

A bibliography of research reports about patients', clinicians' and researchers' priorities for new research

What did we want to know?

The James Lind Alliance has been funded by the Medical Research Council (MRC) and the Department of Health to foster discussion among patients and clinicians (doctors, nurses, therapists, and others who treat patients) about variations in health care practice and the related unanswered research questions about the effects of care. The Alliance has assembled an initial bibliography of reports of studies comparing patients' and clinicians' research questions and outcome priorities with researchers' priorities or activities relevant to this aim. It was not known whether there were other, similar studies that could inform discussions among patients and clinicians, by reporting either their ideas about priorities for new research, or ways in which these priorities might be identified.

Who wants to know?

Clinicians, patients, researchers and research funders.

What did we find?

This scoping study identified a substantial literature addressing patients' and clinicians' research priorities that has not been included in previous systematic reviews. Further studies may be identified through searching studies citing those already identified, or by searching the reference lists of those already identified. Within this literature there is likely to be informative evidence addressing therapeutic questions and treatment outcomes of importance to patients and clinicians.

Studies identified address the priorities of clinicians or patients, either separately or compared with each other or with researchers or research funders. More could be learnt from appraising and synthesising this evidence. Not only will this literature inform researchers and funders of patients' and clinicians' priorities, it will also describe methods employed to elicit these priorities developed in different settings with different groups: who was approached, how they were engaged, and how their views were analysed.

What are the implications?

We recommend:

Extending the James Lind Alliance Bibliography by retrieving the full reports of the studies identified and if they appear relevant, make the citations publicly available through the James Lind Alliance.

Building on this scoping study with a systematic review; starting with duplicate independent screening of the downloaded citations and abstracts, then retrieving and re-screening the full reports of potentially relevant studies before describing the studies in terms of their health topic focus, clinician and/or patient involvement, and methods employed to elicit priorities.

Comparing patients' and the wider public's research priorities identified within this literature with social researchers' conclusions about research priorities for health care and assessment derived from their studies of patients' experiences of health, ill-health and health care.

How did we get these results?

To identify relevant studies we examined the references of nine papers from the original James Lind Alliance bibliography, conducted electronic searches for publications by key authors and for citations of key papers, and searched the journal *Health Expectations* by hand.

An electronic search strategy combining keywords and text terms for outcomes and research priorities held by patients, the public or clinicians was developed for MEDLINE and adapted to four other commercially available databases: EMBASE (a biomedical and pharmacological database), PsycINFO (for abstracts of behavioural sciences and mental health literature), CINAHL (covering nursing and allied health), AMED (Allied and Complementary Medicine database), and the Cochrane Methodology Register.

Between us, we screened the titles and abstracts of reports published over the past ten years. We were over-inclusive in the first instance, discussed difficulties in discriminating between relevant and irrelevant studies and then one of us inspected the potentially relevant studies a second time.

Relevant studies were categorised in six sets:

- 6 Compared patients' and researchers' research priorities for research or outcomes for assessing the effects of treatments
- 3 Compared clinicians' and researchers' research priorities or outcomes for assessing the effects of treatments
- 42 Compared patients' and clinicians' research priorities or outcomes for assessing the effects of treatments
- 96 Described patients' priorities for research or outcomes for assessing the effects of treatments
- 156 Described clinicians' priorities for research or outcomes for assessing the effects of treatments
- 71 Advocating or describing patient involvement methods in setting research priorities

This report should be cited as: Oliver S, Gray J. A bibliography of research reports about patients', clinicians' and researchers' priorities for new research. London: James Lind Alliance, December 2006.