

The James Lind Alliance
Scoping research priority setting, and the presence of patient and public involvement, with UK clinical research organisations and funders
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SUMMARY

Background

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 aims to raise awareness among those who fund health research of what matters to both patients and clinicians so that clinical research is relevant and beneficial to the end user.

Aims of the research

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. Given the growing profile of the public and patient involvement agenda, the JLA was interested to see if this stated commitment was being translated into practical action.

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 those UK clinical research funding organisations that identify research priorities or commission research were interviewed, and a brief review of the literature on peer review and public and patient involvement in making funding decisions was conducted.

Key findings

Identifying priorities for research

- Most research funders operate in responsive mode, relying on researchers to submit ideas rather than themselves 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 patients and public 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 to developing a research strategy and to identifying research priorities, because researchers are concerned 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.

Recommendations for the James Lind Alliance

While this research adds to the evidence base around research priority setting and patient and public involvement, it also makes recommendations to help the JLA consider how to encourage UK clinical research funders to address the priorities of patients and clinicians, including:

- Encourage clinical research funders to rethink the purpose of identifying research priorities.
- Offer and promote a robust process for identifying and interpreting priorities.
- Share the results of its Priority Setting Partnerships, which bring patients, carers and clinicians together to identify and prioritise questions for research.
- Support Priority Setting Partnerships to develop more detailed commissioning briefs from lists of identified research priorities.
- Develop best practice for identifying and funding research priorities.

For further information

The full report is available at:

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

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