

Summary

Background

The potential for patient and public involvement in clinical research is increasingly recognised, the rationale being that it leads to research that meets the needs of patients and the public, is more reliable and more likely to be put into practice. In order to learn from earlier experiences of such involvement, the James Lind Alliance (JLA) set out to assemble a bibliography of studies about patients' and clinicians' research priorities studies.¹ In 2008 the JLA then commissioned research, reported here, to explore this literature in more detail, and to reflect on the work in the JLA in relation to this literature.

Methods

Having worked with research users to plan this project, we extended and updated the original search for relevant literature and collected full text reports of relevant studies. We developed a framework for describing the various reported priority setting activities and used this to describe the literature, aided by specialist reviewing software. Lastly, we reflected on possible implications for the JLA and discussed our findings with the JLA Strategy and Development Group.

Findings

1. We identified 258 studies for consideration

- These were identified from: the initial JLA bibliography, contacting key authors, the PRIME database of potentially relevant research, re-searching the Cochrane Methodology Register.
- A preliminary list of 640 potentially relevant studies was reduced to 258 included studies by two independent researchers.

2. Scoping this literature has revealed different routes for clinicians and patients to contribute to research priorities.

- Exploring these 258 accounts improved understanding of how clinicians and patients might contribute to research priorities, namely:

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

3. Information about patients' and clinicians' views is valuable to funders of responsive programmes, funders of commissioning programmes and research teams.

- Information about patients' and clinicians' views about topics (gaps and priorities) yet to be addressed by research should be useful to funders of responsive programmes to judge the importance of topics proposed by research teams.
- Information about patients' and clinicians' research questions yet to be addressed should be useful to funders of commissioning programmes and to research teams seeking funds from responsive programmes.
- Information about patients' and clinicians' priorities about measures for use in research should be useful to research teams.

4. The focus of patients' and clinicians' contributions vary from general topics to specific research questions.

- Of the 258 studies explored in this map, 148 studies report patients' or clinicians' engagement with research.
 - 61/148 (41.2%) only describe broad research areas, in terms of populations (5/61), interventions (11/61), outcomes (20/61), or broad research topics (44/61).
 - 96/148 (64.9%) report patients' or clinicians' identifying research questions.
 - 5/148 (3.4%) report patients' or clinicians' views on research measures.

5. Clinicians are more involved than patients in the whole process.

- Patients are less likely to be involved in writing reports of these activities than clinicians: 4/258 reports or 1.6% of the literature explored in this map were authored by service users compared to 196/258 or 76.9% authored by clinicians.
- Patients were also less likely to be consulted as to their research priorities than clinicians: 27/148 or 18.2% of studies eliciting views on research included patients as opposed to 131/148 or 88.5% which included clinicians.

- Only 12/96 or 12.5% of studies eliciting full research questions included patients and 93/96 or 96.9% included doctors or other health professionals.

6. Clinicians and patients are more likely to work separately on identifying research topics, than collaboratively.

- In 148 studies people identified research topics, 120 (81.1%) included people of a single type (nurses, doctors, patients etc) and 28 (18.9%) included people working together in mixed groups.

7. Patient and clinician involvement in prioritising research questions has taken place for a range of health topics

- These activities have covered a wide range of health topics, in particular in the areas of cancer (15/96 studies or 15.6%) and mental health (10/96 studies or 10.4%).
- Further investigation is needed of the 61/96 studies which did not fall into any specific health condition.

8. The JLA Working Partnerships are highly distinctive

- We found that the JLA Working Partnerships are highly distinctive, with only 9 other accounts of clinicians and patients working together to identify and prioritise research questions (as opposed to general topics).
- Of particular significance to the current JLA partnerships are two accounts of similar activities in the areas of asthma and urinary incontinence.

Conclusions

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 and public involvement in setting research agendas would inform these discussions.

ⁱ Oliver S, Gray J. A bibliography of research reports about patients', clinicians' and researchers' priorities for new research. 2006. London, James Lind Alliance.