James Lind Alliance Priority Setting Partnerships

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What are JLA Priority Setting Partnerships (PSPs)?

JLA principles

Completed, current and international PSPs

How to do a PSP

What happens after the Top 10 has been agreed

Outcomes and funded research

What people say about JLA
What is the JLA?

The JLA provides a method that brings patients, care givers and health and social care professionals together in Priority Setting Partnerships, (PSPs) to identify and agree the Top 10 priorities for research in a particular area of health.
Why involve patients and clinicians?

Who normally decides what gets researched?

- Researchers
- Pharmaceutical industry

*The priorities of people with conditions and the people who treat and care for them can be very different from those of researchers.*
A mismatch

Interventions mentioned in commercial trials, non-commercial trials and research priorities identified by JLA PSPs, 2003-2012.

Crowe et al. (2015) ‘Patients’, clinicians’ and the research communities’ priorities for treatment research: there is an important mismatch’, Research Involvement and Engagement, 1:2
NIHR Adding Value in Research
Raising the probability of benefits to society from health-related research for the tangible and intangible costs involved

<table>
<thead>
<tr>
<th>Relevance and expressed need</th>
<th>High quality research that minimises bias</th>
<th>Open + transparent research funding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Set justifiable research priorities</td>
<td>Design, conduct and analysis are robust and appropriate</td>
<td>Regulation and management are proportionate to risks</td>
</tr>
<tr>
<td>1. Priorities are set involving those who use and are affected by health research</td>
<td>3. Designed using advances in research methods and taking steps to reduce bias</td>
<td>4. Actively manage research in a risk proportionate way</td>
</tr>
<tr>
<td>2. New research should be set in the context of a systematic review or rigorously determined evidence gap</td>
<td>5. Studies registered at inception</td>
<td>6. Protocols, methods and materials should be made available early</td>
</tr>
<tr>
<td>7. Methods, interventions and findings reported in full</td>
<td>8. Support replication and reuse of data</td>
<td>9. Findings should be set in the context of previous evidence and systematic reviews.</td>
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<tr>
<td>10. Disseminate knowledge to end users. Usage of new knowledge should be supported and facilitated</td>
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The initial framework was developed based on the 2009 work of Sir Iain Chalmers and Professor Paul Glasziou on avoidable waste in research and the later Lancet series
JLA established in UK in 2004

First PSP completed in 2007 in Asthma
The JLA now

JLA Advisers

JLA Guidebook

James Lind Alliance
Priority Setting Partnerships

The JLA coordinating team at NIHR, Wessex Institute, University of Southampton
Why James Lind?

May 20, 1747 - Scottish physician James Lind conducted the first clinical study of the treatment of scurvy on 12 sailors. Lind discovered that of six therapies, oranges and lemons had the greatest positive effect on the sailors' health.

TREATISE OF THE SCURVY.
IN THREE PARTS.
JLA principles

• **Transparency** of the process, so that what the PSP has done is clear

• **Balanced inclusion** of patient, carer and clinician interests and perspectives

• **Exclusion** from voting of those professionals who don’t treat patients

• **Exclusion** of groups or organisations that may have competing interests, e.g., pharmaceutical companies

• **Using the existing evidence** base to make sure questions are not already answered
Completed PSPs in the UK
Current PSPs in the UK

- Children's Cancer
- Exacerbations of COPD
- Complex fractures
- Foot Health
- Elbow Surgery
- Revision Knee Replacement
- Occupational Therapy
- Diabetes and Pregnancy
- Blood Pressure in Pregnancy
- Broken Bones of the Upper Limb in People over 50
- Blistering Disease Disorders
- Rare Mitochondrial Disease
- Foot and Ankle Surgery
- Paediatric Neurology
- Advanced Heart Failure
- Stroke
- Psoriatic Arthritis
- Vascular Surgery
International PSPs

• Netherlands
  - Eating Disorders
  - Juvenile Idiopathic Arthritis

• Germany
  - Pancreatic Cancer
  - Colorectal Cancer

• International (multi-country)
  - Hyperemesis Gravidarum
  - Liver Glycogen Storage Disease
  - Degenerative Cervical Myelopathy

• Uganda
  - Maternal Health

• Ethiopia
  - Pelvic Floor Disorders

• Canada
  - Anaesthesia
  - Cardiac Arrest
  - Dementia
  - Epilepsy
  - Fibromyalgia
  - Frailty
  - Head and Neck Cancer
  - Hypertension
  - Kidney Cancer
  - Metastatic Breast Cancer
  - Myeloma
  - Neurodevelopmental Disorders
  - Post Mastectomy Breast Reconstruction
  - Seniors’ Health (Alberta)
  - Sleep Apnoea (Saskatchewan)
  - Resuscitation
  - Venous Thromboembolic Disease
Method explained in detail in the JLA Guidebook

Gathering
Gathering potential uncertainties via paper and online surveys and literature search

Analysis
‘Raw’ questions counted, categorised and refined, duplications combined. Indicative questions created and checked against existing evidence

Prioritisation
Interim uncertainty prioritisation via paper and online surveys

Steering Group
Establish a steering group

Top 10 uncertainties
Final priority setting workshop

This Guidebook is a step-by-step guide to the processes involved in a James Lind Alliance (JLA) Priority Setting Partnership (PSP) and it is intended that anyone wanting to run a PSP in their local area will find these processes and tools easy to follow, including those running their first PSP. It will help PSPs to work effectively using tested and tested methods to ensure credible and useful outcomes.

The left-hand menu lists the chapters. Many of them contain examples that illustrate the process. The final chapter, the Toolbox of key PSP documents, highlights more examples and gives templates which can be adapted for use by new PSPs.

The JLA method is constantly evolving. As evidence of new approaches and good practice emerges, the Guidebook will be updated.

You can download the JLA Guidebook if you prefer.
Set up Steering Group

- Patient, caregiver and clinician representatives
- Collective responsibility
- Transparency – declare interests
- Resources and expertise
  - Regular meetings
  - Publicising the project
  - Overseeing the process
  - Responsible for dissemination
- Chaired by JLA Adviser – a neutral facilitator
- Agree protocol
Gather uncertainties

Mesothelioma PSP

• Do you have questions or comments about your experience of the **diagnosis** of mesothelioma?

• Do you have questions or comments about your experience of mesothelioma **treatments**?

• Do you have any other questions or comments about your experience of the **care** of someone with mesothelioma?
### How many uncertainties?

<table>
<thead>
<tr>
<th>JLA PSP</th>
<th>Survey respondents</th>
<th>Submitted uncertainties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bipolar</td>
<td>3,285</td>
<td>14,398</td>
</tr>
<tr>
<td>Depression</td>
<td>3,000</td>
<td>10,000+</td>
</tr>
<tr>
<td>Sight loss</td>
<td>2,220</td>
<td>4,461</td>
</tr>
<tr>
<td>Dementia</td>
<td>1,563</td>
<td>4,116</td>
</tr>
<tr>
<td>Dementia (Canada)</td>
<td>1,217</td>
<td>8,203</td>
</tr>
<tr>
<td>Tinnitus</td>
<td>835</td>
<td>2,483</td>
</tr>
<tr>
<td>Fibromyalgia (Canada)</td>
<td>550</td>
<td>4,557</td>
</tr>
<tr>
<td>Hypertension (Canada)</td>
<td>386</td>
<td>673</td>
</tr>
</tbody>
</table>
Check the uncertainties

- Prepare the dataset
- Remove out-of-scope submissions, store and decide how to deal with them
- Categorise eligible submissions
- Format submissions
- Check the uncertainties against existing evidence
- Identify research recommendations
- Prepare the long list
Interim priority setting

• To move from a long to a short list of questions

• Ask patients, carers and professionals to vote on the most important questions in their experience
Priority Setting Workshop

- For patients, carers and professionals, facilitated by JLA Advisers
- A day of democratic discussion to prioritise the 25 – 30 most important questions and jointly agree the Top 10
- Recognition that all of the questions are important and are published on the JLA website www.jla.nihr.ac.uk
Next steps

• Promote priorities to researchers and funders

• Ongoing dissemination of findings
  o Launch event
  o Publications – Journals, plain language report
  o Detailed reports and explanation to funders
  o Conferences
  o Social media, blogs
The Top 10 Priorities for Adult Cardiac Surgery Research

1. Quality of Life
   How does a patient’s quality of life (QOL) change (e.g., disability-free survival) following heart surgery and what factors are associated with this?

2. Frailty
   How can we address frailty and improve the management of frail patients in heart surgery?

3. Chronic Conditions
   How can we improve the outcomes of heart surgery patients with chronic conditions (obesity, diabetes, hypertension, renal failure, autoimmune diseases etc.)?

4. Prehabilitation
   Does prehabilitation (a programme of nutritional, exercise and psychological interventions before surgery) benefit heart surgery patients?

5. Heart Valve Intervention
   When should heart valve intervention occur for patients without symptoms?

6. Surgical Methods
   How does minimally invasive heart surgery compare to traditional open surgery?

7. Organ Damage
   How do we minimise damage to organs from the heart-lung machine/heart surgery (heart, kidney, lung, brain and gut)?

8. 3D Bio-Printing
   Can we use 3D bio-printing or stem cell technology to create living tissues (heart valves/heart) and repair failing hearts (myocardial regeneration)?

9. Atrial Fibrillation
   What are the most effective ways of preventing and treating post-operative atrial fibrillation?

10. Infection
    How do we reduce and manage infections after heart surgery including surgical site/ternal wound infection and pneumonia?
Outcomes

Q10. What interventions could reduce weight gain in schizophrenia?
Q7. What are the benefits of breathing exercises as a form of physical therapy for asthma?
Its not just the NIHR that funds PSP Priorities

- 2017 Canadian Frailty Network announced a Catalyst Grant Competition for proposals to address one or more of the Top 10 priorities from the Frailty PSP

- Parkinson’s UK, 2015-16 funded 8 research projects worth more than £6 million

- Fight for Sight, over £6.5 million to projects addressing priorities from the Sight Loss and Vision PSP

- Marie Curie, Chief Scientist Office, MND Association, 9 projects worth £1,425,000

- British Tinnitus Association, Sands, MS Society, Diabetes UK, Intensive Care Foundation
Impact

“It was an incredible process and we know from surveys that every participant felt it was a valuable use of their time. There is value in the process beyond developing the top 10. It helps build community, raise awareness, strengthen relationships with partners.”

Neurodevelopmental Disorders (Canada) PSP
What people say

“This has changed how I practice medicine. It has changed my understanding of what it means to listen to patients. It has changed the language I use when I speak with them. Most importantly it has changed my vision of how to deliver the care we give them. It has made it our vision.”

Noémi Roy, Rare Inherited Anaemias PSP
Challenges?

- Engaging with patients
- Engaging with clinicians
- Unpredictability
- Difficult data
- Measuring impact
What do PSPs need to get right

• A committed Steering Group
• Administrative support
• Resources
• A well-defined scope
• A vision beyond the top 10 and working with funders to define research questions
How you can get involved?

www.jla.nihr.ac.uk

Current surveys

If you are a patient, carer or family member, or a health professional with experience of any of the following areas, please get involved with JLA Priority Setting Partnerships (PSPs) by completing their surveys.

Initial surveys currently open - tell a PSP what comments or questions you have that you think more research might help to answer, in the following areas (please click on the link to go to the survey):

- Anaesthesia (Canada)
- Foot Health
- Heart Surgery
- Hyperemesis Gravidarum
- Nutritional Screening and Malnutrition
- Hypertension in Pregnancy
- Revision Knee Replacement

Interim prioritisation surveys currently open - tell a PSP which of the questions they have collected are most important to you:

- Broken Bones of the Upper Limb in People over 50
- Healthcare Associated Infections
- Oral and Dental Health
- Safe Care for Adults with Complex Health Needs
Top 10s of priorities for research

The final 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.

Whilst 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 The PSPs 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 20-30 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 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.

You can also find identified priorities for research alongside the key evidence around each health area at NICE Evidence search. Just enter your search term and filter by ‘Evidence Uncertainties’ to see the JLA priorities.
For more information...

www.jla.nihr.ac.uk

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