The James Lind Alliance

Finding out the questions that patients and clinicians want research to answer

Beccy Maeso 28 September 2023
What is the James Lind Alliance?

A method that brings patients, carers and health and social care professionals together in Priority Setting Partnerships (PSPs) to agree the Top 10 priorities for research in a particular condition or setting.
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
The JLA’s founders

Sir Iain Chalmers

Dr John Scadding

Sir Nick Partridge
James Lind?
What is a Priority Setting Partnership (PSP)?

- Patients, carers and clinicians working as equals
- Focusing on a single condition or area of health and social care
- Identifying unanswered questions (evidence uncertainties)
- Prioritising the most important into a Top 10
- Promoting the Top 10 to researchers and funders
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 – equal voice

- 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
The PSP process

Work with a JLA Adviser
- form a PSP Steering Group

Gather Uncertainties
- Launch a consultation survey

Analysis
- Analyse responses
- Check existing evidence
- Form summary questions

Prioritise questions

Agree the ‘Top 10’
- Final priority setting workshop
- Long term dissemination of the Top 10 to funders & researchers

12 – 18 month process
Priority setting workshop – final stage

In person

Online

[Images of workshop activities in person and online]
Over 150 Completed PSPs

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<th>Health settings</th>
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<th>Funders</th>
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<td>• Global burns (ongoing)</td>
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Global Reach of JLA Priority Setting Exercises

- Lead location for priority setting exercise
- Locations reached by priority setting exercise
- Number of priority setting exercises in location
Top 10s
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
Q7. What are the benefits of breathing exercises as a form of physical therapy for asthma?
"I then learned of the opportunity to participate in the UK Epilepsy PSP Workshop and felt that I could add huge value by not only representing other parents like myself, but by giving my little girl a voice."

Parent involved in the Epilepsy UK PSP
“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 Priority Setting Partnership
For more information...

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