered questions for research into a ‘Top 10’, with the aim of making researchers and funders aware of the questions that will make the most difference to people who live with health issues, and those who treat and care for them.
Why is this important?

Making sure the right, most important questions are being addressed by research – justifiable research priorities - a step on the pathway of making sure we get the most out of valuable research funding.
Oranges and Lemons?
How does the JLA work?

**The JLA Coordinating Team**
Based in the UK, supporting enquiries and development of new PSPs, monitoring and quality assurance of PSPs, communications and website (where all the research priorities are published), identifying impact.

**JLA Advisers**
In the UK, Canada and Netherlands, to support and quality assure each PSP. Independent consultants. Expert chairs and facilitators who are recruited and trained by the JLA Coordinating team.

**The JLA Guidebook**
A step-by-step guide to JLA priority setting method.
Where are JLA PSPs?

• 167 PSPs completed, and between 30-40 ongoing at any one time, in:
  • UK
  • Canada
  • Ireland
  • Germany
  • the Netherlands
  • Australia
  • Sweden
  • Ethiopia
  • Uganda
  • and globally across multiple countries
What topics do PSPs cover?

24 PSPs related to Women’s Health, eg, Endometriosis, Polycystic Ovary Syndrome, Female Fertility Preservation, Diabetes and Pregnancy

Mental Health, eg, Mental Health in Children and Young People, Schizophrenia, Bipolar

Under-served regions and communities, eg, Gorton Community Priority Setting in Manchester in the UK, and East London Pandemic PSP for Ethnic Minority Communities

Broad areas and multiple long-term conditions, eg Multiple Conditions in Later Life, Palliative and End of Life Care, Emergency Medicine, Intensive Care

Musculoskeletal topics, eg, Foot and Ankle Surgery, Revision Knee Replacement, Early Hip and Knee Osteoarthritis
What topics do PSPs cover?

Plus pioneering PSPs in research methodology – Recruitment to Randomised Trials, Retention in Randomised Trials, Methods of Rapid Reviews

And working with Health and Care Research Wales and Social Care Research Wales to set research priorities around Care and Support of Older People, and Family Support Services
JLA Principles

- **Transparency** of the process – reporting of each PSP on the JLA website so it is clear what each PSP did
- **Balanced inclusion** of patient, carer and clinician interests and perspectives
- Using the **existing evidence** base to make sure questions are not already answered to make sure topics are **relevant** and an **evidence gap** exists
- Clinicians and people with lived experience are all involved in setting **high quality, justifiable research priorities**
- **Appropriate and effective dissemination** of findings by PSPs and by publishing Top 10 priorities on the JLA website
- **Exclusion** of groups or organisations that may have **competing interests** that could lead to bias, eg, pharmaceutical companies
Who funds PSPs?

• Charities, eg, Asthma & Lung UK, Muscular Dystrophy Canada, Children’s Cancer Foundation Australia, Crohn’s & Colitis Australia

• Royal Colleges, eg, the Royal College of Midwives, and the Royal College of Emergency Medicine in the UK

• Clinical groups and networks, eg, the Orthopaedic Trauma Society in the UK, Canadian Concussion Network, Australian Association of Gerontology

• Research funders, eg, the Canadian Institutes of Health Research (CIHR), the National Health and Medical Research Council (NHMRC, Australia), Wellcome, NIHR, charitable trust funding

• UK Government eg, Office for Life Sciences, Office for Veterans’ Affairs
Collaborations

• Individual clinicians, clinical academics and researchers

• Charities – over 40% of members of the UK’s Association of Medical Research Charities (AMRC) have been involved in PSPs in some way

• Royal Colleges, universities, clinical groups, societies, foundations

• Advisers based in Canada and the Netherlands to particularly support PSPs in these countries and UK–based Advisers supporting other PSPs around the world

• NIHR and other funders globally
The Top 10s

Top 10s of priorities for research

The finale workshop of a Priority Setting Partnership (PSP) enables patients, carers and clinicians to agree the Top 10 priorities for future research. We have listed all of the Top 10s below. The dates in brackets are the year in which the Top 10 was published.

While the JLA refers to each list as a Top 10, a few of the PSPs have not limited their list to exactly 10 priorities. To find out more about how each PSP arrived at their Top 10, please visit the JLA section of the website.

Regardless of their position, all of the unanswered questions for each PSP are important. Where provided by the PSP, further details of the 20–29 unanswered questions discussed at the final workshop are shown, including their ranking, an explanation of the uncertainty, and details of any existing research reviewed.

The agreement of a Top 10 marks the beginning of the next stage of work for a PSP. The research priorities need to be promoted to key groups such as research funders, researchers, patients, and carers and the wider research community, and individual more specific research questions need to be developed from the priorities.

The Guidebook contains more advice on how PSPs can formulate research questions and work with researchers and research funders.

NIHR is interested in funding research which addresses any of the PSP priorities through its ongoing call for research.

<table>
<thead>
<tr>
<th>Priority</th>
<th>Year</th>
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<tbody>
<tr>
<td>Acne</td>
<td>2014</td>
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<tr>
<td>Adult Social Work</td>
<td>2018</td>
</tr>
<tr>
<td>Advanced Heart Failure</td>
<td>2020</td>
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<tr>
<td>Alcohol-related Liver Disease</td>
<td>2016</td>
</tr>
<tr>
<td>Anaesthesia and Perioperative Care</td>
<td>2015</td>
</tr>
<tr>
<td>Kidney Cancer (Canada)</td>
<td>2015</td>
</tr>
<tr>
<td>Kidney Transplant</td>
<td>2016</td>
</tr>
<tr>
<td>Learning Difficulties (Scotland)</td>
<td>2018</td>
</tr>
<tr>
<td>Lichen Sclerosus</td>
<td>2018</td>
</tr>
<tr>
<td>Life after Stroke</td>
<td>2011</td>
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An example

Top 10 Major Trauma (International) Top 10 priorities

The most important questions

1. How can different specialities and teams work better together to improve patient care for major trauma patients (e.g. Pre-hospital, Intensive care, therapists)?
2. How can the detection and treatment of complications of surgery be improved (e.g. using technology or novel strategies to detect infection)?
3. How can psychological input for major trauma patients and their families be improved?
4. What outcomes are important to patients after major trauma?
5. What are the most effective and safest methods for pain relief after major trauma?
6. How can early involvement of physiotherapy, occupational therapy, and other allied health professionals be used to improve patient outcomes following major trauma?
7. How can the care of older major trauma patients and those with existing medical conditions (e.g. bone health and falls assessments) be improved?
8. How can support and communication be improved for patients and their families after major trauma?
9. How can volunteer or peer support benefit patients after major trauma?
10. Which pre-hospital interventions improve major trauma patient outcomes?
Making a Difference

- Charity research funding strategies are shaped by their communities.
- Charities involved in PSPs form collaborations that often didn’t previously exist, eg, Fight for Sight’s PSP in Sight Loss and Vision led to them collaborating with over 40 other organisations.
- NIHR and other funders supporting research informed by patient, carer and clinician need.
- Adding value to the research agenda by setting justifiable research priorities.
- Empowering patients, carers and clinicians to have their say and develop skills towards future involvement in research.
- Reaching communities which have been less involved in research, eg, children and young people, rural communities in Ethiopia.
- Allowing patients, carers and clinicians to work together and learn from each other in ways that they haven’t experienced previously.
NIHR JLA rolling call

- Rolling call for research applications addressing JLA PSP priorities across NIHR programmes:
  - Health Technology Assessment Programme (HTA)
  - Health and Social Care Delivery Research Programme (HSDR)
  - Efficacy, Mechanism and Evaluation Programme (EME)
  - Public Health Research Programme (PHR)
NIHR working with a JLA priority

James Lind Alliance supports a priority setting partnership project to identify uncertainties from patients, carers and clinicians about treatments for Schizophrenia (2011).

Patient, carer and clinician community identify research priorities

Researchers respond with research in a priority area

Included on the PSP priority list is the question: “What training is needed to recognise the early signs of recurrence?”

Researchers respond to this priority and secure joint funding from the NIHR Health Technology Assessment Programme (2016 - 2019) and the Australian NHMRC.

The EMPOWER feasibility study shows that a mobile app, alongside peer support and clinical triage may be effective in monitoring early warning signs of schizophrenia to detect and prevent relapse.

Research tests innovative solution

The EMPOWER Algorithm becomes regulated under the Medicines and Healthcare Products Authority - the first Mental Health App to be subjected to this process. (2018)

Research demonstrates signals of impact for patients

NICE has requested sight of the project findings (2023).
A JLA PSP identifies uncertainties about **Mesothelioma (2014)** from patients, carers and clinicians.

Patient, carer and clinician community identify research priorities.

Researchers respond with research in a priority area.

PSP priorities include: “Does boosting the immune system improve response and survival rates for mesothelioma patients?” & “In mesothelioma patients, what is the best second line treatment?”

Funding from Cancer Research UK’s Stand up to Cancer campaign allows researchers to address these priorities and assess **Nivolumab as a treatment for mesothelioma that has returned after chemotherapy**.

The CONFIRM study showed longer progression-free survival and overall survival in patients treated with Nivolumab compared with placebo.

Research tests Nivolumab (an immunotherapy) and shows positive impact on patients.

The National Cancer Medicines Advisory Group (NCMAG) **supports the off-label use of Nivolumab** in Scotland for the treatment of mesothelioma, allowing clinicians in Scotland to prescribe the drug for patients diagnosed with pleural or peritoneal mesothelioma (2023).
Funded research addressing women’s health priorities

Women, families and healthcare professionals agree on the priorities at the JLA priority setting workshop

Priority 1: How can diabetes technology be used to improve pregnancy, birth, and mother and child health outcomes?

Funding allocated through the NIHR Health Technology Assessment Programme JLA rolling call to address Priority 1.

The PROTECT study around continuous glucose monitoring technology in pregnant women is due for completion in May 2027.

Funding is secured to address key priority areas

Priority 8: What are the outcomes and/or success rates for surgical or medical treatments which aim to cure or treat endometriosis, rather than manage it?

Priority 10: What are the most effective non-surgical ways of managing endometriosis-related pain and/or symptoms?

Funding through the NIHR Health Technology Assessment Programme for the following active trials to address these priorities:

- ESPriT2 trial
- DIAMOND trial
- REGAL trial

A JLA PSP identifies evidence uncertainties about Diabetes and Pregnancy (2020). 1,161 questions received from women, carers and healthcare professionals.

A JLA PSP identifies evidence uncertainties about Endometriosis (2017). 4,767 questions received from women, carers and healthcare professionals.
Get in touch

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