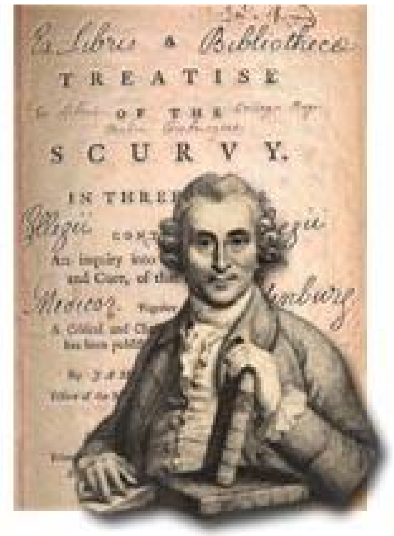

The James Lind Alliance

"Tackling treatment uncertainties together"

Report

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

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EXECUTIVE SUMMARY

Background

Since the early 1990s efforts have been growing to set research agendas in discussion with clinicians, patients and the wider public. Whilst clinicians may be expected to have an awareness of research and the need for research to inform their decisions as part of their professional knowledge, the same cannot be assumed for patients or the wider public. Engaging patients and the wider public can be achieved through conventional social research about their experiences of health, ill-health and treatment followed by analyses and interpretations by the researchers to draw out the implications for research agendas. A more direct engagement of patients and the wider public with research has policy support. This relies less on researchers' analyses and interpretations, but more on patients' and the wider public's understanding of the need for research to inform decisions about health care.

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.

Aims

The aims of this scoping study were to:

1. Extend the bibliography of the James Lind Alliance
2. Describe the scope of the literature addressing patients' and clinicians' priorities for research and outcomes for assessing the effects of treatments

The primary objectives were to search systematically for additional reports:

(a) Comparing patients' and researchers' research priorities for research or outcomes for assessing the effects of treatments
(b) Comparing clinicians' and researchers' research priorities or outcomes for assessing the effects of treatments

The secondary objectives were to search systematically for reports of:

(c) Comparing patients' and clinicians' research priorities or outcomes for assessing the effects of treatments
(d) Describing patients' priorities for research or outcomes for assessing the effects of treatments
(e) Describing clinicians' priorities for research or outcomes for assessing the effects of treatments
(f) Advocating or describing patient involvement methods in setting research priorities

METHODS

To identify relevant studies we examined the references of nine papers from the original 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 included studies a second time.

Relevant studies were described as in the categories described under ‘Aims’, above. In addition, we have compiled a bibliography of other studies for example, those describing methods for eliciting priorities, or promoting such work. These bibliographies will be relevant in future for preparing systematic reviews of research in this field. For example, we are aware of two reviews addressing patient and public perspectives on research agenda setting (Grant-Pearce et al 1998; Oliver et al 2004).

Results

We identified citations and abstracts of studies that appear to address the priorities of patients, clinicians or researchers, in a variety of combinations.

Focus of title/ abstract	**No. citations**
Patients' priorities for research or outcomes for assessment compared with researchers’ priorities	6
Clinicians’ priorities for research or outcomes for assessment compared with researchers’ priorities	3
Patients’ and clinicians’ priorities for research or outcomes for assessment	42
Patients’ priorities for research or outcomes for assessment	96
Clinicians’ priorities for research or outcomes for assessment	156
Reports advocating or describing methods for patient involvement in prioritising research or outcomes for assessment	71

From the information available in the abstracts, none of these appears to address the priorities of both patients or the public and clinicians, and also take into account researchers’ priorities.

Six appear to be comparative studies of research agendas and patients’ priorities. A further three comparative studies address researchers’ and clinicians’ priorities. Forty-two reports address patients’ and clinicians’ priorities but not necessarily researchers’ priorities. Ninety-six reports address patients’ or the public’s priorities, but not necessarily clinicians’ priorities or researchers’ priorities. One hundred and fifty six reports address clinicians’ priorities, but not necessarily patients’ priorities or researchers’ priorities.

Seventy-one reports advocate or describe patient involvement in setting research priorities.

Conclusions

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.

Recommendations

We recommend:

1. Making the report and citations publicly available through the JLA web site
2. 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;
3. 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.
4. 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.

1. BACKGROUND

1.1 Setting research agendas for the NHS

The evidence for informing decisions about health treatments is based largely on research agendas set in an uncoordinated fashion by academics and industry. The launch of the NHS Research and Development programme, in 1991, instigated a needs-led programme of commissioned research to counterbalance the responsive programmes which rely primarily on researchers suggesting potential research projects to funders (Peckham 1991). This was the beginning of a “systematic approach to identifying and setting R&D priorities in which NHS staff and the users of the Service are being asked to identify important issues which confront them and, in partnership with the research community, to characterise and prioritise these problems as the basis for seeking solutions” (Department of Health 1993). This approach has evolved through a series of agenda setting exercises by multidisciplinary advisory groups, some of which have involved patients, service users or their representatives.[1]

Long standing interest in service users’ perspectives on, and participation in, research (Chalmers 1991, 1995; Oliver 1995) prompted an explicit policy interest to include service users in NHS R&D from the inception of the national strategy (Peckham 1991). The Standing Advisory Group for Consumer Involvement in R&D (now INVOLVE) was established by the Department of Health to develop and support public involvement in R&D. It commissioned a review which revealed a number of mismatches in priorities for health research between professionals and the public (Grant-Pearce et al 1998). More recent examples have highlighted such mismatches in the areas of arthritis (Tallon et al 2000a,b), Alzheimer’s disease (Cream and Cayton 2001), and mental health (Griffiths et al 2002).

INVOLVE continues to develop strategic alliances among and across key groups in order to maximise effective public involvement in research in the NHS, social care and public health, and to monitor progress. INVOLVE asserts that engaging patients and members of the public leads to research that is more relevant to people’s needs and concerns, more reliable and more likely to be put into practice (Research and Development Directorate, 2006). It is also believed that broad involvement may lead to research with greater uptake of findings (Whitstock 2003).

INVOLVE’s policy for public involvement in setting research priorities is matched by the efforts of the NHS Health Technology Assessment Programme since 1997. A pilot study assessed the feasibility of public involvement and reflected on the contributions elicited from patient and carer organisations (Oliver et al 2001 a and b). Royle and Oliver (2004) have since described a cycle of development to support public involvement. This cycle has identified the resources and methods required for explicit, inclusive and reproducible methods for supporting public

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[1] Many terms are used to describe people who’s principle interest is in their own health and that of their families: patients, service users, consumers, the public. Although each term can be justified with different reasons, the term used by the James Lind Alliance is patients. We use the same term in this report even where it might include a wider range of people, including past and future patients, carers and the wider public. Similarly, the term ‘clinicians’ in this report also implies other health practitioners such as health promotion practitioners.

involvement alongside clinicians and researchers, which satisfy NHS policy recommendations.

There are three elements to setting research agendas for publicly funded research: identifying important questions; assessing whether they really are 'uncertainties' or whether there is already existing research on them; and, if genuine uncertainty exists, which of the 'questions' should be prioritised.

Learning how to identify the research priorities of different groups has involved developmental work in international, national, regional and local programmes. The NHS Health Technology Assessment programme commissioned a systematic review that identified a range of methods for public involvement in setting research agendas: involving individuals or organisations, in one-off or repeated events, using a range of forums (e.g. committee meetings, town meetings, written consultations, interviews and focus groups) (Oliver et al 2004). The more successful initiatives were collaborative, working with well networked consumers, and providing them with information, resources and support to empower them in key roles for consulting their peers and prioritising topics. Consultations needed to engage people directly and repeatedly in facilitated debate when discussing research. There was a noticeable gap in that reports rarely provided any detail on the precise methods for eliciting public priorities or making decisions about priorities. At that time, such efforts were largely preliminary, and briefly reported in policy documents.

Since then the James Lind Alliance has been supported by the MRC and the Department of Health to foster discussion among patients and clinicians (doctors, nurses, therapists, and others who treat patients) about variations in practice and the related unanswered research questions about the effects of care. The aim is to identify which uncertainties about the effects of treatments are sufficiently important that they should be addressed in systematic reviews of existing research evidence or additional primary research. The Alliance is attracting people with interests in a range of areas (Thornton 2005; Jobling 2005; Whitton 2005) and a substantial number of organisations have become affiliates because they support its objectives.

The Alliance assembled an initial bibliography of reports of studies comparing patients’ and clinicians’ research questions and outcome priorities with researchers’ priorities or activities relevant to the Alliance’s aims (Appendix 1).

Two of these studies are conspicuous for their attention to both patients’ and clinicians’ priorities, and for comparing these with past research in the areas of osteoarthritis of the knee (Tallon et al 2000a,b) and rheumatoid arthritis (Kirwan et al 2005). Tallon et al (2000a,b) found that patients' and clinicians’ highest priorities for research were surgery and educational interventions, despite the fact that few had had surgery and education was not perceived as very effective. They concluded that the lack of a patient-centred approach to care leads researchers to a preoccupation with pharmaceutical interventions, rather than the treatment options that patients and clinicians prefer.

Kirwan et al (2005), investigating research outcomes for rheumatoid arthritis, not only elicited concerns from patients and professionals, but also compared this with the research base and developed a research agenda through a consensus development exercise. This resulted in a research agenda that included exploring subjective experiences of rheumatoid arthritis identified by patients as important, such as a sense of well being, fatigue, and disturbed sleep.

These studies may be exceptional, or they may represent a larger literature that could inform how to elicit patients' and clinicians' questions about treatment uncertainties and priority outcomes. Where it is difficult to visualise the extent and distribution of the literature, Mays et al (2001) recommend a scoping study that rapidly identifies the key concepts underpinning a research area and the main sources and types of evidence available. In this newly emerging area a scoping study could identify comparative studies that indicate the extent to which discrepancies between research agendas and the priorities of patients and clinicians have been considered a problem; and studies reporting the priorities of patients and clinicians, and the methods employed to elicit these priorities.

1.2 Aims

The aims of this scoping study were to:

3. Extend the bibliography of the James Lind Alliance
4. Describe the scope of the literature addressing patients' and clinicians' priorities for research and outcomes for assessing the effects of treatments

The primary objectives were to search systematically for additional reports:

(g) Comparing patients' and researchers' research priorities for research or outcomes for assessing the effects of treatments
(h) Comparing clinicians' and researchers' research priorities or outcomes for assessing the effects of treatments

The secondary objectives were to search systematically for reports of:

(i) Comparing patients' and clinicians' research priorities or outcomes for assessing the effects of treatments
(j) Describing patients' priorities for research or outcomes for assessing the effects of treatments
(k) Describing clinicians' priorities for research or outcomes for assessing the effects of treatments
(l) Advocating or describing patient involvement methods in setting research priorities

2. METHODS

2.1 Identifying studies

2.1.1 Hand searching

All issues of the journal *Health Expectations* (i.e. since 1998) were searched for relevant studies.

2.1.2 Searching for key authors and key citations

Papers published by the following authors identified from the James Lind Alliance bibliography were also sought: Chalmers, I; Chard, J; Cohen CI; Cream J; Dieppe P; Kirwan J; Oliver S; Tallon D. Cascade searching was undertaken by examining the references of nine papers from the original bibliography.

Citation searching for eight relevant papers was carried out in the Science Citation Index Expanded (SCI-EXPANDED)-1970-present, Social Sciences Citation Index (SSCI)-1970-present and Arts & Humanities Citation Index (A&HCI)-1975-present.

2.1.3 Electronic search strategy

Sixteen studies from the existing James Lind Alliance Bibliography (appendix 1) were examined to obtain keywords and descriptors for a search identifying papers comparing patients' and clinicians' research questions and treatment outcomes with those of researchers. The keywords and descriptors thus identified were used to formulate a highly specific search. The results of the highly specific search were screened for relevant studies to provide further keywords and frequently occurring descriptors which were used to build a more sensitive search strategy in the MEDLINE database. The final MEDLINE search strategy as shown in appendix 2 was adopted and adapted to the following databases:

MEDLINE 1996 – present
EMBASE 1974 – present
PsycINFO – 1806 to date
CINAHL (R) – 1982 to date
AMED 1985 – present
The Cochrane Methodology Register

2.1.4 Screening

Between them two researchers screened the titles and abstracts of reports published in the last ten years. They were over inclusive in the first instance, discussed difficulties in discriminating between relevant and irrelevant studies and then one of them inspected the included studies a second time.

2.2 Describing studies

At the same time as screening titles and abstracts for relevance, the researchers allocated relevant studies to the following categories.

Studies addressing:

- Patients' priorities for research or outcomes for assessment, compared with researchers' priorities

- Clinicians’ priorities for research or outcomes for assessment, compared with researchers’ priorities
- Patients' and clinicians' priorities for research or outcomes for assessment
- Patients' priorities for research or outcomes for assessment
- Clinicians' priorities for research or outcomes for assessment
- Studies advocating, or describing methods for involving patients in prioritising research or outcomes for assessment

3. RESULTS

Initial electronic searches of 5 databases produced 6373 unique references. An amended electronic search identified a further 68 citations.

Hand searching, cascade searching, citation searching and the key author search produced a further 59 unique, relevant references.

After screening, 344 of these were found to be relevant, and were categorised (see appendices 3-8) according to their focus on the priorities of patients, clinicians or researchers, in a variety of combinations.

Focus of title/ abstract	**No. citations**
Patients' priorities for research or outcomes for assessment compared with researchers' priorities	6
Clinicians' priorities for research or outcomes for assessment compared with researchers' priorities	3
Patients' and clinicians' priorities for research or outcomes for assessment	42
Patients' priorities for research or outcomes for assessment	96
Clinicians' priorities for research or outcomes for assessment	156
Reports advocating or describing methods for patient involvement in setting research priorities	71

From the information available in the abstracts, none of these appear to address the priorities of both patients or the public and clinicians, and also take into account researchers' priorities (see figure 1).

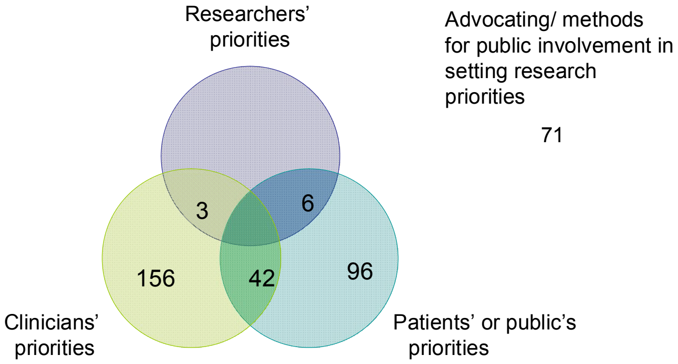

Figure 1: Studies addressing patients', clinicians' and researchers' priorities for research

Six appear to be comparative studies of research agendas and patients' priorities. A further three comparative studies address researchers' and clinicians' priorities. Forty-two studies address patients' and clinicians' priorities but not necessarily researchers' priorities. Ninety-six address patients' or the public's priorities, but not necessarily clinicians' priorities or researchers' priorities. One hundred and fifty six address clinicians’ priorities, but not necessarily patients’ priorities or researchers’ priorities.

Seventy-one reports advocate patient involvement in setting research priorities.

4. DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

4.1 Summary of findings

Systematic electronic and hand searching has identified a literature of studies addressing patients' and clinicians' priorities for outcomes and research.

Most studies addressed clinicians' priorities, often DELPHI[2] studies of nurses' priorities. Some of these studies have been included in a systematic review (Rudy et al 1998).

Fewer studies were comparative: six compared patients' priorities with priorities set by researchers or funding agencies; three compared clinicians' priorities with priorities set by researchers or funding agencies; 42 compared patients' priorities with clinicians' priorities.

Some studies addressed the priorities of people other than patients, for instance, policy makers or administrators.

4.2 Strengths and weaknesses of the study

The electronic search strategy was developed and piloted carefully and retrieved most of the studies on the JLA initial bibliography. Developing a search from the indexing of known studies is challenging. This is such a new area the key concepts of interest do not seem to be well defined and indexers of bibliographic databases seem not to have identified what we consider to be the distinguishing features of these studies. To compensate for this we combined index terms with free text terms in the MEDLINE search strategy.

The penultimate search strategy provided 4873 hits in MEDLINE to be screened, and picked up 8 of 16 of the original James Lind Alliance Bibliography. Reasons for missing studies in the James Lind Alliance Bibliography included:

- Journal not on MEDLINE (3)
- Article not on MEDLINE yet (1)
- No abstract, descriptors not helpful (2)
- No mention of priorities or outcomes, descriptors unhelpful (1)
- Obscure title (1)

We did not use the terms 'research agendas' and 'patient centred research', both of which featured in the original James Lind Alliance Bibliography because these were too broad and didn't deal with priorities, outcomes or questions. Expanding the search to encompass these concepts would likely have produced a more sensitive, but less specific search resulting in an unfeasibly large number of studies.

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[2] The Delphi Method is based on a structured process for collecting and distilling knowledge from a group of experts by means of a series of questionnaires interspersed with controlled opinion feedback (Adler and Ziglio, 1996).

Screening the references was less reliable than electronic searching. This was because only titles and abstracts have been screened, and no full reports retrieved for more detailed inspection, and because distinguishing between treatment preference and treatment outcome was particularly challenging. Furthermore, time did not allow for two researchers to screen references independently and compare their results. Sharing the screening and discussing general issues as they arose was sufficient to conclude that a relevant literature exists, but if a systematic review is to follow, the references should be screened again by another researcher independently to allow a more careful scrutiny.

Allocating each study to one of six categories was not a reliable procedure using citations and abstracts alone. Nevertheless, there appear to be reports of both clinicians' and patients' priorities, but very few comparative studies.

The scope of this extended bibliography is broader than the scope of interest of the James Lind Alliance. Many of the studies of research priorities and key outcomes for evaluation are likely to include the real focus of interest: studies eliciting therapeutic questions and treatment outcomes of importance to patients and clinicians. Such studies cannot be reliably identified from their citations and abstracts alone.

The scope of this extended bibliography is much narrower than the qualitative literature about patients' experiences of health, ill-health and health care from which some social researchers draw conclusions about research priorities health and outcomes for assessing treatment. Studies identified here addressing patients' priorities for research, require patients to engage with concepts of intervention assessment and evidence-informed health care.

An alternative approach is to conduct qualitative research about people's experiences of ill-health and care and how they value these. This allows people to consider their own personal experiences and views without considering how these relate to research priorities, but requires greater interpretation by social researchers to draw out the implications for research agendas. For instance, there is a broad literature about patients' experiences of tuberculosis which has been systematically reviewed to explore barriers to adherence to treatment (Munro et al 2006). This review included 44 studies and drew out hypotheses for further research. In comparison, the current work identified only two studies about tuberculosis, neither addressing patients' priorities (Assaad 1983; McNulty et al 2001). It is not yet known whether, or how, engaging patients directly in discussions about research agendas leads to different priorities from more conventional social research about their experiences.

4.3 Conclusions

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.

4.4 Recommendations

We recommend:

1. Making the report and citations publicly available through the JLA web site
2. 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;
3. 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.
4. 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.

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APPENDIX 1: A bibliography of studies eliciting therapeutic questions and treatment outcomes of importance to patients and clinicians

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Kirwan JR, Hewlett S, Heiberg T, Hughes RA, Carr M, Hehir M, Kvein T, Minnock P, Newman SP, Quest EM, Taal E, Wale J (2005). Incorporating the patient perspective into outcome assessment in rheumatoid arthritis – progress at OMERACT 7. *Journal of Rheumatology* 32:2250-6.

APPENDIX 2: Search strategy and results for MEDLINE

No.	Database	Search term	Results
1	MEDLINE - 1996 to date	CONSUMER-ADVOCACY.DE. OR CONSUMER-PARTICIPATION.DE. OR CONSUMER-SATISFACTION.DE.	10649
2	MEDLINE - 1996 to date	(CONSUMER OR CONSUMERS).TI,AB.	13274
3	MEDLINE - 1996 to date	PATIENT-ADVOCACY.DE. OR PATIENT-PARTICIPATION.DE. OR PATIENT-SATISFACTION.DE. OR PATIENT-RIGHTS.DE. OR PATIENTS.W..MJ.	42342
4	MEDLINE - 1996 to date	(PATIENT OR PATIENTS).TI.	378616
5	MEDLINE - 1996 to date	NURSE-CLINICIANS.DE.	3686
6	MEDLINE - 1996 to date	HEALTH-PERSONNEL.DE. OR PHYSICIANS.W..DE.	23301
7	MEDLINE - 1996 to date	NURSES.W..DE.	7804
8	MEDLINE - 1996 to date	(DOCTOR OR DOCTORS OR NURSE OR NURSES OR CLINICIAN OR CLINICIANS OR PRACTITIONER OR PRACTITIONERS OR PHYSICIAN OR PHYSICIANS).TI,AB.	224016
9	MEDLINE - 1996 to date	RESEARCHER-SUBJECT-RELATIONS.DE. OR RESEARCH-PERSONNEL.DE.	3967
10	MEDLINE - 1996 to date	(RESEARCHER OR RESEARCHERS).TI,AB.	26716
11	MEDLINE - 1996 to date	(STAKEHOLDER OR STAKEHOLDERS).TI,AB.	2946
12	MEDLINE - 1996 to date	(PRIORITIES OR PRIORITY OR PRIORITISATION OR PRIORITIZATION OR PRIORITIZING OR PRIORITISING OR PREFERENCE OR PREFERENCES OR PREFERRED).TI,AB.	74158
13	MEDLINE - 1996 to date	(PRIORITIES OR PRIORITY OR PRIORITISATION OR PRIORITIZATION OR PRIORITIZING OR PRIORITISING OR PREFERENCE OR PREFERENCES OR PREFERRED).TI.	9848
14	MEDLINE - 1996 to date	HEALTH-PRIORITIES.DE.	3793
15	MEDLINE - 1996 to date	(RESEARCH NEAR (PRIORITIES OR PRIORITY OR PREFERENCE OR PREFERENCES)).TI,AB.	1984
16	MEDLINE - 1996 to date	RESEARCH.W..DE. OR HEALTH-SERVICES-RESEARCH.DE. OR NURSING-RESEARCH.DE. OR RESEARCH-SUPPORT.DE. OR RESEARCH-SUPPORT-NON-U-S-GOVT.DE. OR SUPPORT-OF-RESEARCH.DE. OR RESEARCH-SUPPORT-U-S-GOVT-P-H-S.DE. OR THERAPEUTIC-HUMAN-EXPERIMENTATION.DE.	2263747
17	MEDLINE - 1996 to date	RESEARCH.W..MJ. OR HEALTH-SERVICES-RESEARCH.MJ. OR NURSING-RESEARCH.MJ. OR RESEARCH-SUPPORT.MJ. OR RESEARCH-SUPPORT-NON-U-S-GOVT.MJ. OR SUPPORT-OF-RESEARCH.MJ. OR RESEARCH-SUPPORT-U-S-GOVT-P-H-S.MJ. OR THERAPEUTIC-HUMAN-EXPERIMENTATION.MJ.	23808
18	MEDLINE - 1996 to date	OUTCOME-AND-PROCESS-ASSESSMENT-HEALTH-CARE.DE. OR OUTCOME-ASSESSMENT-HEALTH-CARE.DE.	28882
19	MEDLINE - 1996 to date	OUTCOME-AND-PROCESS-ASSESSMENT-HEALTH-CARE.MJ. OR OUTCOME-ASSESSMENT-HEALTH-	11212

		CARE.MJ.	
20	MEDLINE - 1996 to date	**TREATMENT-OUTCOME.DE.**	**235173**
21	MEDLINE - 1996 to date	**TREATMENT-OUTCOME.MJ.**	**1871**
22	MEDLINE - 1996 to date	**(RESEARCH NEAR (QUESTION OR QUESTIONS)).TI,AB.**	**3665**
23	MEDLINE - 1996 to date	**(OUTCOME OR OUTCOMES).TI,AB.**	**296356**
24	MEDLINE - 1996 to date	**(OUTCOME OR OUTCOMES).TI.**	**55638**
25	MEDLINE - 1996 to date	**RESEARCH.TI.**	**46563**
26	MEDLINE - 1996 to date	**(CLIENT OR CLIENTS OR CUSTOMER OR CUSTOMERS OR CITIZEN OR CITIZENS OR COMMUNITY OR PUBLIC OR LAY OR USER OR USERS).TI,AB.**	**216913**
27	MEDLINE - 1996 to date	**1 OR 2 OR 3 OR 4 OR 26 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11**	**815290**
28	MEDLINE - 1996 to date	**12 OR 14 OR 15**	**76398**
29	MEDLINE - 1996 to date	**13 OR 14 OR 15**	**14099**
30	MEDLINE - 1996 to date	**15 OR 16 OR 18 OR 20 OR 22 OR 23 OR 25**	**2618529**
31	MEDLINE - 1996 to date	**15 OR 17 OR 19 OR 21 OR 22 OR 24 OR 25**	**122980**
32	MEDLINE - 1996 to date	**27 AND 29 AND 31**	**1205**
33	MEDLINE - 1996 to date	**27 AND 28 AND 30**	**10687**
34	MEDLINE - 1996 to date	**27 AND 29 AND 30**	**2722**
35	MEDLINE - 1996 to date	**27 AND 28 AND 31**	**2106**
36	MEDLINE - 1996 to date	**34 OR 35 NOT 34**	**3623**

Subsequent modifications

After the search strategy had been executed additional terms were tested: Comparative Study, Needs Assessment, Clinical Trials/trends, Research Design/trends, and Attitude of Health Personnel. Only the last two terms identified new citations. Research Design/ Trends gave 331 citations in a search of MEDLINE, 2 of which were relevant but both already uncovered by existing search strategy. Attitude of Health Personnel identified a further 48 citations, 8 of which look like they might be relevant. For this reason, the last term, Attitude of Health Personnel, was incorporated into the search strategy for each bibliographic database.

Searches incorporating the additional term identified the following numbers of new citations:

Medline: 48 new hits, 9 relevant
Embase: 1 new hit, brought up in Medline search above
Psychinfo: 3 new hits, none relevant
Cinahl: 15 new hits, 5 relevant
Amed: 1 new hit, not relevant

APPENDIX 3: Reports of patients' priorities for research or outcomes for assessment compared with researchers' priorities

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APPENDIX 5: Reports of patients' and clinicians' priorities for research and outcomes for assessing treatment

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APPENDIX 6: Reports of patients' priorities for research and outcomes for assessing treatment

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APPENDIX 7: Reports of clinicians' priorities for research or outcomes for assessing treatment

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