The James Lind Alliance

"Tackling treatment uncertainties together"

Report

A systematic map of studies of patients' and clinicians' research priorities

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Abbreviations

AIDS	Acquired Immuno-Deficiency Syndrome
DUETS	Database of Uncertainties of Effects of Treatment
HIV	Human Immuno-Deficiency Virus
JLA	James Lind Alliance
JLI	James Lind Initiative
LADRIG	Lancashire Dementia Research Interest Group
MRC	Medical Research Council
NGO	Non-governmental organisation
R&D	Research and development
UKCRC	United Kingdom Clinical Research Collaboration

Glossary

Aetiology	Identification of factors that are involved in the cause, risk or development of ill health
Ankylosing spondylitis	A chronic, painful, degenerative inflammatory arthritis
Cochrane Collaboration	An international organisation which aims to improve healthcare decision-making globally, through systematic reviews of the effects of healthcare interventions
Delphi Study	A Delphi Study includes two or more rounds of surveys to experts where their views are collated and returned to them all between rounds for further comment. This allows future expectations or needs to be informed by all participants' individual views and their interaction.
Fibromyalgia	A disorder classified by the presence of chronic widespread pain
Features-Resources Trade-Off Game	An exercise in which participants are asked to allocate and 'trade' limited resources to address a list of different health problems. In doing so, they are prioritising which health problems they feel should be addressed and how much should be invested in each.
Systematic review	A systematic review is a literature review focused on a single question which tries to identify, appraise, select and synthesize all high quality research evidence relevant to that question

Summary

Background

The NHS Research and Development strategy includes drawing on the views of clinicians and patients, the rationale being that research which meets their needs is more relevant 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 researchers working independently.

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 research topics 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 assessment 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%) 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 with 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 compared with 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 James Lind Alliance Working Partnerships are highly distinctive**

➢ We found that the James Lind Alliance 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 James Lind Alliance 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.

1. What work has already been done in this area?

1.1 Setting research agendas

Traditionally health research agendas have been set in an uncoordinated fashion by academics and industry.[2] This changed in the UK in the early 1990s with the launch of the NHS Research and Development programme which heralded the introduction 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 mixed groups, some of which have involved patients, carers, service users or their representatives.[i] Alongside these developments, in 1996 the Department of Health established the Standing Advisory Group for Consumer Involvement in R&D (now INVOLVE) to develop and support public involvement in R&D. In 2003, following publication of 'Clinical Trials for Tomorrow'[3], the Medical Research Council (MRC) and the Department of Health funded the James Lind Initiative to promote public and professional knowledge about, and engagement with, clinical trials. As one of the initiatives taken under the aegis of the James Lind Initiative, the James Lind Alliance was launched in 2004 to foster collaboration between patients and clinicians in 'working partnerships' to identify research priorities addressing uncertainties about the effects of treatments.

1.2 Learning from the literature

In order to learn from earlier efforts to identify research priorities, the James Lind Alliance assembled an initial bibliography of studies known to them that addressed patients' or clinicians' research questions and outcome priorities, some of which also addressed researchers' priorities or research activities. Subsequently the Alliance commissioned a more detailed bibliography of studies comparing patients' and clinicians' research questions and outcome priorities with researchers' priorities or activities relevant to the Alliance's aims. This was a scoping study

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[i] Many terms are used to describe people whose principal interest is in their own health and that of their families. In this report we refer to patients/carers to incorporate this wide ranging group of people.

which identified a substantial literature addressing patients' and clinicians' research priorities that had not been included in previous systematic reviews.[1] It was based on a sensitive search and screening of over 6,000 citations from electronic databases. The citations and abstracts identified were analysed in terms of whose priorities they address: patients', clinicians' or researchers. Citations were analysed according to the focus of the questions: populations, health conditions or health interventions. These citations have been appended to the appropriate modules of DUETS (Database of Uncertainties of Effects of Treatment) to make potentially relevant literature about treatment uncertainties and research priorities more readily available to people conducting or funding research.

This scoping study was limited by its reliance on an electronic search strategy and analysis of titles and abstracts rather than full reports. There was no contact with experts, searching for more recent studies citing those already identified, or searching for earlier studies through the reference lists of those already identified. Since the scoping study, the addition of a new keyword ("timing and choice of research questions") into the Cochrane Methodology Register offers a more sensitive and specific search for relevant studies from this source. More may be learnt from these other sources about patients' and clinicians' research priorities, and by considering the current activities of the James Lind Alliance in the light of the wider literature.

2. What did we set out to do?

We had four aims for the work we report here:

Aim 1. To develop the bibliography of the James Lind Alliance by locating full reports of patients' and clinicians' priorities for research

Aim 2. To understand better how patients and clinicians can contribute to priorities for research

Aim 3. To describe this literature in terms of who was setting priorities and in what health areas

Aim 4. To reflect on the work of the James Lind Alliance in relation to the wider literature.

3. How did we go about this?

We describe briefly here how we sought and described relevant literature. Further details are in Appendices 1 and 2.

3.1 Working with research 'users'

The focus of this work was set by the James Lind Alliance Strategy and Development Group, which includes members who are clinicians, service users, research funders and managers, and academics. They refined the focus of the work and signposted some reports at one of their regular meetings. Their discussion of the emerging findings informed the final report.

3.2 Searching for relevant literature

In order to identify relevant literature we started with the references from the James Lind Alliance Bibliography, we conducted some additional electronic searching of the Cochrane Methodology Register and we contacted key individuals asking them to send us any relevant reports. We also conducted citation searches (looking for papers which cited relevant reports) and checked the reference lists of relevant reports for additional relevant literature.

Two researchers independently screened potentially relevant abstracts to identify those about patients' and clinicians' research priorities. We then collected full text copies which were again screened by two researchers to retain only those that were relevant.

3.3 Describing the relevant literature

In order to ensure accuracy and reduce bias studies were independently described by two researchers and the descriptions compared and discussed.

Each study was described in terms of who authored the report(s), whose priorities were being identified, whether participants identified full research questions or just broad topics, and focus of the health topic(s).

4. What did we find?

4.1 The results of our searching[ii]

Our first aim was to develop the bibliography of the James Lind Alliance to identify full reports of patients' and clinicians' priorities for research.

Initially we identified 675 potentially relevant references.[iii] After screening abstracts of these for relevance, collecting full text reports and screening these again to retain only those that were relevant, we were left with 258 studies of clinicians' and patients' views.

4.2 How patients' and clinicians' can contribute to research priorities

Our second aim was to understand better how patients and clinicians can contribute to research priorities. From the studies we found we could recognise several different routes for patients and clinicians to contribute priorities for research. Some studies reported researchers listening to patients or clinicians and then making decisions informed by their views (consultation). Other studies reported researchers and patients or clinicians making decisions between them about priorities (collaboration). The former approach describes a relatively passive involvement of patients or clinicians. The latter approach describes a more active involvement where patients and clinicians share decisions with researchers.

[ii] For a full break down of our searching results see Appendix 3.

[iii] This includes 35 potentially relevant reports identified at the very end of the project, by searching for papers which cited those we knew were relevant and searching the reference lists of the most relevant reports. These are listed in Appendices 4 and 5 and should be considered in any subsequent research on this topic.

Our literature searches found some studies that prompted a further distinction in terms of how directly clinicians and patients engaged with the concept of research needs and priorities. The searches found some studies that were familiar to us already, and other similar studies, where clinicians or patients were directly involved in consultations or collaborations about research and research needs. They also found studies that drew conclusions about patients' and clinicians' research priorities in ways we had not anticipated. These included studies where researchers decided the research priorities after listening to patients' or clinicians' descriptions of their experiences, preferences, values or 'measures' of success as they talked about:

- o services or interventions (for example treatments or therapies)
- o health conditions (for example disability or illness)

Although these routes did not involve patients or clinicians directly in considering research priorities, they did draw on patients' or clinicians' perspectives more than if the researchers drew conclusions about research priorities from their observations alone. This last approach is typical of most research reports which often end with recommendations for further research supported with references to research knowledge, whether or not this has been selected systematically, to identify research gaps.

Where researchers drew on patients' or clinicians' perspectives as they described their experiences, values, preferences, or measures for success relating to health and services, the researchers could draw out implications for research, implications for topics deserving research, research questions, or measures for conducting research. By engaging patients and clinicians in further discussions about research directly, recommendations for research could be drawn from the interpretations of patients and clinicians as well as researchers. This may entail patients and clinicians themselves identifying or prioritising topics deserving research, research questions or measures for use in research. As patients and clinicians become increasingly engaged, the role of researchers may diminish, where they relinquish sufficient control for their role to become a facilitator.

The distinctions between collaboration and consultation and between engaging with research directly or indirectly are visualised in Figure 1.

Figure 1: Routes available for non-researchers to influence research priorities

		Non-researchers' engagement with research	
		Directly	**Indirectly**
Non-researchers' involvement in decisions	**Yes: Collaboration**	Setting priorities for topics deserving research (services, interventions outcomes), or measures to use in research	Setting priorities for health topics (services, interventions, outcomes), or their measures
	No: Consultation	Talking about research, topics deserving research (services, interventions outcomes), or measures to use in research	Talking about health topics (services, interventions, outcomes), or their measures

Another distinction within this literature is the extent to which studies link patients' and clinicians' views to subsequent research. Some individual studies ask for patients' and clinicians' views but do not explicitly link these to subsequent research. Some individual studies provided a direct link between patients' or clinicians' views and individual studies conducted in light of these views. Some others linked their views directly with funded research programmes. This prompted us to consider who how patients' and clinicians' views expressed in this literature as a whole might inform subsequent research.

We concluded:

- Health or intervention topics that patients or clinicians considered deserving research may be useful to funders of responsive programmes in setting the scope of their programmes, or the priorities within them.
- Research questions from patients or clinicians yet to be addressed may be useful to funders of commissioning programmes and to research teams seeking funds from responsive programmes.
- Measures for use in research endorsed by patients or clinicians may be useful to research teams.

In summary, different approaches to eliciting research priorities could be distinguished in terms of:

- Whether non-researchers were engaged directly or indirectly with research
- Which non-researchers were engaged (patients, clinicians, others)
- What their endeavours achieved – identifying topics deserving research, specific research questions, or measures to use in research
- How the outputs were achieved, through
    - working with patients or clinicians separately or in mixed groups
    - consultation to elicit ideas from patients and clinicians, or collaborative partnerships in which patients or clinicians shared decisions about priorities with researchers
- Whether the outputs were directly linked to subsequent research projects or programmes.

Once clear about the range of approaches for patients and clinicians to contribute to research agendas, and the potential for influencing research projects or programmes, we set about scoping the size and authorship of this literature, and describing the groups who engaged directly with research and the outputs of their efforts.

4.3 Describing the literature about patients' and clinicians' research priorities

Our third aim was to describe the focus of this literature, but not to assess its quality, in order to judge the value of preparing a full systematic review. We describe below the number of studies and their authors, and the outputs of by those directly engaged with research. We do not consider the quality of the engagement methods, the quality of the research, or how well the outputs linked directly to subsequent research projects or programmes. However, we have included abstracts of a sample of 12 studies to provide additional insight into the range of activities undertaken. Details of how people were engaged, and who well, awaits further appraisal in a full systematic review.

a. Scoping the literature and authorship

We found 258 relevant studies, 257 full texts and one conference abstract. All 258 are written by researchers: in 196 the authors are researchers who are also qualified health professionals and in four the authors are also described as service-

users.[iv] Sixty of the 258 studies included authors who were neither health professionals nor service-users.

b. Indirect engagement with research

Of the 258 studies, many drew on patients' or clinicians' experiences of health or services more than their preferences or reflections about research topics, questions or measures. Seventy six were about participants' experiences or preferences for health states, where researchers' interpretations informed the recommendations for research. A further 27 were about participants describing their experiences of, or preferences for, research procedures (not shown in matrix). Examples of these include participants sharing their views on how to recruit people to a trial, or what they think of the consent arrangements.

Eleven described clinicians and / or patients contributing to the development of assessment tools for use in clinical settings (see Box 1).

Box 1: The topics considered in the 11 studies which described the development of clinical assessment tools

- Identifying patient defined endpoints for remission and clinical improvement in ulcerative colitis[4]
- Developing an assessment tool based on patient preferences among men with prostate cancer[5]
- Identifying patient preferred health outcomes relating to low back pain for an assessment tool for clinical practice[6]
- Developing a tool to measure patient preferences in plastic surgery[7]
- Comparing four pain scales for burns victims for use in clinical practice[8]
- Developing valid measures for an assessment tool for use in ambulatory settings[9]
- Using patient priorities to develop and test and outcome measure for ankylosing spondylitis and fibromyalgia[10]
- Presenting the Features Resources Trade Off Game as a new method for comparing preferences for alternative outcomes among different groups of people in the area of recovery and physical rehabilitation[11]

[iv] Two of the reports authored by service-users also include authors who are qualified health professionals.

- Three studies relating to mental health:
  - Constructing and evaluating a multidimensional, preference weighted mental health index[12]
  - Developing a utility function for multiple outcome measurements in mental health evaluation[13]
  - Developing outcome indicators for monitoring the quality of mental health[14].

c. Direct engagement with research

Of the 258 studies, 156 described participants engaging directly with research rather than only their experiences or perceptions of health.

Of these 156, five did not specify the involvement of clinicians or patients / carers, but referred instead to other groups, for example 'policy makers' or 'technical experts'. This left 151 studies which definitely included clinicians or patients.

Of the 151 studies about participants' research priorities, one was a review. This considered the published literature on mental health users' involvement in setting research priorities and identified five priority topic areas: social and welfare issues, involvement in services, medication, alternative treatments, and ethnicity. Individual studies are not reported in detail and neither are specific research questions. This review is therefore not considered in further detail in this report.

d. Outputs of engagement

Of the 150 remaining studies in which patients or clinicians engaged directly with research rather than only their experiences or perceptions of health, 148 described participants identifying important research topics or questions and five described participants contributing to research measurements for assessment tools. Three did both.

In two of the five studies, it was the researchers who chose the outcomes and invited participants to contribute to developing tools for assessing those outcomes. Saunders and colleagues described working with cancer consumers and community members' to develop an appraisal instrument for the inclusion of consumer and community values in cancer research funding decisions,[15] whilst Revicki and colleagues described the development and evaluation of a brief

symptom assessment scale for use as a preference-based outcome measure in clinical trials and cost-effectiveness studies in asthma.[16] These two studies are not considered further here.

Three further studies that involved participants in the development of assessment tools for research also involved them in setting broader research priorities. Devane and colleagues described the identification of outcome measures for use in midwifery research,[17] and Hagen and colleagues reported the development of a tool to allow research priorities of practitioners to be identified to inform research strategy of the Nursing Research Initiative for Scotland.[18] The OMERACT programme aimed to standardise outcomes for assessment in clinical trials on arthritis, drawing on the experience of those who experience the disease themselves.[19-25] The development of these assessment tools is not considered further here, but the identification of research priorities by patients and clinicians reported in the same studies is considered below as part of a larger literature.

Of the remaining 148 studies reporting research priorities, participants identified general topics (44), interventions (11), populations (5) or outcomes (20) as important. In 96 of the 148, they prioritised specific research questions.

In summary, of the 258 identified studies, 150 related specifically to clinicians and patients engaging with research. Of these 150, two only considered participant priorities within narrow pre-determined topics as part of the development of assessment tools for research. The remaining 148 reported patients and clinicians identifying research priorities.

Figure 2 illustrates this literature in terms of direct and indirect engagement of non-researchers with research, and the outputs of these activities.

Figure 2: Patients' and clinicians' engagement with research directly and indirectly, and their outputs

Studies of non-researchers' engagement with research	
Direct engagement	**Indirect engagement**
61 studies identifying non-researchers priorities, of which • 44 describe health conditions / states which are a priority • 11 describe interventions they want researching • 20 describe their priority health outcomes • 5 describe priority populations 5 studies report non-researchers views on measurement tools for research 96 studies of non-researchers priority research questions	76 studies of non-researchers perspectives on health / health services 11 studies report non-researchers views on clinical measurement tools • 3 on Quality of Life tools • 8 on condition-specific tools
Total: 150	**Total: 87**

e. Working in single or mixed groups

Thus far we have considered "clinicians and patients" as a single group of 'non-researchers'. However, we know that they are likely to have differing research priorities[26] and need to be considered separately.

We found that within the 148 studies, in which participants identified research topics, 38 included doctors, 123 included other health professionals (in 93 of which these were nurses), 27 included patients or carers and 17 included additional groups such as researchers, research funders, national agency staff, local government officials and administrators.

It was more common for patients and clinicians to work separately on identifying research topics, rather than collaboratively. Furthermore patients were less likely to be consulted as to their research priorities than clinicians.

In 120/148 studies, the people included were all of a single type. Ten included only doctors, 99 included only other health professionals, and 11 included only patients or carers (see Figure 3).
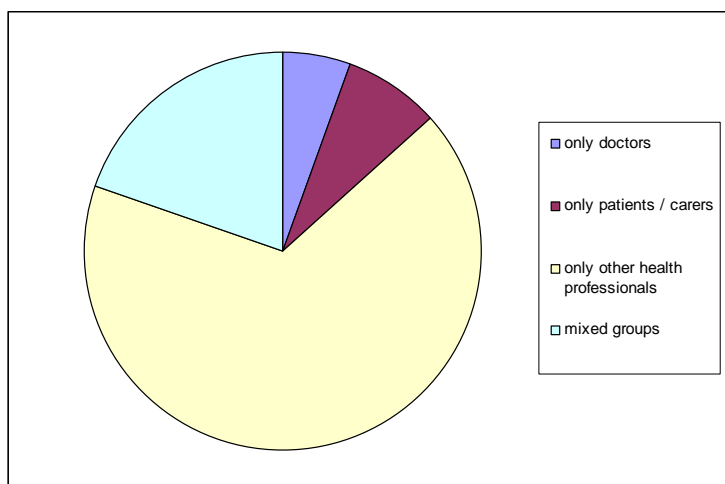
Figure 3: How people worked to identify research topics

In 28/148 studies people worked together in mixed groups. Ten studies included doctors and other health professionals. Four included doctors and patients/carers. Six included doctors, other health professionals and patients/carers, while a further six included doctors, other health professionals, patients/carers and other groups who were neither clinicians nor patients/carers. Lastly two included doctors and other groups.

Focusing on the 96 examples where patients and clinicians specified detailed research questions: 12 included the views of patients' and carers', 24 included the views of doctors, 71 included the views of nurses, 24 included the views of health professionals other than nurses and doctors, and 5 included other groups in addition to patients and clinicians.

Of the 12 which included the views of patients' and carers', three included patients working on their own, 9 included patients working alongside doctors, and 4 included both doctors and nurses.

f. The health focus of research questions

The 96 examples between them, where patients and clinicians were involved in identifying full research questions, included a wide range of health conditions (see

Figure 4[v] and Appendix 6 for full details). Many studies include more than one health condition. Many studies included priorities relating to generic health care such as nursing care, or general health services, rather than specific conditions. Whilst further classification may be possible in the future, at present these are encompassed within 'other'.

Figure 4: An overview of the health topics included in the 96 studies in which research questions are identified

Health topic	Count
Cancer (including Head and Neck cancer)	15
Cardiovascular diseases (including Heart disease, heart failure, stroke)	2
Ear, nose & throat (incl hearing disorders, otitis media, Rhinitis, Tonsilitis)	2
Oral and dental conditions	1
Gastroenterological and liver diseases	0
Eyes and vision	1
Neurological conditions (inc Epilepsy)	2
Haematological disorders	2
Infection	5
Musculoskeletal diseases	5
Mental health (incl Learning disabilities, Depression and Schizophrenia)	10
Neonatal diseases	3
Women's health conditions (inc Endometriosis, Pregnancy and childbirth and Hypertension in pregnancy)	5
Urological and genital (inc Incontinence and Kidney diseases)	5
Nutritional metabolic and endocrine disorders (incl Diabetes and thyroid disorders)	2
Respiratory diseases (inc asthma)	2
Skin disorders (acne vulgaris, atopic eczema, Psoriasis, skin infections)	2
Symptoms	2
Trauma	4
Other	61

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[v] These are presented according to the DUETS categories, but are also available in the UKCRC health categories.

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g. Eliciting patients' research questions

In order to provide further insight into the priority setting activities in which patients and carers were engaged, we selected the studies that described patients and carers identifying full research questions.[26-37] Of these 12 studies, six were written by researchers who were also practitioners, and two by user-researchers. All 12 included patients as participants in identifying research questions. Three of these included only patients, 9 also included doctors and 4 included both doctors and nurses.

The 12 studies varied in the health topics covered including: cancer, respiratory diseases (specifically asthma), nutritional metabolic and endocrine disorders (specifically diabetes), urological and genital (specifically incontinence and kidney disease), infection' mental health (including depression) and general health relevance.

Two of the 12 studies did not report the actual research questions identified. Ten of the 12 reported the prioritised research questions.[27-33;35-37] An abstract for each of these ten is included below and the identified research questions are listed in Appendix 7.

Brown and colleagues reported the research priorities of people with diabetes from an inner-city community, compared with current expert-led research priorities in diabetes.[27] This was a qualitative study using a participatory approach with consumer groups in Nottingham, England. 39 adult patients with diabetes with varying ethnic backgrounds were recruited from three general practices. Six focus groups were conducted (Asian women; Asian men; Afro-Caribbean men; mixed culture and sex; white mixed sex). Participants were asked firstly to consider important areas in their life and secondly how these would influence research they would like to see carried out in diabetes. They were asked to think about order of priority, but this was not a consensus seeking exercise. The results were analysed using the constant comparative method. Nine main themes around important aspects of the lives of people with diabetes were identified, each leading to the development of nine specific research themes/questions.

Caron-Flinterman described patients and carers, clinicians and other health professionals, as well as researchers and scientists, working together to identify research questions in Chronic Obstructive Pulmonary Disease (COPD), asthma

and kidney disease.[38] Participants included a broad range of healthcare professionals concerned with these conditions. Professionals were drawn from "a variety of medical and paramedical disciplines", including biomedical, social, clinical and epidemiological scientists researching asthma and COPD. Initially different stakeholder groups (health care professionals, biomedical scientists, socio-cultural scientists and patients) identified their research priorities. A mixed group of 24 stakeholders, which included representatives from each of these groups, then met to identify a shared list of research questions and identified 14 high priority questions.

Corner and colleagues reported the findings of a consultation conducted with UK cancer patients concerning research priorities, using an exploratory, qualitative approach.[29] Consultation groups were the main method of data collection, combining a focus group approach with an adapted Nominal Group technique. Seventeen groups were held with a total of 105 patients broadly representative of the UK cancer population. 15 areas for research were identified.[vi]

The aim of **James and colleagues'** work was to identify local research priorities for primary care mental health.[30] A conventional three-round Delphi exercise was used involving approximately 30 participants, including GPs, psychiatrists, primary care nurses, a clinical psychologist, directors of the mental health charity MIND, and users of primary care services. In the first round participants were asked to nominate up to 5 topic areas relating to mental health in primary care which they felt required further research. Their responses were used to construct questionnaires for rounds 2 and 3, which required them to rate and re-rate the relative importance of items on a scale from 1 (essential) to 5 (unimportant). Where a participant's rating differed considerably from the group median, he or she was invited to comment further. No items received a median rating of 1 (essential) or 5 (unimportant). Twenty two items received a median rating of 2 (very important).

Johanson and colleagues describe a research meeting of the ASQUAM group (Achieving Sustainable Quality in Maternity).[31] The objectives were to choose a new set of research priorities for the year 2000, and to ascertain the voting pattern of consumers in comparison to health professionals. There were 10 discussion groups, each with approximately 10 participants from a mixture of backgrounds,

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[vi] Whilst not all of these research priorities were worded as full questions, they can be interpreted as such if you assume the intention is 'to evaluate x,y and z'.

including obstetricians, senior midwifery staff, general practitioners, paediatricians and consumers. In all there were 90 health professionals and 11 consumers. The leader of each group introduced key research issues and welcomed novel ideas from participants. From the many topics discussed during the one-hour session, each of the 10 groups chose by consensus two topics that they wished to propose (framed within the terms of health technology assessment). Following short presentations on all 20 topics, all delegates voted on paper for up to 10 topics, without ranking, in order to identify the ten most popular. These ten questions are reported.

Johnson and colleagues described an initial information gathering exercise during a 6-month outreach effort which generated 150 research questions in child welfare.[32] A subset of 97 stakeholders who had participated in the original exercise was selected to clarify and prioritise these questions, although only 61 eventually participated. Participants were selected based on their knowledge, experience and responsibility for serving children and families in connection with the Illinois Department of Children and Family Services (DCFS), or their membership of the Child Care Association of Illinois. The researchers were also part of the stakeholder group. A Delphi technique was used to gain consensus on the research questions. By the final round, 34 research priorities were identified as a feasible agenda.

Jones and colleagues reported and reflected on an advisory group which met during 1993 to determine 21 priority topics for research and development funding, in relation to the interface between primary and secondary care.[33] The group consisted of 16 members from a range of disciplines, including nursing, medicine, management, researchers and consumers. The advisory group formed 3 panels which considered, respectively, entry to secondary care, exit from secondary care and shifts in the balance of care. Each panel reviewed existing evidence, considered responses to large scale consultations, and identified key issues to forward to the advisory group. Twenty five topics were forwarded and a master list of 21 was agreed for scoring. Topics of low agreement were discussed and rescored. Mean scores were used to produce a list of topics in priority order. The top ten topics were reported.[vii]

[vii] Whilst not all ten are reported as full research questions, they can be interpreted as such if you assume the intention is 'to evaluate x,y and z'.

Renvoize and Patel reported initiatives undertaken by the Lancashire Dementia Research Interest Group (LADRIG) for the positive promotion of research into dementia.[35] This group attempted to give people with dementia and their carers an active role in the development of research projects. At an initial, exploratory meeting, three sub-groups were established to generate potential research ideas, involving two or three brainstorming sessions. All groups included a mix of professionals (academic and clinical), representatives of the users of older people's psychiatric services, carers and voluntary agencies. The number of people is not reported. Each group reported back to the main group with a maximum of three possible topics for research, 6 of which are reported in the paper.

Whitehead and colleagues described patients, doctors, nurses and other health professionals identifying research priorities for faecal and urinary incontinence.[36] Prior to a consensus conference, an unspecified number of representative experts from all disciplines that treat incontinence (gastroenterology, urology, urogynaecology, colorectal surgery, geriatrics, neurology, nursing and psychology), were asked to identify the three most important research priorities from the perspective of their disciplines. Following the consensus conference, which also included patient advocates, a steering committee generated 12 revised priorities.

Zulu and colleagues reported patients and carers, clinicians and other health professionals working together to identify research questions in HIV/AIDS.[37] Participants included representatives from the Zambia Network of People living with HIV/AIDS and international HIV clinicians, as well as researchers from medical institutions, members of the Ministry of Health, National AIDS Council staff, NGO representatives, and members of the public media. Together they prioritised six questions.

4.4 Reflecting on the work of the James Lind Alliance in relation to the wider literature

The James Lind Alliance (JLA) describes itself as focussing on 'tackling treatment uncertainties together'. It facilitates patient organisations and clinician organisations working together to identify and prioritise uncertainties about the effects of treatments. Each Working Partnerships includes at least one patient organisation and at least one clinician organisation. They work on the principle that

patients should, whenever possible, present their interests and views in JLA Working Partnerships. When they are unable to so, the families or other carers of patients, or other non-clinician advocates, may try to represent their interests. Similarly they believe that the clinicians taking part in a JLA Working Partnership should include those who are routinely involved in treating patients with the health problem(s) being considered.

The James Lind Alliance draws on and informs the Database of Uncertainties about the Effects of Treatments (DUETs). This resource collates and publishes research questions for which there is no systematic review evidence, encouraging researchers and research funders to focus on these unanswered questions. How DUETS has been populated was not included in the map reported here.

In the context of this map of the literature, it is worth noting that reports of the James Lind Alliance's activities[39-41] are authored by James Lind Alliance staff or consultants, rather than either the clinicians or the patients involved in the working partnerships. As such they fall within the 60 studies (60/258 or 23.3%) considered in this map which were authored by neither health professionals nor service-users. This raises questions about who is drawing conclusions about James Lind Alliance working partnerships.

The James Lind Alliance Working Partnerships involve patients and clinicians working separately to identify research questions of importance to them and coming together in working partnership meetings to discuss and prioritise these. This review found that 148/258 or 57.4 % of studies described participants identifying research priorities, of which 96 (96/148 or 57.4%) include identification and prioritisation of full research questions (not only topics). Of these 96, only 12 included the views of patients' and carers', three of which included patients working on their own, 9 included patients working alongside doctors, and 4 included both doctors and nurses i.e. only 9 of the 148 studies (6.1%) included patients and clinicians working alongside one another to prioritise research questions. These results show that the activities of the JLA working partnerships, bringing patients and clinicians together to prioritise research questions, are rare, with only 9 other accounts identified in the literature of patients and clinicians working together in this way.

Thus far the James Lind Alliance has formed two working partnerships in the areas of asthma and urinary incontinence. Two reports of activities in these areas

identified in this map are likely to be particularly significant to these JLA Working Partnerships, Francisca Caron-Flintermans' account of patients and clinicians prioritising research questions in asthma[38], and William Whitehead's report of similar work in the area of urinary incontinence.[36]

5. So what do our findings mean?

5.1 What have we learnt?

We found a sizable research literature (258 reports) addressing patients' and clinicians' priorities for research and outcomes for assessment. This literature described different routes for patients and clinicians to contribute to research agendas, engaging directly or indirectly with research, in order to identify important areas for research, questions for research and tools for assessment.

Clinicians tend to be more involved than patients in the whole process. Patients are less likely to be involved in writing reports of these activities than clinicians and less likely to be consulted as to their research priorities than clinicians. It was more common for patients and clinicians to work separately on identifying research topics, than collaboratively.

We found that patient and clinician involvement in setting research agendas has taken place of a wide range of health topics, and in particular in the areas of cancer and mental health. There are 148 studies of patients or clinicians directly engaged with research in order to identify important research topics, questions and assessment tools.

Ten studies that reported patients identifying research questions employed a range of approaches to developing priorities, including explicit consensus development methods. This is in contrast to an earlier systematic review of public involvement in setting research agendas, where few studies reported their methods in detail, and very few reported sharing decisions with patients using explicit consensus development methods.[42]

Reflecting on the activities of the JLA Working Partnerships in relation to the findings of this map of the literature, we found that the work of the James Lind Alliance is highly distinctive, with only nine other accounts of patients and clinicians 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[38] and urinary incontinence.[36]

5.2 Is what we found reliable and trustworthy?

In order to conduct this work we developed clear definitions for approaches that researchers have adopted to involve patients and clinicians directly or indirectly in priorities for research and outcomes for assessment. These definitions covered areas of discussion (services, health and research); what was elicited from participants (their descriptions, preferences, values, measures and research questions). These definitions were complemented by definitions of health conditions supplied by UKCRC. These definitions were successfully applied to describe the literature about patients' and clinicians' research priorities across a range of health conditions.

We took steps to ensure the descriptions are as accurate as possible with two researchers independently describing each study and then comparing their work. Furthermore by accessing full texts of reports rather than only abstracts we have increased the reliability compared with earlier work.

Despite our efforts to reduce inaccuracies and bias, it is possible that we have missed some important examples of patients' and clinicians' and research priorities. We drew on searches conducted in the autumn of 2006[1], without updating them, but extending them by searching other sources. Not all reports were available within the timeframe for this project. Since conducting the search and analysis for this report we have become aware of another recently published and potentially relevant example of patient involvement in setting research agendas for patient safety and a systematic review of studies determining which outcomes to measure in clinical trials with children, both of which warrant further investigation in a full systematic review.[43;44]

Lastly, whilst this map of the literature on patients' and clinicians' research priorities is the most comprehensive that we know of, it only describes the relevant literature and does not assess its quality.

5.3 Conclusions and recommendations

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 clinician involvement in setting research agendas would inform these discussions. In particular, having identified a literature about patients' and clinicians' priorities for research and outcomes for assessment, we recommend:

1. The studies that report patients' and clinicians' engagement with research are investigated in more detail for their methods and the quality of those methods, and the priorities they identify.
2. The DUET bibliographies relating to particular health categories (Appendix 6) are updated.
3. The James Lind Alliance highlights on its web site findings of interest to key potential users:
   a. Health or intervention topics that patients or clinicians considered deserving research highlighted for funders of responsive programmes to inform the scope of their programmes, or the priorities within them.
   b. Research questions from patients or clinicians yet to be addressed highlighted for funders of commissioning programmes and research teams seeking funds from responsive programmes.
   c. Measures for use in research endorsed by patients or clinicians highlighted for research teams.
4. Priority research topics and questions, and the studies that identified them, are matched to funders of relevant commissioned and responsive programmes to inform their agendas and procedures for patient and clinician involvement (see report by TwoCan Associates for the James Lind Alliance).

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Ref Type: Report

Appendix 1: Methods

1.2 Identifying studies

Building on the James Lind Alliance Bibliography

All included studies from the James Lind Alliance Bibliography (2006) were included in the review, the search strategy for which is described in Appendix 2.

Additional electronic searching

We searched the Cochrane Methodology Register for reports coded "timing and choice of research questions".

Contacting key individuals

Rather than relying on electronic databases alone, we sought reports from members and affiliates of the James Lind Alliance. Relevant 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; and Tallon D.

Creating a shortlist of potentially relevant papers to be included in further stages of this review

On the completion of this systematic map we sought additional potentially relevant studies by:

- Searching electronically for reports citing key papers. Citation searching for these key papers was carried out in the Science Citation Index Expanded (SCI-EXPANDED)-1970-present, Social Sciences Citation Index (SSCI)-1970-present and the Arts & Humanities Citation Index (A&HCI)-1975-present.
- Inspecting the reference lists of relevant studies to extend the search.

These papers were not available in time for inclusion in this report, however, we recommend that full text copies be obtained and examined for relevance for any subsequent work.

Screening

Between them two researchers screened the titles and abstracts of reports all reports identified in our searching. Full reports of all those deemed to be about patients' or clinicians' research priorities were sought. The full reports were then screened a second time by both researchers to ensure they were relevant.

1.2 Describing studies

Ensuring accuracy in describing studies

Two researchers independently described each study and compared their answers until they were confident that they were describing the studies in this way. In all, 60% of studies were described by two researchers. The remainder of the studies were then coded by one researcher.

How each study was described

In describing each study, the researchers considered:

- Who authored the report, specifically whether the researchers involved were also service users and / or health practitioners.

- Whether the report described:
  o Participants describing experiences of or preferences for health or health services
  o Participants describing experiences of or preferences for research processes in general
  o Participants contributing to the development of an assessment tool for clinical practice or for research
  o Participants identifying research topics, including patients or carers, medics, nurses, other health professionals, or other groups of people.

Those papers which described participants identifying research topics, including patients or carers, medics, nurses, other health professionals, or other groups of people; were then described in more detail in terms of:

- Whether the participants identified:

  o full research questions
  o specified only the outcomes, populations or interventions for research
  o specified only broad topics for research

- What health topic was the focus of the study

Lastly, those papers which described patients and carers contributing to research priorities where the participants identified full research questions were described in terms of the UKCRC research activities, namely:

  o Underpinning Research
  o Aetiology
  o Prevention of Disease and Conditions, and Promotion of Well-Being
  o Detection, Screening and Diagnosis
  o Development of Treatments and Therapeutic Interventions
  o Evaluation of Treatments and Therapeutic Interventions
  o Management of Diseases and Conditions
  o Health and Social Care Services Research

Appendix 2: Search strategy for the James Lind Alliance Bibliography[i]

Hand searching

All issues of the journal *Health Expectations* (i.e. 1998-2006) were searched for relevant studies.

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.

Electronic search strategy

Sixteen studies from the earliest James Lind Alliance Bibliography 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 below was adopted and adapted to the following databases:

- MEDLINE 1996 – present
- EMBASE 1974 – present
- PsycINFO – 1986 to date
- CINAHL (R) – 1982 to date
- AMED 1985 – present
- The Cochrane Methodology Register

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

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

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-CARE.MJ.	11212
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	216913

		OR LAY OR USER OR USERS).TI,AB.	
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: The results of our searching

We identified 640 citations for screening from the following sources. (NB some papers were identified from more than one source.)

- o 296 from the JLA bibliography (systematic searching done in 2006)

- o 13 from contacting authors identified from the James Lind Alliance Bibliography: Chalmers, I; Chard, J; Cohen CI; Cream J; Dieppe P; Kirwan J; Oliver S; Tallon D.

- o 13 from additional contacts

- o 85 from PRIME database (suggested by a member of the James Lind Alliance Strategy and Development Group), searched 30/01/08

- o 244 from re-searching the Cochrane Methodology Register on 29/01/08

Duplicates were removed and then two researchers independently screened all citations for relevance based on the title and abstract. As a result 401 studies were included in the review and full texts sought. We were able to collect 382 full reports:19 weren't available within the time frame of this work.

Two researchers then double screened on full reports and identified linked papers leaving 258 studies of clinicians' and patients' views.

At the completion of the project (June 08) we identified the 27 key papers from the 258 within the review (specifically those which described patients'/carers' research priorities - see 4.3c) and ran citation searches on these. The results of these citation searches are described below.

We identified 163 additional references, 122 of which were excluded on titles. The abstracts of the remaining 41 were obtained and screened to identify whether or not they described clinicians' or patients' research agenda setting, and if so, whether they were already included in the review or were in fact 'new' reports.

18/41 were identified as relevant to this map of the literature and 13/18 were identified as 'new' reports. They are listed in Appendix 4.

In addition, the reference lists of these 27 key papers (those which described patients'/carers' research priorities - see 4.3c) were searched and potentially relevant papers identified.

This yielded a further 22 potentially relevant papers. These are listed in Appendix 5.

The results of our searching are illustrated in Figure 1.

Figure 1: The results of our searching

SEARCHING

- 296 from the JLA bibliography
- 13 from contacting authors identified from the JLA bibliography
- 13 from additional contacts
- 85 from PRIME database
- 244 from re-searching the Cochrane Methodology Register
- 163 from citation searches
- Reference lists of 27 papers searched

SCREENING ON TITLE AND ABSTRACT

640 citations for double screening

239 excluded as duplicates or irrelevant

401 Included and full texts sought

13 included on abstract

22 included on title

COLLECTING FULL TEXTS

19 full reports unavailable

382 full reports collected for further screening

SCREENING ON FULL TEXTS

124 excluded as linked papers or irrelevant

258 studies included in this map

35 for inclusion in any subsequent work on patients' and clinicians' research priorities

Appendix 4: Additional references identified from citation searches

1. Hanley B, Truesdale A, King A, Elbourne D, Chalmers I. (2001) Involving consumers in designing, conducting, and interpreting randomised controlled trials: questionnaire survey. *British Medical Journal*, 322 (7285): 519-523

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Appendix 5: Additional references identified from searching reference lists

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Appendix 6: The health topics included within the 96 studies in which research questions are identified

Health topics	N
Cancer (including Head and Neck cancer)	15
Head and neck cancer	1
Cardiovascular diseases (including Heart disease, heart failure, stroke)	2
Stroke	0
Heart disease	0
Heart failure	0
Ear, nose & throat (incl hearing disorders, otitis media, Rhinitis, Tonsilitis)	2
Hearing disorders	1
Otitis media	0
Rhinitis	0
Tonsillitis	0
Oral and dental conditions	1
Gastroenterological and liver diseases	0
Eyes and vision	1
Neurological conditions (inc Epilepsy)	2
Epilepsy	0
Haematological disorders	2
Infection	5
Musculoskeletal diseases	5
Mental health (incl Learning disabilities, Depression and Schizophrenia)	10
Learning disabilities	1
Depression	2
Schizophrenia	1
Neonatal diseases	3
Women's health conditions (inc Endometriosis, Pregnancy and childbirth and Hypertension in pregnancy)	5
Endometriosis	0
Pregnancy and childbirth	4
Hypertension in pregnancy	0
Urological and genital (inc Incontinence and Kidney diseases)	5

Incontinence	1
Kidney diseases	4
Nutritional metabolic and endocrine disorders (incl Diabetes and thyroid disorders)	2
Diabetes	2
Thyroid disorders	0
Respiratory diseases (inc asthma)	2
Asthma	1
Skin disorders (acne vulgaris, atopic eczema, Psoriasis, skin infections)	2
Acne vulgaris,	0
Atopic eczema,	0
Psoriasis,	0
Skin infections	0
Symptoms	2
Trauma	4
Other	61

Appendix 7: Research questions identified in the sample of ten studies

STUDY: Brown K, Dyas J, Chahal P, Khalil Y, Riaz P, Cummings-Jones J. (2006). Discovering the research priorities of people with diabetes in a multicultural community: a focus group study. British Journal of General Practice, **56,** 524, 206-213.

1. *Improving information.* What are the best ways of delivering information about diabetes to certain communities?

2. *Lack of public awareness.* What is the extent of knowledge and understanding of diabetes in the general population? Does improving certain groups' knowledge help improve the outcomes of people with diabetes?

3. *Improving information about food.* How can information about food and diet best be delivered to people with diabetes? What factors influence the application of knowledge about food and diet into improving health outcomes for diabetic people?

4. *One-to-one support:* Investigating the role of 'important others' in the health education of people with diabetes

5. *Health services:* How can services best support people with diabetes?

6. *Prevention and screening:* How best can the messages of prevention of diabetes be delivered? What is the understanding of risk in people with diabetes?

7. *Difficulties of co-morbidity:* How does co-morbidity influence the self-management of diabetes?

8. *Value of exercise:* How can exercise be incorporated into the management of people with diabetes? How is the value of exercise best delivered to people with diabetes?

9. *Self-management:* What factors influence the self-management of diabetes in the Asian community? What are the perceptions of people with diabetes about their condition and how does it influence their self-management?

STUDY: Caron-Flinterman F. (Sep 2005) A New Voice in Science. Patient participation in decision-making on biomedical research. PhD Thesis. Vrije University, the Netherlands.

1. research on genetic factors causing asthma

2. research on genetic factors causing COPD

3. research on environmental factors and lifestyles that influence the onset of asthma

4. research on environmental factors and lifestyles that influence the onset of COPD

5. research on causes and mechanisms of increase or decrease of asthma symptoms

6. research on the cause and mechanisms of COPD during life

7. Research on relations between COPD and other diseases

8. Research on smoking behaviour and on interventions that influence starting and stopping with smoking

9. Research on interventions that prevent the onset of asthma

10. Research on interventions that prevent the onset of COPD
11. Research on the earliest stages of asthma and on methods to detect these stages
12. Research on the earliest stages of COPD and on methods to detect these stages
13. Research on improving the treatment of asthma based on individual disease characteristics
14. Research on improving the treatment of COPD based on individual disease characteristics
STUDY: Corner J, Wright D, Hopkinson J, Gunaratnam Y, McDonald JW, Foster C. (2007). The research priorities of patients attending UK cancer treatment centres: findings from a modified nominal group study. British Journal of Cancer **96**, 875-881
1. Impact on life, how to live with cancer and related support issues
2. Risk factors and causes
3. Early detection and prevention
4. Research into general information needs (on cancer, treatment, research and access to)
5. Use and effectiveness of complementary and alternative therapies
6. General education of public about cancer
7. Research into different cancer and patient types
8. Research on treatment (curative treatment, treatment types and improvements)
9. Experiences and management of side effects
10. Organisation of funding of health and social care services
11. Co-ordination, impact and funding of research
12. Research into recurrence
13. General communication issues involving all parties
14. Accessing patients' views about cancer, services and research
15. Health and safety in the hospital
STUDY: James P, Aitken P, Burns T. (2002). Research priorities for primary care mental health: a Delphi exercise. Primary Care Psychiatry **8**, 1, 27-30
1. The best use of counselling psychology in primary care
2. The use of registers for sever mental illness in general practice
3. The ideal primary care-secondary care interface
4. The effectiveness of advice, guidance and structured review in the pharmacological treatment of depression in adults of working age
5. What are the minimal competencies required for delivering effective counselling in

	primary care?
6.	The management of anxiety/depression (implementing National Service framework)
7.	Can 'problem-solving' therapy reduce somatic presentation in primary care?
8.	Regular reviews of medical problems of the chronically mentally ill
9.	Patient satisfaction with primary mental health care
10.	More work on practice-based registers for seriously mentally ill
11.	GP criteria for antidepressant use in primary care
12.	What core competencies should a specialized mental health GP possess?
13.	The management of the physical and mental health of patients with severe and enduring mental illness
14.	Developing and testing training for the management of seriously mentally ill in primary care (GPs/practice nurses)
15.	Consultation intervals and best outcomes for treatment of depression in primary care
16.	Does primary care address the needs of carers who look after seriously mentally ill?
17.	The use of pharmacists for monitoring medication collection of seriously mentally ill
18.	Do seriously mentally ill registers improve chronic disease management in primary care?
19.	Interaction, communication and information sharing between primary and secondary care
20.	Identifying and measuring the needs of dependent children of mentally ill patients at a practice level
21.	The effectiveness of 'counselling' versus cognitive behaviour therapy in the treatment of common mental disorders in primary care
22.	The role of primary care in promoting mental health within the community (i.e. improving mental health)
STUDY: Johanson R, Rigby C, Newburn M, Stewart M, Jones P. (2002) Suggestions in maternal and child health for the National Technology Assessment Programme: a consideration of consumer and professional priorities. The Journal of The Royal Society for the Promotion of Health, **122** (1), 50-54	
1.	Ways of avoiding urinary incontinence after childbirth.
2.	Ways of providing appropriate information preconceptually to patients with existing medical conditions.
3.	Ways of improving community postnatal care.
4.	Fluid management in pre-eclampsia.
5.	Neonatal examination. What form is best: none, by midwife, by doctor?

| 6. | Using limited resources well, e.g. 'Why do women choose an elective caesarean section?' |

| 7. | Best ways of achieving genuinely informed consent to take part in a trial. |

| 8. | Assessment of ways of optimising foetal position antenatally and during labour. |

| 9. | Interpretation and expectations of tests, including the best ways of predicting foetal weight and assessing impact of follow-up of identified high-risk cases. |

| 10. | Does training people specifically to 'listen to the patient' improve outcomes? |

STUDY: Johnson MA, Wells SJ, Testa MF, McDonald J (2003) Illinois's child welfare research agenda: an approach to building consensus for practice-based research. Child Welfare, **82**, 1, 53-75.

CHILD PROTECTIVE SERVICES

1. Domestic violence and child maltreatment: What is the relationship between domestic violence and child maltreatment? How many children who come to the attention of DCFS come from domestically abusive environments? How does ongoing domestic violence affect the recurrence of child abuse and neglect?

2. Welfare reform: How will changes in welfare policy impact caseload dynamics? Is income loss due to Temporary Aid to Needy Families sanctions associated with increased child maltreatment reports, investigations, or recurrence of abuse and neglect?

3. Subsequent indicated report: What factors are associated with recurrence of child abuse and neglect after case opening? Do children with indicated reports after case opening differ by care type, e.g. kinship, institutional, family foster homes?

4. Reasonable efforts: How are reasonable efforts to prevent placement defined, and what do they mean to front-line workers?

5. Defining maltreatment and injury: Are there specific definitions of child maltreatment and injury that can be used uniformly in the field? Are there standards for deterring these definitions?

6. Factors affecting reporting and placement: What factors account for racial and ethnic disparities in the population rates at which children are reported, later removed, and placed into substitute care?

7. Prediction of safety and evaluation of the state's risk-assessment protocol: What factors best predict the safety of a child in each type of living arrangement? Did the implementation of the Child Endangerment Risk Assessment Protocol (CERAP) result in reduced rates of recurrence of maltreatment for families diverted from DCFS involvement? Do CERAP safety plans address safety factors checked? What interventions are most effective in ensuring child safety in different types of family circumstances?

8. Effectiveness of service delivery reforms: How will reuniting investigation, assessment and services components through front-end redesign affect service delivery and child safety?

FAMILY MAINTENANCE

9. Outcomes associated with provision of intact family services: What is the average length of time from intact case closure to subsequent oral report, indicated

subsequent oral report, and the child's re-entry into care?
10. Effectiveness of specific intact family services interventions: What is the effectiveness of specific interventions used in intact family services? How do the structure and delivery of specific interventions affect case outcomes? Do outcomes differ for cases receiving different types and intensities of services? What is the effectiveness of specific interventions used in intact family services?
11. Relationship between client needs and service provision: What is the relationship of service provision to client needs? What services are provided? Who received what services?
FAMILY REUNIFICATION
12. Impact of timelines of service delivery: Do delays in receiving services impact outcomes in a way that is different from cases receiving timely service provision?
13. Factors associated with family reunification declines: What percentage of children should not or cannot go home? Why? What factors help explain the continuous decline in family reunification rates in Illinois in comparison with other large states? What interventions (e.g. visitation) will result in more timely and permanent reunification? How can DCFS ensure appropriate use of interventions?
14. Effectiveness of parent education: What are the functions and relevance of parent education classes in child protection cases? What models of parent education (e.g., hands-on classes, traditions formats, etc.) are most effective in chills protection classes?
TARGET POPULATIONS: SUBSTANCE-EXPOSED INFANTS
15. Short and long-term effectiveness of enhanced substance abuse treatment programs: Do enhance substance abuse treatment programs for drug-affected parents significantly increase rehabilitation rates over and above regular programs? What are the characteristics of these programs (type of program, nature and extent of participation)? How do these programs impact child welfare outcomes? What are the short-and long-term results of participation in these programs for children and families? What is the incidence of maltreatment reports among families with substance-exposed infants in states that monitor and provide services to families with substance-exposed infants but do not automatically open a child welfare case for families?
16. Variations in hospital screening: How do drug testing and screening protocols and practiced of welfare recipients for substance-exposed infants vary among hospitals?
SUBSTITUTE CARE
17. Well-being of children in substitute care and factors related to deficits: What is the general well-being of children in substitute care, and how does well-being vary by living arrangement? What accounts for well-being deficits of children in care?
18. Long-term outcomes for children leaving care: What are the long-term outcomes for wards after they leave DCFS care? What would longitudinal study of wards leaving care demonstrate?
19. Prevalence and outcomes of use of psychotropic medications with children in care: What number of children in DCFS custody are prescribed and taking psychotropic medications? What are the types of medications wards are taking, the behaviours for which they are prescribed, and the effectiveness of those medications? Does the number of children in DCFS custody prescribed psychotropic medications differ by

region and ethnicity?

20. Delinquency and violent offenses for children in care: How many wards have delinquency charges and are later charges (after the age 13) with serious violent felonies? How much later? In what statuses? How do these numbers compare with the general child population?

21. Perspectives of children in care and their caregivers: How do parents with children in state custody and foster parents experience their involvement with DCFS? How do their perspectives affect their children? How do children experience their living situations and their involvement with DCFS?

22. Assessment techniques and practice integration: What methods exist for helping workers evaluate he needs of children in care and how can their assessments be assembles into service plans and tracked for progress? To what extent does the assessment address the issues that result in involuntary DCFS involvement or placement? To what extent do goals and plans target the issues identified in the assessment and do workers follow the service plan or explain deviations form it? Do goals and plans that track from first referral to current interventions result in greater case success? How does this differ by type of case?

23. Success and improvement of service linkages: How can children be better linked to services (e.g. health, behavioural health, education, developmental disabilities)? What is the current status of linkage to service, follow-up, and actual service delivery by team? What practices or situations are not effective in ensuring successful linkages? What DCFS practices create a supportive environment for ensuring linkages?

24. Effectiveness of substitute care settings in addressing child problems: How effective is residential treatment/care and foster care in addressing children's presenting problems? How do the effectiveness of different types of care compare? What factors contribute to the effectiveness of treatment/care? What steps can DCFS take to ensure quality and the effectiveness of substitute care?

25. Methods of enhancing practice and performance: What changes in management information systems, administrative case review, and quality assurance management systems can be implemented to enhance practice and performance at all systems levels to improve child welfare outcomes?

26. Impact of performance contracting: How does performance contracting affect quality care and long-term outcomes? What agency practices contribute to the success of performance contacting?

ADOPTION AND GUARDIANSHIP

27. Factors associated with disruption and dissolution: What child, family and service factors either support or jeopardize adoption and guardianship stability?

28. Differences in outcomes by permanency arrangement: How do outcomes differ by type of permanency arrangement (relative adoption, foster care adoption, new parent adoption, and subsidized guardianship)?

29. Identification of permanency achievements factors: What factors, individually and collectively, promote the timely, safe achievement of permanency for children?

30. Prevalence of termination of parental rights in the absence of permanent placements and effects on children: Are parental rights being terminated when no potential permanent placement exists? What are the effects on the child of termination when no other potential family connections exist? Should termination occur in this situation?

31. Effects of separating sibling for adoption: What is the effect of not placing siblings together for adoption on children and reunification?
32. Commitment of families to children and children's sense of belonging in subsidized guardianship and long-term relative care arrangements: Are families in subsidized guardianship arrangements more committed (e.g., more ready to accept permanent responsibility for the child, more accepting of the child as part of the family) to children in their care compare to those in long-term kinship foster care?
33. Impacts of new permanency initiatives and concurrent planning on achievement of permanency: What effects do the new permanency initiatives and concurrent planning have on achieving permanent homes for children?
34. Best practices in achieving permanency: What is best practice in adoption services, including post-legal service? What strategies result in reducing the period of time children remain in care before termination of parental; rights? What strategies result in stabilizing adoptive parental rights? What strategies result in stabilizing adoptive placements and adoptions? What strategies increase the adoptive placement minority children?
STUDY: Jones R, Lamont T, Haines A. (1995). Setting priorities for research and development in the NHS: A case study on the interface between primary and secondary care. British Medical Journal **311,** 7012, 1076-1080.
1. Transfer of information across interface between health care professionals and other agencies
2. Evaluation of clinical guidelines at the interface
3. Appropriate access, use, and location of diagnostic facilities and new technologies
4. Impact on referrals and discharge of including patients and carers in decision making
5. Appropriateness of outpatient follow up
6. Evaluation of treatment by referral versus management in primary care
7. Impact of purchasing arrangements on interface
8. Aftercare: rehabilitation and community care for priority groups
9. Prescribing across the interface
10. Models of intermediate care
STUDY: Renvoize E, Patel J. (2002) Consumer voices steer the course of research. Journal of Dementia Care **10**, 5, 37-8
1. The use of eye movement tests and neuropsychological measures in diagnosis of dementia
2. The relationship between beta-amyloid and Alzheimer's disease and the action of 'anti-dementia' drugs
3. An epidemiological study across the trust to investigate prevalence, type of dementia and service needs of people with younger-onset dementia
4. Carers' groups – a comparison of the benefits of educational versus support groups
5. A study of interactions between ward staff and patients with dementia in comparison

with interactions between staff and patients with functional problems
6.   A study to investigate nurses' knowledge of patients with dementia in ward settings ('life review' information)

STUDY: Whitehead WE, Wald A, Norton N.J. (2004) Priorities for treatment research from different professional perspectives. Gastroenterology **126**, S180-S185.

FAECAL INCONTINENCE

1. Randomised controlled trials: evaluate different treatments and different combinations of treatments, i.e.: biofeedback vs. education and medical management; biofeedback strength training vs. sensory training; combined biofeedback plus surgery vs. each alone; combined biofeedback plus drugs vs. each alone; sacral nerve stimulation vs. biofeedback or surgery.

2. Development of novel treatments: develop and test new drugs for faecal incontinence; identify the most effective surgery for obstetric tears.

3. Optimise existing therapies: improve adherence and maintenance; evaluate long-term outcomes of surgery; identify psychological symptoms that predict who consults

4. Geriatric population: practical treatments for frail/demented/elderly; evaluate assisted toileting in nursing homes

5. Diagnostic tests: develop normative values for diagnostic tests; compare history and physical examination with diagnostic tests in predicting pathophysiology and response to biofeedback; evaluate electromyogram of external anal sphincter and puborectalis muscle for diagnosis of nerogenic faecal incontinence; evaluate relationship of quality of life to faecal incontinence severity (*patient advocate*); standardise evaluation of severity and quality of life (*patient advocate*); further studies of pathophysiological mechanisms

6. Prevention: determine which diagnostic tests predict obstetric injury; longitudinal studies of relationship of faecal incontinence to functional gastrointestinal disorders; prevent anatomic defects leading to surgery by modifying behaviours (e.g. straining or hard stools) (*clinician and patient advocate*)

7. Patient concerns: counter social stigma associated with faecal incontinence (*patient advocate*); provide better patient education regarding risk factors (*patient advocate*)

8. Paediatric gastroenterology: randomised controlled trial of laxative regimens in paediatric faecal incontinence; compare enemas with oral laxatives in paediatric faecal incontinence; compare enemas with toilet training in functional nonretentive faecal soiling; randomised controlled trial comparing appendicostomy, colostomy, sphincter reconstruction, and artificial sphincter in spinal cord injury and anorectal malformations.

URINARY INCONTINENCE

1. Treatment: compare drug, behavioural and surgical therapies; modify bothersome consequences of urinary incontinence in elderly; evaluate containment devices

2. Prevention: identify obstetric practices that are risk factors (*clinician and patient advocate*); modify surgical practices in radical prostatectomy (*patient advocate*); prevent/delay institutionalization of frail elderly; toilet training and early learning effects on development of urinary incontinence in later life *(patient advocate)*

3. Mechanism: develop mechanisms to block afferent nerves in bladder; investigate

mechanism for neuromodulation; investigate reflex inhibition of bladder contraction elicited by pelvic floor contraction; investigate pathophysiology of urinary incontinence to identify new therapy targets; investigate how treatment works in order to optimise it; identify predictors of outcome

4. Patient concerns: identify ways to reduce stigmatisation (*patient advocate*); investigate personal effects of urinary incontinence: depression and shame (*patient advocate*); increase coverage of incontinence in medical training (*patient advocate*); establish criteria for competence in continence treatment and educate third-party carriers (*health professional and patient advocate*).

STUDY: Zulu I, Schuman P, Musonda R, Chomba E, Mwinga K, Sinkala M, Chisembele M, Mwaba P, Kasonde D, Vermund SH (2004) Priorities for antiretroviral therapy research in sub-Saharan Africa: a 2002 consensus conference in Zambia *Journal of Acquired Immune Deficiency Syndromes* 36(3) pp. 831-834.

1. To determine when to initiate HAART in relation to CD4+ cell count

2. To assess whether HIV/AIDS can be managed well without the use of costly frequent viral load measurements and CD4+ cell count monitoring

3. To assess whether HIV/AIDS can be managed in the same fashion in patients co-infected with opportunistic infections such as tuberculosis and HIV-related chronic diarrhoea, taking into consideration complications that may occur in tuberculosis such as immune reconstitution syndrome and medication malabsorption in the presence of diarrhoea

4. To carefully assess and characterise toxicities; adverse effects, and viral resistance patterns in Zambia, including studies of mothers exposed to prepartum single-dose nevirapine

5. To conduct operational research to assess clinical and field-based strategies to maximise adherence for better outcomes of ART in Zambia

6. To assess ART approaches most valuable for paediatric and adolescent patients in Zambia.