

House of Lords Science and Technology Committee

Call for evidence: Setting science and technology research funding priorities

Evidence from the James Lind Alliance – 21st September 2009

This evidence addresses the following questions:

- *How are public funds for science and technology research allocated? Who is involved at each level and what principles apply?*
- *Are existing objectives and mechanisms for the allocation of public funds for research appropriate? If not what changes are necessary?*

About the James Lind Alliance

Research on the effects of medical treatments often overlooks the shared interests of patients and clinicians. Questions important to both these groups may not be identified by others who influence the research agenda, such as industry or academia, and vital research areas may therefore be neglected.

The James Lind Alliance (JLA) was established in 2004 to bring patients and clinicians together to identify and prioritise the unanswered questions about treatments they agree are most important. The JLA (www.lindalliance.org) aims to raise awareness among those who fund health research about what matters to both patients and clinicians so that clinical research is relevant and beneficial to end users.

The Alliance has several hundred affiliates - organisations and individuals that identify strongly with the objectives of the JLA, and wish to be involved in it and to support it. The JLA is funded by the National Institute of Health Research (NIHR) and the Medical Research Council and has input from most of the key health research groups in the UK, for example the, NIHR Evaluation Trials Coordinating Centre, and the Cochrane Collaboration.

As well as practical experience of developing priorities in treatment uncertainties in different clinical areas, the Alliance has also commissioned research that has revealed the lack of systematic priority setting in public and voluntary health research funding and commissioning, and the disconnect between priorities identified and funding awarded.

The first study provided the JLA with a 'snap shot' of priority setting activity, and the key findings are outlined in the box below.

The JLA commissioned this scoping study to find out whether and how clinical research organisations currently set research priorities and whether and how patients and the public are involved in this work. The exercise involved a review of the websites of 104 UK clinical research organisations, and further analysis of 55 of those, of which 52 fund research. Of these, 49 were voluntary sector organisations or medical charities and three were government funding bodies. Twenty two of the UK clinical research funding organisations that identify research priorities or commission research were interviewed.

Key findings

Identifying priorities for research

- The majority of research funding bodies operate in responsive mode, relying on researchers to submit ideas for research rather than identifying priorities.
- Fewer than half the organisations surveyed state priorities for research. They are reluctant to place restrictions on researchers by asking them to address priority topics.
- The organisations which do identify research priorities do so for a range of reasons, in a number of different ways, including surveying patient members or researchers or simply relying on informal communication with them.

Involving patients and the public

- Few organisations identify the research priorities of clinicians and patients. Only a small proportion is aiming to address the priorities of both groups.
- There is a tendency to consult the research community as part of developing a research strategy, rather than consulting clinicians and patients.
- The type of patient and public involvement in decision-making processes varies between the organisations surveyed. Where they are involved, they are more likely to be asked to review research proposals than to identify priorities for research which is important to them.
- There is a growing trend towards patient and public involvement among patient organisations that fund research, but the impact of this on funding decisions is not currently measured.

Challenges to identifying research priorities

- There is no agreed best practice or consistent approach for identifying priorities.
- Some organisations have faced resistance from researchers both to developing a research strategy, and to identifying research priorities, due to concerns about the usefulness of the research and potential funding cuts.
- Where organisations have involved patients in the prioritisation process, they have found it difficult to interpret and summarise views accurately and to manage expectations of how quickly priorities can be addressed, if at all.

The current influence of research priorities

- Only a small number of organisations that identify priorities actually commission research to address them.
- A minority of organisations interviewed allocate funding solely to applications that address one of their identified research priorities.
- Most organisations do not take a systematic approach to addressing identified priorities and very few ring-fence budgets to fund prioritised research.
- Funding decisions are largely based on judgements about scientific merit, rather than on the relevance and importance of outcomes to end-users.

The full report of this work is available at:

http://www.lindalliance.org/Scoping_research_priority_setting_PPI.asp

Related research done by the Social Science Research Unit at the Institute of Education looked at priority setting from a different perspective. After a thorough search of the literature a preliminary list of 640 potentially relevant studies two researchers independently reduced the list to 258 studies with abstracts suggesting that clinicians and patients might contribute to research priorities, namely:

- Directly, through patients' and clinicians' consideration of research, through active collaboration in setting research priorities and consultations seeking their views about research priorities;
- Indirectly, through patients' and clinicians' consideration of health and services, through active collaboration and consultations, following which researchers interpreted the implications for research priorities.

Clinicians are more involved than patients in the whole process of priority setting, with patients less likely to be consulted about their research priorities than clinicians (18.2% of studies elicited patients' views, 88.5% among which included clinicians' views as well) and patients were less likely to be involved in writing reports of these activities than clinicians. Clinicians and patients are also more likely to work separately on identifying research topics, than collaboratively. 77.0% of studies included people of a single type (nurses, doctors, patients etc) and 18.9% included people working together in mixed groups. This makes the JLA process of Priority Setting Partnerships highly distinctive.

Key findings

Despite policy support for patient and public involvement within health research, such involvement rarely extends to influencing clinical research agendas. Furthermore, clinicians and patients seldom work together to identify and prioritise research. There is a need for careful consideration of these findings by those involved in funding, commissioning and undertaking research. Further investigation of the nature and outcomes of patient/public and clinician involvement in setting research agendas would inform these discussions.

The full report of this work is available on:

http://www.lindalliance.org/Map_studies_patients_clinicians_research_priorities.asp

Finally the JLA has practical and pragmatic evidence in its own programme of Priority Setting Partnerships. Each Priority Setting Partnership (PSP) will have contributed to the NHS Evidence UK DUETs (Database of Uncertainties about the Effects of Treatments) collection of treatment uncertainties www.library.nhs.uk/duets. To achieve this, partner organisations have to have canvassed their membership for uncertainties, or unanswered questions, about the effects of treatments. Methods to gather questions may have included questionnaires, focus groups and internet message boards.

They will also have appraised documents/policies/guidelines that identify unanswered questions about treatments, such as BMJ Clinical Evidence, Clinical Practice Guidance, Cochrane Reviews, NICE Guidance Research Recommendations and registers of ongoing research, such as those identified through the UK Clinical Trials Gateway. Partner organisations may also have existing research strategies/priorities that should be considered. Some partners may have extended this consultation exercise to patients/health professionals who are not necessarily members of the partnership organisations, but have valuable perspectives to offer.

In the JLA's experience, this process can yield between 200 and 1100 potential treatment uncertainties. Further refinement and checking ensures that uncertainties that are entered into UK DUETs are genuine and accurate. The refinement process will record the provenance of each uncertainty, where they are duplicated, where themes of uncertainties exist, and where there are shared uncertainties (i.e. the same uncertainty has been submitted by different groups). The JLA has trialled and reported on methods for

interim and final priority setting that are robust, inclusive and transparent. The JLA believes that these should be the core principles and values that underpin the allocation of public funds for science and technology.

The partnership between the British Thoracic Society and Asthma UK was the first formal Priority Setting Partnership (PSP) to complete the JLA process in 2007. The Urinary Incontinence PSP followed in 2008, and Vitiligo and Prostate Cancer PSPs will complete in 2010. Eczema will follow in 2011, and it is likely that there will be PSPs in type 1 diabetes, schizophrenia, wound management and stroke.

Summary of key messages from the James Lind Alliance

How are public funds for science and technology research allocated? Who is involved at each level and what principles apply

The JLA research suggests that systematic processes for transparent, equitable and robust priority setting are not in place. Indeed peer review is the only consistent process for judging the merit of funding applications – and whilst this has its merits, assessing scientific quality does not necessarily address or assess the health and economic benefit of research for patients, or place it in contexts from which its importance can be measured from a variety of perspectives.

Are existing objectives and mechanisms for the allocation of public funds for research appropriate? If not what changes are necessary?

The process needs to take account of multiple perspectives, especially from those that either live with or treat health conditions. There are pockets of existing good practice for priority setting, and more can be learned from these. There is also a growing community of interest from researchers, patient groups and clinicians who see that models for priority setting could democratise the research agenda in a systematic and thoughtful way.

The JLA has worked hard to pilot and provide working models for priority setting in health research, and sees its role in the next 3 years to mainstream this activity and explore areas beyond treatment uncertainties, such as research on diagnosis and prognosis, and early stage trials.

Thank you for the opportunity to present our views and experience.

Sally Crowe

Chair Monitoring and Implementation Group, James Lind Alliance
sally@crowe-associates.co.uk

JLA Contact details:

Patricia Atkinson
James Lind Alliance
Summertown Pavilion
Middle Way
Oxford OX2 7LG.
patkinson@lindalliance.org
01865 517635
www.lindalliance.org