

The James Lind Alliance: frequently asked questions

What is the James Lind Alliance (JLA)?

The JLA is a non-profit making initiative which was established in 2004. It brings patients, carers and clinicians (healthcare professionals) together in Priority Setting Partnerships to identify and prioritise the unanswered questions about treatments that they agree are most important. The JLA is a small operation, with just four part-time people running it.

What are JLA Priority Setting Partnerships?

Priority Setting Partnerships focus on a particular condition or healthcare issue. They consist of individuals and organisations representing patients with the condition, their carers and the healthcare professionals who treat them. The JLA has worked with a wide range of Priority Setting Partnerships including for asthma, urinary incontinence, vitiligo, prostate cancer, type 1 diabetes, schizophrenia, eczema, stroke, sight loss & vision, cleft lip & palate, dementia, preterm birth, tinnitus and Lyme disease.

What do Priority Setting Partnerships do?

Priority Setting Partnerships work to identify and prioritise unanswered questions about treatment, for research. These are also known as treatment uncertainties. A Partnership will go through a process of ranking/voting and discussion to agree a final list of 10 top priorities, which will then be available to research funders.

Why patients, carers and clinicians?

Research on the effects of treatments often overlooks the shared priorities of patients, carers and clinicians. The pharmaceutical industry and academia play essential roles in developing and testing new treatments, but their priorities are not necessarily the same as those of patients, carers and clinicians. Many areas of potentially important research are therefore neglected. The JLA exists to address this imbalance.

What are treatment uncertainties?

They are questions about treatment which cannot be answered by existing research. The JLA identifies uncertainties by consulting with patients, carers and clinicians, and by looking at existing research recommendations and literature. The treatment uncertainties are stored in the UK Database of Uncertainties about the Effects of Treatment (UK DUETs).

What is UK DUETs?

The UK Database of Uncertainties about the Effects of Treatments (UK DUETs) is part of NHS Evidence and was established to publish uncertainties about the effects of treatment. UK DUETs focuses on treatments or interventions, including prevention and care, and does not include unanswered questions about the frequency, causes and diagnosis of health problems. For further information please visit www.library.nhs.uk/duets.

What happens to the treatment uncertainties which are not prioritised or put in the top 10?

Those uncertainties are not lost. They are still part of UK DUETs and can still be accessed by researchers and research funders.

How is the JLA funded?

The JLA is funded by the National Institute for Health Research (NIHR) and is supported by Medical Research Council. From April 2013 the JLA will be part of the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), home to a growing number of research programmes.

Who was James Lind?

Two hundred and fifty years ago, there were many conflicting ideas and unanswered questions about how to treat the deadly disease scurvy. Scottish naval surgeon James Lind (1716-1794) confronted this uncertainty by treating his patients within a clinical trial comparing six of the proposed remedies. His trial showed that oranges and lemons were the best treatment.



Where can I find out more?

Go to www.lindalliance.org. For practical guidance on the JLA's priority setting process, visit www.JLAguidebook.org. Or follow us on Twitter www.twitter.com/LindAlliance.