



**James
Lind
Alliance**

Priority Setting Partnerships

The James Lind Alliance (JLA)

Tackling treatment uncertainties together



NHS

*National Institute for
Health Research*

The JLA infrastructure is funded by the NIHR

The James Lind Alliance

The James Lind Alliance (JLA) is a non-profit-making initiative, established in 2004. It brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 uncertainties, or unanswered questions, about the effects of treatments. The aim of this is to make sure that health research funders are aware of the issues that matter most to patients and clinicians.

The JLA believes that:

- addressing uncertainties about the effects of a treatment should become accepted as a routine part of clinical practice
- patients, carers and clinicians should work together to agree which, among those uncertainties, matter most and deserve priority attention.

The National Institute for Health Research (NIHR) funds the infrastructure of the JLA.

To find out more about current and completed PSPs, please visit www.jla.nihr.ac.uk.



“It’s a great time to be starting a JLA PSP. There are so many examples of how the process has worked in various settings and with different patient groups. There’s also a growing community of PSPs and a real willingness to share ideas, learning and good practice around setting priorities and influencing research.”

Katherine Cowan, Senior Adviser to the JLA



“The idea of bringing together clinicians, patients and carers to discuss research priorities seems obvious – why shouldn’t all those affected have a chance to jointly discuss frustrations about the things we don’t know, and aspirations for the future? Being involved in the Sight Loss and Vision PSP, gave me a much-needed platform to relate these frustrations and aspirations to some of those actually responsible for improving treatments in the future.”

Irenie Ekkeshis
Patient involved in
the Sight Loss and Vision
PSP

How do Priority Setting Partnerships work?



The JLA is about ‘tackling treatment uncertainties together’, although it is recognised that many PSPs now interpret this definition more broadly and extend their scope beyond treatment uncertainties. PSPs enable clinicians, patients and carers to work together to identify and prioritise important uncertainties in a particular health area, that could be answered by research. They follow the JLA’s tried-and-tested method as set out in the guidebook: www.jla.nihr.ac.uk/jla-guidebook/. The JLA facilitates these partnerships – funding and organising is done by the partnership itself.

Focusing on specific conditions or healthcare settings, the JLA facilitates PSPs which:

- bring patient, carer and clinician groups together on an equal footing
- identify treatment uncertainties which are important to all groups
- work with all groups to jointly prioritise identified uncertainties
- produce a final list (often a ‘Top 10’) of jointly agreed research priorities, publicise them widely, and make sure that other uncertainties are recorded and available for researchers and research funders to access
- provide a rare and valuable opportunity for patients and clinicians to shape the health research agenda.

You can find much more information about the health areas that PSPs have covered by visiting www.jla.nihr.ac.uk.

What do we mean by treatment uncertainty?

Treatment uncertainties are questions about treatments which cannot be answered by existing research. These might be questions about particular treatment options, methods of care, or diagnostic tests. The JLA definition of a treatment uncertainty is that:

- no up-to-date, reliable systematic reviews* of research evidence addressing the uncertainty about the effects of treatment exist
- up-to-date systematic reviews* of research evidence show that uncertainty exists.

*A systematic review combines evidence from existing studies.

Why include patients, carers and clinicians?

Research on the effects of treatments often overlooks the shared interests of patients, carers and clinicians. As a result, questions they all consider important are not addressed and many areas of potentially important research are therefore neglected. The JLA exists to help address this imbalance.

Even when researchers address questions of importance to patients and clinicians, they often fail to provide answers that are useful in practice. Another purpose of the JLA therefore, is to address the mismatch between what researchers want to research, and the practical information that is needed day-to-day by patients and health professionals.

“The JLA process was at all stages transparent, inclusive and consensus-based. It did exactly what it said on the tin - bringing patients, carers and clinicians together - and allowed us to integrate viewpoints from all these stakeholder groups effectively...quite a different dynamic from professional Anaesthetic research meetings. This diversity of opinion helped produce research priorities that really embody what matters most to patients and the public as well as healthcare professionals.”

Oliver Boney, ST6 Anaesthetic trainee/National Institute of Academic Anaesthesia Research Fellow, involved in the Anaesthesia and Perioperative Care PSP



Who was James Lind?

The James Lind Alliance is named after a pioneer of clinical trials, James Lind. Three centuries ago, sailors were dying of scurvy. There were many conflicting ideas about how to treat this deadly disease. James Lind, a Scottish naval surgeon, decided to confront these uncertainties by treating his patients within what is thought to have been the first ever clinical trial, comparing the proposed remedies. He allocated two sailors to each of six different treatments for a period of 14 days. His trial showed that oranges and lemons were dramatically better than the other suggested treatments. You will find links to more information about him at www.jla.nihr.ac.uk.



“So often, priorities for research are decided by one group of stakeholders. The Alzheimer’s Society supported a James Lind Alliance Priority Setting Partnership to challenge this; so that the views of clinicians, practitioners and patients were considered equally. We are delighted with the result. Taking the Top 10 priorities forward will help to address most urgently the needs of those affected by dementia and those that support and care for them.”

Dr James Pickett
Head of Research
Alzheimer’s Society

Contact us

The JLA is based at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), at the University of Southampton. NETSCC manages evaluation research programmes and activities for the National Institute for Health Research (NIHR).

If you have any questions, please contact the JLA team:

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“It was wonderful that after the initial introductions, everyone - patients, carers and doctors - were all on a level playing field. Everybody's viewpoint mattered equally.”

Julie, Patient Contributor to the Hair Loss PSP workshop.



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