The James Lind Alliance (JLA)
Tackling treatment uncertainties together
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). These partnerships identify and prioritise uncertainties, or ‘unanswered questions’, about the effects of treatments that they agree are the most important. The aim of this is to help ensure that those who fund health research are aware of what really matters to both patients and clinicians.

The JLA believes that:

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

The JLA is funded by the National Institute for Health Research (NIHR) and is coordinated through the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC).

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

“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
The JLA is about ‘tackling treatment uncertainties together’. PSPs enable clinicians, patients and carers to work together to identify and prioritise important uncertainties about the effects of treatments in their area of interest. They may also, if appropriate, address other issues such as diagnosis and aetiology (cause). The JLA facilitates these partnerships – funding and organising is done by the partnership itself.

Focusing on specific conditions or healthcare settings, JLA PSPs aim to:

- bring patient and clinician groups together on an equal footing
- identify treatment uncertainties which matter to both groups
- work with both groups to jointly prioritise the uncertainties
- produce a final list (often a ‘top 10’) of jointly agreed research priorities, publicise them widely, and make sure that other uncertainties they have discovered 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](http://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. 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 really needed by patients and clinicians every day.

“The Cleft Priority Setting Partnership was not only important for establishing the research priorities for us in this country but also a great opportunity to engage with patients and their families in a really meaningful manner, which will hopefully pave the way for a closer working relationship in the future.”

Nicky Kilpatrick
Paediatric Dentist
Who was James Lind?

Three centuries ago, sailors were dying of scurvy. There were many uncertainties about the effects of treatments that were being used at the time. A Scottish naval surgeon, James Lind, decided to confront these uncertainties by comparing six of the different remedies in use at that time in a controlled trial amongst 12 men. By conducting this first ever clinical trial, James Lind showed that patients treated with citrus fruits recovered much more rapidly than patients given other treatments. You will find links to much 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
The NIHR Evaluation, Trials and Studies Coordinating Centre, based at the University of Southampton, manages evaluation research programmes and activities for the National Institute for Health Research (NIHR).

If you have any questions, please contact us using the details below, and a member of the JLA team will be happy to help.

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