The James Lind Alliance
"Tackling treatment uncertainties together"

Report

Scoping research priority setting (and the presence of PPI in priority setting) with UK clinical research organisations and funders

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- The expertise and networks of the UKCRC Patient and Public Involvement Project Group
- The expertise of medical charities involved in a PPI learning set programme, which is part of the wider work on PPI by the AMRC

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Acronyms used

AMRC	Association of Medical Research Charities
HTA	Health Technology Assessment
JLA	James Lind Alliance
MRC	Medical Research Council
NCCHTA	National Coordinating Centre for Health Technology Assessment
NICE	National Institute for Health and Clinical Excellence
NIHR	National Institute for Health Research
PPI	Patient and public involvement
PSP	Priority Setting Partnership
UKCRC	UK Clinical Research Collaboration

"OH, IT'S AN ACRONYM FOR 'IT DOESN'T STAND FOR ANYTHING.'"

The James Lind Alliance

The James Lind Alliance (JLA) is funded by the Department of Health and the Medical Research Council. It has a range of activities devoted to priority setting in research on treatment uncertainties and these include:

- Supporting Priority Setting Partnerships (PSPs), formerly known as Working Partnerships, which are made up of patient and clinician groups. These PSPs undertake shared activity, reviewing data on treatment uncertainties in their areas of interest, and developing a 'top ten' list of shared research priorities.

- Piloting methods for priority setting and engaging with patient/clinical groups on areas of treatment uncertainty that are not being addressed by current research.

- Developing resources to support partnerships and other organisations to set shared research priorities.

- Facilitating several symposia each year that address core issues relating to priority setting in clinical research, patient related outcomes, and patient and public involvement in all aspects of research.

- Providing presentations, articles and useful information to the research community, about priority setting in research.

- Commissioning projects to increase the evidence base on priority setting in research.

For more information about the JLA see

www.jla.nihr.ac.uk

TwoCan Associates

TwoCan Associates carry out R&D and provide training and support to help voluntary and statutory organisations involve people who use services in their work. For further information visit www.twocanassociates.co.uk or email us at info@twocanassociates.co.uk

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Executive summary

About us

1.   The James Lind Alliance, which is funded by the Department of Health and the Medical Research Council, undertakes a range of activities devoted to priority setting in research on treatment uncertainties. One of these is to commission projects to increase the evidence base on priority setting in research.

2.   This is a report of a scoping exercise commissioned by the JLA and undertaken by a company called TwoCan Associates (www.twocanassociates.co.uk).

What we did

3.   The aim of this scoping exercise was to find out whether and how clinical research organisations set research priorities and whether and how patients and the public are involved in this work.

4.   The scoping exercise involved:

- A review of the websites of UK clinical research organisations. A total of 104 websites were reviewed and 55 included in our analysis. 52 of the 55 organisations included in the website review provide funding for research.
- Telephone interviews with research managers or other relevant staff in 22 UK clinical research funding organisations that identify research priorities or commission research.
- A brief review of the literature on peer review and PPI in making funding decisions.

5.   This report summarises our findings across these three activities.

What we found

6.   The majority of the research funding bodies included in the review of websites (49 out of 52) were voluntary sector organisations or medical charities. Two were Department of Health funded bodies and one was a research council. Their research budgets ranged from tens of thousands to hundreds of millions of pounds.

7.   The majority of these organisations (31 out of these 52) operate in a responsive mode i.e. they rely on researchers to submit ideas for research and use a process of peer review to decide which applications to fund. Every one of the funding organisations included in the website review use a form of peer review to make decisions about which research to fund.

8.   21 of the 52 organisations reported that they had identified priorities for research. Many of these continue to accept all other research proposals from researchers.

Only a minority of organisations (7 out of 52) will only consider applications that address identified priorities. About one third of the organisations stated that they commissioned research. However, few identified how the topics for commissioned research were selected.

How are patients involved in decisions about funding research?

9.   There is considerable variation in the level of PPI in decision-making processes amongst the organisations included in this review. Some involve patients at every stage and appear to be patient-led in their decisions. Others only involve lay members as Trustees at the very final stage.

10.   If patients are asked to take part in decision-making processes they are often asked to review research proposals. The patient reviewers are usually asked to comment on different aspects of research proposals and/or at different times to the scientific reviewers. 11 out of the 52 organisations included in this review reported that they involve patients in assessing applications for funding.

11.   The literature review found little published evidence of the impact of PPI on funding decisions. However, there appears to be a growing trend towards PPI in peer review amongst patient organisations that fund research. It will be important to capture the impact of this involvement in future.

Why do organisations identify research priorities, and how do they do this?

12.   There are a wide range of reasons why clinical research funding organisations identify research priorities. The most common amongst the 22 organisations we interviewed was that it formed part of the development of their research strategy (8 out of 22 organisations).

13.   There is an equally wide range of processes used to identify research priorities. The most common processes amongst the 22 organisations we interviewed included consulting patients and researchers and/or other stakeholders through surveys, focus groups or meetings; relying on informal communication with patients/members, or asking a group of experts (e.g. a Board or Scientific Committee) to make recommendations.

What challenges have these organisations faced in identifying research priorities?

14.   Some organisations have faced resistance from researchers both to developing a research strategy, and to identifying research priorities. Some of the organisations who have asked patients for their views on research priorities have found a few aspects of the process difficult, in particular:

    • Interpreting the data, especially responses to open-ended questions, when the meaning of what people have said may not be clear

- Summarising the views of large numbers of people in a way that accurately reflects what people have said at the same time as capturing individual nuances
- Potentially creating unrealistic expectations that research priorities will be addressed quickly when limited budgets and research capacity will restrict what can be achieved

Do research priorities influence funding decisions?

15. A small number of organisations we interviewed stated that they will *only* consider applications that address one of their identified research priorities. In effect this means that the entire research budget of these organisations is allocated to projects that address priority areas. Other organisations:

- Publicise the fact that they are seeking proposals that will address any one of their list of priorities, but also state that they will consider any application that is likely to benefit their members.
- Ring-fence part of their research budget specifically to fund research on priority topics. For some this is a significant amount, but for others the vast majority of their funding continues to be allocated in responsive mode.
- Seek external funding for projects addressing specific research priorities.

16. For some organisations, funding a research project to address a priority area is such a rare event that there is no formal mechanism in place.

Do research priorities influence the research agenda?

17. There is little evidence to suggest that generating a list of research priorities on its own has a major impact on the proposals developed by researchers. The stated priorities are often so broad that they do not set any limits on researchers. None of the 22 organisations we interviewed make an assessment of 'how well a proposal fits with a research priority' a major or explicit part of the decision about which projects to fund.

How can we ensure that research priorities have an impact?

18. The most effective way for research priorities to have an impact seems to be through commissioning projects that will answer specific, well-defined questions. Only a small number of the organisations we interviewed adopt this approach (4 out of 22).

Conclusions

19. *Most organisations are reluctant to place restrictions on researchers by asking them to address priority topics.* This means that most funders operate in a responsive mode and that, despite its recognised problems, peer review is widely accepted as the only way to choose between the research proposals put forward.

Funding decisions are therefore largely based on judgments about scientific merit, rather than on the relevance and importance of outcomes to end-users.

20. *Few organisations identify the research priorities of clinicians and patients.* 40% of the organisations reviewed for this scoping exercise report that they identify research priorities, but only a small proportion of these are aiming to address the priorities of clinicians and patients in a way that is consistent with the JLA's mission. There is more of a tendency to consult the research community as part of developing a research strategy, rather than aiming to deliver the research that will meet the expressed needs of clinicians and patients.

21. *Identified priorities have a limited impact on the research agenda.* Many priorities that are identified are so broad that they have limited influence on the ideas that come forward. Judging whether an application is addressing a research priority is not often a major part of the decision-making process. It is usually only one of many criteria used to make an assessment.

22. *Few organisations ring-fence budgets to fund prioritised research.* In most cases, the vast majority of an organisation's research budget is allocated via responsive mode.

23. *Few organisations take a systematic approach to addressing identified priorities.* Based on the findings from this scoping exercise, it appears that a systematic approach would involve the following steps:

    - Using a robust mechanism (like that developed by the JLA) to identify the research most likely to benefit patients and clinicians in making decisions about treatments

    - Identifying gaps in research, and commissioning research to fill these gaps

    - Increasing capacity to conduct research in areas where it is lacking

    - Dedicating funds to this research and incorporating a meaningful assessment of how well priority areas are being addressed in the evaluation of proposals

    - Involving patients and clinicians in all stages in the process

    There are only one or two organisations that are taking such an approach. The majority follow only one or two of these suggested steps.

24. *There is no agreed best practice for identifying priorities.* There is no consistent process for identifying priorities. Many different methods are being used, which in part reflects the many different aims of identifying priorities.

25. *Promoting the JLA's agenda will require action at many levels.* Changes would need to happen at multiple levels for patients' and clinicians' views of research priorities to influence funding of research. Promoting the JLA's agenda will

require action to tackle the cultural issues as well as the provision of practical support and advice.

Implications for the JLA

26. One of the objectives of this scoping exercise was to help the JLA consider how they might encourage UK clinical research funders to fund research that addresses the priorities of clinicians and patients. There are a number of possibilities open to the JLA, both to promote its current activities and/or to develop new workstreams. These include:

- *Encouraging clinical research funders to rethink the purpose of identifying research priorities i.e. specifically to meet the needs of patients and clinicians.*

- *Offering a robust process for identifying priorities - through supporting PSPs.*

- *Sharing the results of PSPs.* There is a need for further analysis of the results of PSPs to draw out information that is relevant to different funders. It would also be helpful to disseminate the results more to researchers, research funders and members of research committees.

- *Supporting PSPs to develop more detailed commissioning briefs from a list of identified research priorities.* This is a crucial step if the priorities are to be meaningful to funders. Many organisations would benefit from a source of independent advice/ support on this process.

- *Facilitating shared learning amongst organisations to develop guidance on 'best practice' for identifying priorities and funding this research.* There are many examples of good practice across different organisations, each of whom is developing specific aspects of the priority setting process. Bringing these organisations together to share their experiences could help develop a more consistent and robust process. This would help to ensure that identified priorities have more of an impact and lead to the commissioning of more relevant and useful research.

1. Introduction

1.1   The aim of this project was to carry out a review of how clinical research organisations set their priorities and whether and how patients and the public are involved in this work. It was commissioned by the James Lind Alliance (JLA) to contribute to the evidence base around research priority setting and patient and public involvement (PPI) in priority setting.

1.2   The results of this exercise also provide a context for the outcomes of JLA activity. They will help the JLA to consider how best to present their findings to research funders, so as to influence funding decisions and the wider research agenda.

1.3   Throughout this review we focused on how identified priorities for research (where they existed) are translated into decisions about which research to fund. We have not evaluated the methods used for identifying research priorities, nor the differences between the views of patients, clinicians or researchers. These topics are being researched by a team at the Social Science Research Unit, at the Institute of Education, London.

1.4   The remainder of the report is structured as follows:

Section 2:   Our approach

Section 3:   Characteristics of the organisations included in the website review

Section 4:   Making decisions about which research projects to fund

Section 5:   Identifying research priorities

Section 6:   Funding research to address identified priorities

Section 7:   Commissioning research to address identified research priorities

Section 8:   Conclusions

Section 9:   Implications for the JLA

2. Our approach

2.1 The scoping exercise involved:

- A review of the websites of UK clinical research organisations
- Telephone interviews with staff in organisations that either identify research priorities and/or commission research
- A brief review of the literature on peer review and PPI in making funding decisions

The methods used will now be discussed in turn. The combined findings from all three areas of research are summarised in Sections 3-7.

Review of the websites of UK clinical research organisations

2.2 This research was undertaken over a period of 4 days between November and December 2007. It involved reviewing the websites of a selection of UK clinical research organisations that were identified as a priority by a project steering group (which was set up by the JLA to oversee the scoping exercise), or were JLA affiliates or members of the Association of Medical Research Charities (AMRC).

2.3 Within the resource constraints of the project we were not able to verify the information provided on all the websites by contacting the organisations directly. (We also note that information published on websites is often limited and may be out of date).

2.4 A total of 104 websites were reviewed and 55 included in our analysis (see Appendix 1). Organisations *were not* included if they funded only basic science, or research within a specific institution, or had not provided detailed information on their website about their decision making processes.

2.5 Our analysis of these 55 organisations' websites asked the following questions:

- How much does the organisation spend on research per year?
- What type of research do they fund – e.g. basic (laboratory based science) and/ or clinical (testing or developing treatments)?
- What health conditions do they cover?
- How do they fund research in terms of the type of grant available? (We only considered information of direct relevance to the JLA so for example we did not include information about travel or equipment grants.)
- Have they identified research priorities?
- Do they commission research on specific topics?
- How are decisions made about which research to fund?
- Are patients or the public involved in any aspect of making funding decisions?

Telephone interviews with staff

2.6   A series of telephone interviews were undertaken with the research managers or other relevant staff in UK clinical research funding organisations. These organisations were selected on the basis that they had reported identifying research priorities and/ or commissioning research on their website, or they were prioritised by the project steering group. The interviews aimed to find out:

- Why the organisation had decided to identify research priorities
- The methods they had used, and whether patients and the public had been involved
- Whether and how identified priorities influenced funding decisions
- Plans for the future development of policy and practice in this area

2.7   A total of 34 organisations were invited to take part in the interviews and 28 agreed. The interviews took place in February, March and June 2008. The detailed findings from the interviews can be found in Appendix 2.

Literature review

2.8   The literature review focused on peer review and PPI in peer review because the web-based research identified this process as the universally accepted mechanism for making decisions about research funding (See Appendix 3).

3. Characteristics of the organisations included in the website review

3.1   52 of the 55 organisations included in the website review provide funding for research. The other three provide; practical support for research (BioMed Health Technology Cooperative), carry out systematic reviews (Cochrane Collaboration) or develop clinical guidelines (the National Institute for Health and Clinical Excellence - NICE). These three organisations were included because they also have to consider priorities for research areas relevant to treatment uncertainties.

3.2   The majority of the research funding bodies included in this review (49 out of 52) were voluntary sector organisations or medical charities. Senior representatives from the National Institute of Health Research (NIHR) and the NIHR funded Health Technology Assessment Programme were also interviewed, as well as the Medical Research Council.

3.3   The research budgets of these 52 organisations/programmes ranged from tens of thousands to hundreds of millions of pounds. Fig. 1 shows the distribution of the different levels of research funding. (N.B. only approximate figures for research budgets are provided. The information available on the organisations' websites was not always current and budgets may vary from year to year depending on an organisation's income. Also many organisations did not distinguish new spend on research from ongoing expenditure on existing projects. We have assumed that the figures available include both sums as the total research spend).

Fig. 1 Distribution of levels of research funding

Legend:
- under £500k
- £500k - £1million
- £1-5 million
- £5-10 million
- over £10 million
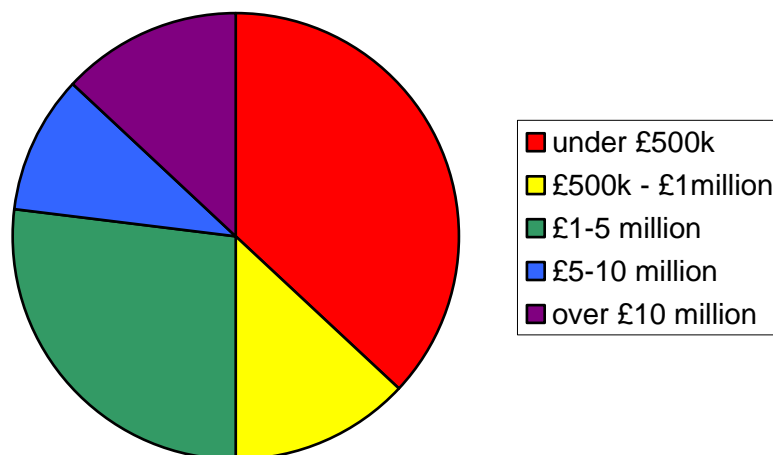
3.4   31 out of the 52 organisations operate in a responsive mode i.e. they rely on researchers to submit ideas for research and use a process of peer review to decide which applications to fund. With patient organisations, there is often only one restriction - that the research relates to the health condition that affects their

members. More information about which organisations operate in responsive mode and or commission priority areas is available in the Appendices.

3.5   Some organisations reported that they had identified priorities for research (21 out of 52). Many of these continued to accept all other research proposals from researchers (14 out of 21). The remainder would only consider applications that addressed identified priorities (7 out of 21). Fig. 2 shows the proportion of organisations that fall into each of these categories. (See Sections 5-7 for further details of how research priorities have been identified and how they influence funding decisions in these organisations).

Fig. 2 Proportion of organisations that identify and fund research priorities

- Responsive only
- Fund priority areas only
- Responsive and identify priorities
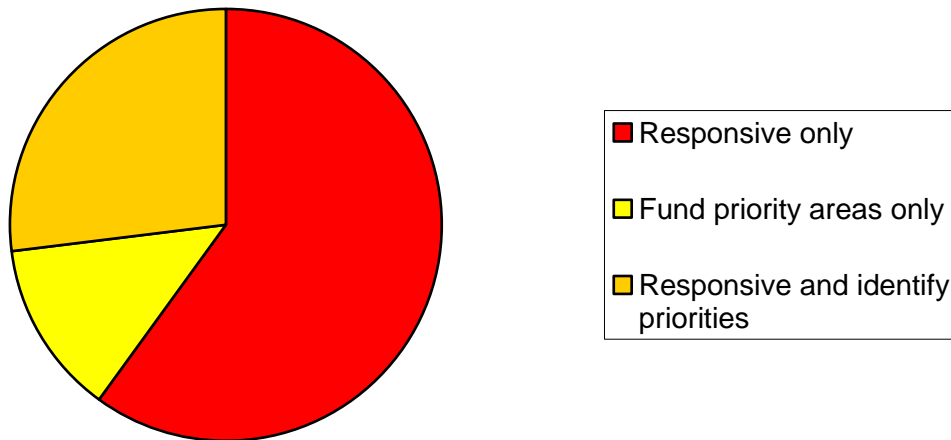
3.6   About a third of the organisations (14 out of 52) stated that they commissioned research. However, few identified how the topics for commissioned research were selected.

4. Making decisions about which research projects to fund

How are funding decisions made?

4.1   Whether research is commissioned or funded in responsive mode, the process of making decisions about which projects to fund typically involves the following steps:

- Researchers submit an outline application

- Outline applications are reviewed internally and successful candidates invited to send a full application

- Full applications are sent to external peer reviewers and also reviewed internally

- The reviewers' comments are considered by an advisory committee. The committee ranks applications in order of priority and/or makes recommendations for funding

- A Board of Trustees or Council makes the final decision about which applications to fund - within the limits of the financial resources available.

4.2   There are some variations to this process. For example, not all organisations ask for outline proposals. Some organisations also ask researchers to respond to peer review comments. These responses are considered by the advisory committee when developing their final recommendations.

4.3   Every one of the 52 funding organisations included in the website review use a form of peer review to make decisions about which research to fund. Although there are well-recognised concerns about peer review (see Appendix 3), the general consensus is that there is no better alternative.

4.4   Of these 52 funding organisations:

- 37% ask for an outline application. 95% review these applications internally. Only one of these organisations involves patients in this initial review.

- 87% ask external experts to peer review full applications, 42% carry out an internal review (with 33% doing both). 21% (11 organisations) involve patients at this stage.

- 8% (4 organisations) ask applicants to respond to reviewers' comments.

- 88% rely on an advisory committee to make recommendations as to which applications should be funded. 23% include patients on this committee.

- 48% rely on the Board of Trustees (or equivalent) to make the final decision about awarding grants.

4.5   Further details of the decision making processes within each organisation can be found in Appendix 1.

Involving patients in decisions about funding research

4.6   There is considerable variation in the level of PPI in decision-making processes amongst the organisations included in this review. Some involve patients at every stage and appear to be patient-led in their decisions. Others only involve lay members as Trustees at the very final stage. (Further details can be found in Appendix 1). Within the resource constraints of the project it has not been possible to evaluate these processes nor assess their impact. However, some general findings emerged from the literature review as discussed below.

4.7   A survey of UK funders of health research, published in 2004, explored whether, why and how funders involve patients in making decisions about funding[1]. There are a variety of reasons for involving patients. For health charities the most common reason is that patient involvement helps to ensure that the research they fund is of genuine relevance and importance to their members.

4.8   If patients are asked to take part in decision-making processes they are often asked to take part at the stage of peer review. The patient reviewers are usually asked to comment on different aspects of research proposals and/or at different times to the scientific reviewers[1]. Examples of the different ways in which patients are involved include:

- Asking members of patient panels to rate lay summaries of research proposals against criteria of importance and relevance, and generating a shortlist of proposals on this basis. Shortlisted research proposals are then reviewed by scientific reviewers on the basis of scientific merit.

- Asking patients to provide individual written feedback on the relevance of research proposals. This is done at the same time as the scientific merit of research proposals is assessed.

- Asking patients to assess the relevance of research proposals in group discussions or by written feedback. This is done after research proposals have been shortlisted by scientific reviewers in terms of scientific merit.

4.9   Some organisations also ask patient reviewers to comment on patient related factors that might affect the feasibility and success of a particular project, for example, whether patients are likely to want to take part in the study[1].

4.10   There have been very few studies as to the impact of PPI in peer review. In general it seems that researchers are concerned that lay involvement will cause an imbalance in research funding, because they believe patients will 'always favour clinical studies over basic science'[2,3]. However, the only study of the impact of patient reviewers suggested their involvement made little difference to the final outcome (see Appendix 3).

4.11   Patients are also often asked to sit on advisory committees that make recommendations for funding and/ or Boards of Trustees that technically make

the 'final decision'. However, the influence that patients have on these committees could be limited by a wide range of factors, including: the ratio of patients to other stakeholders, the assertiveness of the patients and the willingness of other stakeholders to listen seriously to their views[1]. There are few studies of the impact of this type of PPI (see Appendix 3). Some professional committee members have reported that the presence of patients at committee meetings helps to 'keep their mind focused on the issues that are most important to patients' [2,3].

4.12   In conclusion, there is little published evidence of the impact of PPI on funding decisions. However, there appears to be a growing trend towards increasing PPI in peer review amongst patient organisations that fund research. It will be important to capture the impact of this involvement in future.

5. Identifying research priorities

5.1   The findings in this section (and in sections 6 and 7) are based on the more detailed information obtained via telephone interviews with staff in the organisations that identify research priorities and/or commission research (a total of 22 organisations). Further information about these organisations can be found in Appendix 2.

Why did these funding organisations decide to identify research priorities?

5.2   Many members of the AMRC have developed (or started to develop) a research strategy in response to AMRC recommendations. The most common reason that funding organisations gave for identifying research priorities was that it formed part of the development of their research strategy (8 out of 22 organisations*).

5.3   A small number of organisations (4 out of 22) had purposively asked patients for their views on research priorities as part of a wider programme of PPI in research. Their overall aim is to ensure that the research they fund genuinely reflects patients' interests, and is likely to directly benefit their members.

5.4   Three of the 22 organisations had identified research priorities as part of a process of developing clinical guidelines. Their goal was to identify the research needed to fill gaps in the evidence base. This also meant they had limited priority setting to their clinical research funding stream and in a couple of cases they continued to fund basic science in a purely responsive mode.

5.5   Other reasons given for priority setting (by 1 or 2 organisations in each case) included:

- To balance the organisation's research portfolio – reducing the dominance of basic science and targeting more funding on research on care/ treatment
- To co-ordinate funding across similar charities and/ or to influence others to fund research in a specific area
- To be clear about which research areas their organisation is willing to fund, to avoid duplication with others and/or support under-funded areas of research
- To respond to questions or concerns raised by patients/ members
- To respond to organisational change e.g. new staff or new policies

5.6   The two organisations included in this review that do not fund research but do need to prioritise clinical research areas (The Cochrane Collaboration and NICE) both set priorities in order to manage their workload and budgets.

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* (Some organisations gave more than one reason for identifying research priorities.)

How have these organisations identified research priorities?

5.7   The wide variety of reasons for identifying priorities is reflected in an equally wide range of processes used to identify them. The most common processes included:
   - Consulting patients/ members through formal mechanisms e.g. postal surveys, online questionnaires or focus groups (6 out of 22 organisations)

   - Using a combination of approaches, such as meetings, surveys and workshops, to obtain the views of a wide range of stakeholders (6 out of 22 organisations)

   - Relying on informal communication with patients/members e.g. via helpline and email enquiries (3 out of 22 organisations)

   - Asking a group of experts e.g. a Board or Scientific Committee to make recommendations on research priorities (3 out of 22 organisations)

   - Consulting the medical and scientific community alone, via meetings, surveys or conferences (2 out of 22 organisations)

   - Asking a committee made up professionals and patients to make recommendations (1 organisation)

What challenges have these organisations faced in identifying research priorities?

5.8   Some organisations have faced resistance from researchers both to developing a research strategy, and to identifying research priorities. Some researchers were opposed to the concept, particularly in basic science, arguing that the outcomes and usefulness of such research cannot be predicted. Some researchers believe that the only way to ensure high quality outputs is to fund high-calibre individuals proposing to carry out scientifically robust research. Other researchers felt threatened by the process, because they were concerned that a review of their research meant their funding was going to be cut.

5.9   Some of the organisations who have asked patients for their views on research priorities have found some aspects of the process difficult, in particular:
   - Interpreting the data, especially responses to open-ended questions, when the meaning of what people have said may not be clear

   - Summarising the views of large numbers of people in a way that accurately reflects what people have said at the same time as capturing individual nuances

   - Potentially creating unrealistic expectations that research priorities will be addressed quickly when limited budgets and research capacity will restrict what can be achieved

5.10   Staff within research departments often have a research background. Therefore their own values and assumptions are often challenged by a priority setting process, as one research manager described:
   "We've tried to put ourselves in the mindset of the people who enable us to exist - so some of us had to shift outside our comfort zone. It's not easy".

6. Funding research to address identified research priorities

How do research priorities influence funding decisions?

6.1   A small number of the organisations who took part in the interviews (3 out of 22) state that they will *only* consider applications that address one of their identified priorities. All other applications are rejected. The applications that are accepted go through the usual process of peer review etc in order to decide which ones will be funded. In effect this means that the entire research budget of these organisations is allocated to projects that address priority areas.

6.2   Other organisations (3 out of 22) publicise the fact that they are seeking proposals that will address any one of their list of priorities, but also state that they will consider any application that is likely to benefit their members. In these cases, all applications go through the same review process and are all funded from a single research budget. One of these organisations asks researchers to state which priority topic they are addressing in their application form, and if they are not addressing a priority, asks them to justify why their proposal should be considered.

6.3   Two of the 22 organisations put out calls for proposals to address specific research priorities. These are then evaluated alongside applications received in responsive mode and again all applications are funded from a single budget.

6.4   A larger number of organisations (5 out of 22) ring-fence part of their research budget specifically to fund research on priority topics. The amount that is ring-fenced varies considerably from organisation to organisation. For some it is a significant amount, but for others the vast majority of their funding continues to be allocated in responsive mode.

6.5   An alternative approach (adopted by 4 of the 22 organisations) is to seek external funding for projects addressing specific research priorities. These organisations then either work in partnership with other funders, or rely entirely on outside agencies for funds. Calls for proposals may be delayed until funding has been secured.

6.6   For some organisations funding a research project to address a priority area is such a rare event that there is no formal mechanism in place. For example, having identified an issue of concern to their members, one organisation made a one-off request to their Trustees to release funds for a related research project.

Does identifying research priorities influence the research agenda?

6.7   There is little evidence to suggest that generating a list of research priorities on its own has a major impact on the proposals developed by researchers. As a number of the interviewees commented, the stated priorities are often so broad

that they do not set any limits on researchers. The impact is then more on the overall shape of the organisation's research portfolio, as one research manager described:

"Our priorities are broad so they are not very restricting on researchers. Our research priorities mean we fund more care research than we would do otherwise".

6.8   Similarly none of the 22 organisations make an assessment of 'how well a proposal fits with a research priority' an explicit part of the peer review process. One organisation had considered introducing a 'priority score' but had not found a way to make this practical. Some organisations do ask peer and lay reviewers to consider each proposal's 'relevance to recognised research priorities' as part of their review. However this is typically only one of many criteria used to judge an application, and all of these factors are then amalgamated into the reviewers' final scores. Therefore it is unclear whether and how much this particular assessment influences the reviewers' judgements and subsequently the decisions made by research committees/ Boards of Trustees.

6.9   In conclusion, it seems that simply asking researchers to address a list of priorities has little influence on the wider research agenda. The most effective way for research priorities to have an impact seems to be through commissioning projects that will answer specific, well-defined questions. This requires some additional work to:

- scope out each prioritised research area
- identify what research has already been done and what still needs doing
- commission research to fill the gaps

There are a small number of organisations adopting this approach. However, the majority of funding organisations are still sceptical of the value of commissioning research as described in the next section.

7. Commissioning research to address identified research priorities

7.1   Only a small number of the organisations that identify priorities (4 out of 22) commission research to address these priorities. Many organisations state that they only commission research very rarely.

7.2   The process of commissioning involves defining a clear research question and then approaching a limited number of high-calibre researchers with an invitation to bid for funding. This is distinct from an 'open call for proposals' which tends to be less specific and open to all. Open calls sometimes result in the submission of poor quality proposals. Organisations that take a commissioning approach do not report this problem.

7.3   There are several barriers to commissioning which may explain why so few organisations have taken this step. These include:

- ***The dominance of the research culture.*** There is a general acceptance that researchers 'know best' and that the most innovative and exciting research projects will come via responsive mode funding. Commissioning is often thought to set unacceptable restrictions on researchers' 'inventiveness'.

- ***The values and opinions of research staff***. Many research department staff have a background in research themselves and consequently work with a 'researcher's perspective'. As one research manager described:

  "I was fundamentally opposed to commissioning when I started here but I have come round to thinking it's a good thing… I have a background in research and always thought funders were there for the research community rather than other way round… Now having gone out and given talks to support groups for many years I can see the benefits of research for real people and the need to target research funds in areas that will make a real difference".

- ***The difficulty of developing robust research questions***. It is a challenge to develop clear research questions from prioritised research themes. Staff within funding organisations may not have the skills required. There is also a problem with asking researchers to help with this process, as it can create a conflict of interest if the researchers then want to bid for the funding.

- ***Finding high-quality researchers who work in the priority area***. Organisations that have had difficulties in finding high-calibre researchers have looked to developing research capacity instead. One organisation is setting up a mentoring programme to help new researchers develop their proposals as well as providing ongoing support once the project gets going. They have also decided to make funds available to cover the fill-in costs for health professionals so that these individuals can take the time out from their jobs to carry out clinical research.

8. Conclusions

Most organisations are reluctant to place restrictions on researchers by asking them to address priority topics

8.1   The general picture that emerges from this scoping exercise is that the decision-making processes of many UK clinical research funders are shaped by the following cultural assumptions:

- Research is unpredictable – the next 'breakthrough' or 'cure' could come from an unexpected source and therefore restrictions should not be placed on researchers

- Researchers are best placed to identify what research needs to be done

- Asking patients for their priorities for research might inappropriately shift the research agenda away from basic science

8.2   This means that most funders operate in a responsive mode and that, despite its recognised problems, peer review is widely accepted as the only way to choose between the research proposals put forward. Funding decisions are therefore largely based on judgments about scientific merit, rather than on the relevance and importance of outcomes to end-users.

Few organisations identify the research priorities of clinicians and patients

8.3   40% of the organisations reviewed for this project report that they identify research priorities, but only a small proportion of these are aiming to address the priorities of clinicians and patients in a way that is consistent with the JLA's mission. There is a stronger tendency to consult the research community as part of the development of an organisation's research strategy.

Identified priorities have a limited impact on the research agenda

8.4   Many of these identified priorities are so broad that they have limited influence on the ideas that come forward. Researchers can continue to submit proposals that reflect their own interests, because their applications can be easily tailored to address a broad theme.

8.5   Similarly, identified priorities seem to have limited influence on funding decisions made via peer review. Judging whether an application is addressing a research priority is not often a major part of the review process. It is usually only one of many criteria used to make an assessment.

8.6   More generally, there is broad agreement that it is important to fund research that is relevant and important to patients, but it is not always clear how this is being achieved. Peer reviewers and research advisory committees are often asked to make this judgment, but it is unclear on what basis they make their assessments. Lay reviewers are frequently asked to contribute their perspective on this issue.

However, their impact is limited by the fact that they can only effectively choose between proposals that researchers have put forward. This means they can only help shape the proposals that are submitted, rather than help set the agenda in the first place.

Few organisations ring-fence budgets to fund prioritised research

8.7   There does not appear to be any consistent approach to funding research proposals that address identified priorities. Often all research proposals are considered in parallel and funded from a single research budget. Sometimes selected proposals are funded on an ad hoc basis, or in some cases, an entirely separate budget is used to fund prioritised research as part of another programme e.g. clinical guideline development. The general tendency is for the vast majority of an organisation's research budget to be allocated via responsive mode.

Few organisations take a systematic approach to addressing identified priorities

8.8   The process of identifying priorities and then funding relevant research is not difficult in itself. Once the major hurdle of creating the political will has been overcome, the process can be quite straightforward. This is clearly illustrated by the organisations which have made a decision to follow this route e.g. The Alzheimer's Society and the Health Technology Assessment Programme.

8.9   Based on the findings from this scoping exercise, it appears that a systematic approach would involve the following steps:

- Using a robust mechanism (like that developed by the JLA) to identify the research most likely to benefit patients and clinicians in making decisions about treatments

- Identifying gaps by:

    (a) reviewing current research portfolios of UK clinical research funders
    (b) finding out the areas of interest of different research groups
    (c) carrying out a systematic review of the literature

- Commissioning research to fill the gaps

- Increasing capacity to conduct research in areas where it is lacking

- Dedicating funds to this research and incorporating a meaningful assessment of how well priority areas are being addressed in the evaluation of proposals

- Involving patients and clinicians in all steps, including oversight and monitoring of research, to ensure the priorities are genuinely addressed in funded research projects

8.10   There are only one or two organisations that are taking such an approach. The

majority follow only one or two of these suggested steps. This means there would be much to gain from sharing the learning and experience of the organisations that are developing different aspects of this process.

There is no agreed best practice for identifying priorities

8.11   There is no consistent process for identifying priorities and no sense of an 'agreed best practice'. Many different methods are being used, which in part reflects the many different aims of identifying priorities. Again much would be gained from sharing the learning and experience of the organisations who have tried different approaches.

Promoting the JLA's agenda will require action at many levels

8.12   In conclusion it seems that changes would need to happen at multiple levels for patients' and clinicians' views of research priorities to influence funding of research. Promoting the JLA's agenda will require action to tackle the cultural issues as well as offering practical support and advice.

8.13   Both funding organisations and researchers will need to be challenged and encouraged to develop a new way of thinking about research. This would need to include:

a. Challenging the culture in funding organisations – raising questions about the relevance and purpose of research and what is meant by research for patient benefit

b. Encouraging funding organisations to focus more on the outcomes of research and the quality and usefulness of the results to the end-users

c. Increasing researchers' awareness and interest in the priorities of patients and clinicians and encouraging them to try to meet these needs

d. Creating capacity amongst researchers to deliver the research that patients and clinicians see as a priority

9. Implications for the JLA

9.1   One of the aims of this exercise was to help the JLA consider how they might encourage UK clinical research funders to fund research addressing the priorities of clinicians and patients. Based on the picture that has emerged from this review, it seems there are a number of possibilities open to the JLA, both to promote its current activities and/or to develop new workstreams. These options include:

- Encouraging clinical research funders to identify research priorities *specifically* to meet the needs of patients and clinicians

- Offering a robust process for identifying priorities

- Sharing the results of Priority Setting Partnerships

- Supporting Priority Setting Partnerships to develop commissioning briefs from a list of identified research priorities

- Facilitating shared learning amongst organisations to develop guidance on 'best practice' for identifying priorities and funding this research

9.2   Each of these options will now be discussed in turn, with a focus on the most relevant target audiences.

Encouraging clinical research funders to identify research priorities specifically to meet the needs of patients and clinicians

9.3   This concept is likely to be of most interest to the patient organisations that fund research. Whilst many of these organisations state that they only want to fund research of direct relevance to their members, few extend this policy as far as asking patients or clinicians about their priorities. However, they do express an interest in the following objectives, which are entirely consistent with the aims of the JLA:

- Funding research that genuinely meets the needs and interests of patients

- Commissioning research to inform the work of the organisation e.g. producing clinical guidelines

- Ensuring 'value for money' in research spending

- Ensuring accountability to the people who have raised funds as well as to the wider membership

- Increasing user and carer involvement in the management of research

9.4   They may be some value in working with patient organisations to explore how identifying and funding research priorities could help them successfully achieve these wider organisational goals.

Offering a robust process for identifying priorities

9.5　This activity is likely to be of most interest to larger patient organisations that have the resources to invest in the process. Smaller organisations seem reluctant to use their limited research funds for this purpose. However, there may be opportunities for several smaller organisations to work together in a Priority Setting Partnership, if there are common areas of interest.

9.6　Other organisations have asked whether the JLA process could be applied to their specific context. For example The Cochrane Collaboration and NICE have expressed an interest in using the JLA process to help them to prioritise amongst a list of 10-15 topics they will have identified through their own procedures.

Sharing the results of Priority Setting Partnerships

9.7　The Priority Setting Partnerships generate a final list of the top ten shared priorities for research. An important question is how to influence the wider research community to ensure these research topics are addressed. The two key target audiences are large funding organisations and researchers as discussed below:

Large funding organisations

9.8　The large funding organisations, such as the Medical Research Council (MRC), National Institute of Health Research (NIHR) or Wellcome, are only interested in identifying research priorities at a very high level so they can act strategically in response to national issues e.g. to prioritise funding research into prions in response to BSE. They do not set priorities at the level of specific research questions. If they do put out calls for proposals, these tend to be very broad.

9.9　This means that the results of *individual* PSPs are of little direct relevance to larger organisations. However, if common themes emerged from *a number* of PSPs, which required a response at a national level, then this would be of much greater significance. For example if a number of PSPs identified the need for more long-term, follow-up studies of people taking medication, then one of the larger funders might be the appropriate body to develop the necessary capacity or infrastructure to support this kind of research across a wide range of conditions.

9.10　Some research organisations might be able to make direct use of the results of PSPs, but only if the topics directly relate to their area of interest and expertise. For example the Cochrane Collaboration would be interested in priorities for systematic reviews and the HTA programme interested in priorities for testing new forms of health technology. Both organisations aim to be as unbiased as possible when considering priorities and try to gather data from all perspectives. They would greatly value access to JLA outputs as robust evidence of clinicians' and patients' views. In this context it would also be useful to know why certain topics have been considered NOT to be a priority. Sharing the

dialogue around priority setting is therefore as important as sharing the final lists of the 'top ten'.

9.11 In conclusion, there is a need for further analysis of the results of PSPs to draw out the information that is relevant to different funders. This means identifying specific topics of interest as well as identifying common themes. Funders also need to be informed of the rationale for different priorities, and the reasons why other topics were not selected.

Researchers

9.12 Researchers need to be encouraged to respond directly to PSP results by developing research proposals that directly address priority topics. There is an expectation amongst the larger funding bodies that high-calibre researchers will be aware of the research priorities in their field and will use this information as justification for funding their research. This could be made to have more impact if it were a more explicit requirement of funding applicants, for example if application forms asked researchers to explain how their research addresses identified priorities.

9.13 Researchers can also have in indirect impact on the research agenda through their influential role as peer reviewers. Knowledge of clinicians' and patients' priorities would enable reviewers to make better informed assessments of the relevance and importance of different research proposals. This could help influence their decisions about which proposals to recommend for funding.

9.14 It would therefore be of value to ensure that the relevant members of Programme or Commissioning Boards in the large funding organisations were made aware of the priorities for research identified by PSPs. Again there is an expectation that these high-calibre individuals would be up-to-date with current views on priorities for research in their field of expertise. However, there is no formal mechanism to ensure this is the case. Disseminating the results more widely could also ensure that patient/ carer reps on commissioning boards are aware of the priorities.

9.15 At the NIHR peer reviewers are asked to judge proposals on their relevance and importance to the NHS. It is unclear what evidence they use to make this judgement, but it is assumed to depend on the expert reviewer's previous knowledge or experience of working in the NHS. It is likely that these reviewers would welcome the robust evidence from PSPs to help with this aspect of assessing proposals.

Supporting Priority Setting Partnerships to develop commissioning briefs from a list of identified research priorities

9.16 For funding organisations to make more effective use of a list of research priorities, each topic needs to be translated into a more detailed research recommendation that explains exactly what research needs doing, why and how.

9.17 This means developing more detailed commissioning briefs that include the following information:

- The rationale for why the topic is a priority that makes the case for carrying out the research – e.g. How common is the problem? What difference will the research make and to how many people?

- Background on the affected patient group – ages affected etc.

- What research is already out there – what still needs to be researched

- A clear research question

- Proposed methodology

9.18 Asthma UK, which was involved in one of the first PSPs, is currently working on this approach. They have been developing research recommendations from their top ten list of priorities using the EPICOT format (Evidence, population, intervention, comparison, outcome and time period). This format works particularly well for research funders. They are also running a small research project with people affected by asthma to scope out one of the priority topics, to find out what people feel about the issue and what could best be done to help them.

9.19 Translating priority lists into commissioning briefs is a crucial step if the priorities are to be meaningful to funders. It appears that few organisations are familiar with this process, and many would probably benefit from a source of independent advice/ support.

Facilitating shared learning amongst organisations to develop guidance on 'best practice' for identifying priorities and funding this research

9.20 Although a number of organisations are working on identifying research priorities, there is currently little agreement or understanding of what constitutes best practice in this area. Therefore there may be some value in creating opportunities for shared learning across organisations to help them:

- Understand the value of addressing research priorities and hear about evidence of impact

- Learn about the strengths of the JLA process

- Develop a concept of best practice

- Think through the implications of going down this route and prepare for the challenges involved

- Benefit from peer-to-peer support in taking this work forward

9.21 The general picture that emerges from this review is that there are lots of pockets of good practice across different organisations, each of whom are developing specific aspects of the priority setting process. Bringing these organisations

together to share their experiences could help develop a more consistent and robust process. This would help to ensure that identified priorities have more of an impact and lead to the commissioning of important and useful research.

TwoCan Associates, for the James Lind Alliance

December 2008

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Appendix 1: Findings from the review of the websites of organisations that fund clinical research in the UK

Action Medical Research
www.action.org.uk/

Funding available	£7 million allocated across 68 projects in 2007.
Type of research funded	Clinical research or research at the clinical/basic interface with the objective of: • preventing disease and disability (affecting all age groups) • alleviating physical disability
Health conditions covered	All health conditions with the exception of cancer, cardiovascular and HIV/AIDS.
Methods of funding	Project grants and fellowships.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	Grants are assessed by external referees, the number of referees depending on the cost and complexity of the application. The applications and referees reports are assessed by the appropriate advisory panel, namely: a) The Scientific Advisory Panel - members representing the medical sciences; or b) The Advisory Panel on Medical Engineering, Orthopaedics and Hard Tissue Research - members representing orthopaedics, bioengineering and rehabilitation. Grants recommended by the advisory panels are submitted to Council for final approval.
PPI	Not mentioned on website.

Alzheimer's Society
www.alzheimers.org.uk/

Funding available	Research budget 2006: £1.3 million.
Type of research funded	Basic and clinical research.
Health conditions covered	Alzheimer's Disease.
Methods of funding	Project grants, Fellowships and PhD studentships, dissemination grants, Cochrane Review Special Projects Grants.
Prioritise or commission research	Every second year, the Society's consumer QRD network is invited to set research priorities for future funding.
How funding decisions are made	Funding decisions involve the following stages: • Lay summaries are considered by members of the consumer network who give each application a score from 1-10. All applications receiving a high score are shortlisted for the next stage. The network members' comments are sent to researchers who receive low scores. • Shortlisted projects undergo external peer review by researchers. • Applications receiving a positive review proceed to the next stage – a panel interview. The panel consists of three scientific reviewers with expertise relevant to the applications being considered and three consumers. They agree which proposals (usually one or two) should be recommended for funding. • Grants are allocated by the Trustees according to the funds available.
PPI	Consumer network members are involved in all stages.

Arthritis Research Campaign

www.arc.org.uk/

Funding available	£20 million per year.
Type of research funded	Research into the cause, treatment and cure of arthritic conditions.
Health conditions covered	Arthritis and associated rheumatic conditions.
Methods of funding	Project grants, programme grants, fellowships, studentships, educational project grants (to educate medical practitioners), academic posts and clinical trials. Core funding is provided for two major research institutes.
Prioritise or commission research	Priorities have been identified as part of the development of a research strategy and ARC plans to put out calls for proposals.
How funding decisions are made	ARC receives around 400 applications per year. Each application is reviewed by 4 or 5 external experts. Their comments are considered by specialist committees made up of clinicians and scientists. The largest budget is controlled by the Research Sub-Committee which meets three times a year. Other committees, similarly composed, award fellowships, programmes, multi-centre clinical trials, academic posts and educational grants. Two major factors determine the success or failure of an application: scientific excellence and relevance to understanding the cause of arthritis.
PPI	New processes are being developed to involve users in the review of applications.

Asthma UK

www.asthma.org.uk

Funding available	£3 million per year.
Type of research funded	Basic and clinical.
Health conditions covered	Asthma.
Methods of funding	Project grants, professorships, fellowships and studentships.
Prioritise or commission research	Asthma UK has developed a comprehensive research strategy by bringing together the expert knowledge and opinions of people with asthma, researchers, clinicians, the major UK funding agencies, the pharmaceutical industry and the Department of Health. They have also worked with the JLA to identify research priorities.
How funding decisions are made	Researchers submit applications once a year. All applications for funding are assessed for scientific quality and relevance to asthma by a Research Committee, which is comprised of an independent panel of scientists, clinicians and lay representatives. Research proposals of a high standard are subjected to further scrutiny by international experts, who have experience closely related to the subject area. Asthma UK's Council of Trustees then decides how many of the recommended research proposals can be funded, based on the projected income of the charity.
PPI	As above.

Association for Spina Bifida and Hydrocephalus
www.asbah.org/

Funding available	£9k in 2006.
Type of research funded	Basic, clinical and education projects.
Health conditions covered	Neural tube defects/hydrocephalus.
Methods of funding	Project grants and fellowships.
Prioritise or commission research	Occasionally ASBH commissions and funds their own projects by inviting research submissions on topics of key importance.
How funding decisions are made	In response to applications from individual researchers, professional advisory committees in health and education recommend funding for a number of new stand-alone projects each year. External referees are also asked to comment if appropriate.
PPI	Not mentioned on website.

Ataxia UK
www.ataxia.org.uk

Funding available	£200k in 2006.
Type of research funded	Basic and clinical.
Health conditions covered	Conditions in which ataxia is the principle symptom, and in which the ataxia is likely to be progressive. This includes conditions such as Friedreich's ataxia, the spinocerebellar ataxias and other cerebellar ataxias (including idiopathic ones).
Methods of funding	Project grants and studentships.
Prioritise or commission research	Ataxia UK may occasionally commission a specific researcher or research group to investigate a topic of interest. These priorities are identified by members and agreed by the Scientific Advisory Committee, who also carry out the review and assessment.
How funding decisions are made	Initially applicants submit a preliminary application. These are reviewed by the Scientific Advisory Committee, who decide whether an application is within Ataxia UK's remit. If applications pass this initial selection process, applicants are invited to submit a full application. All full research proposals are reviewed by at least 2 peer reviewers, and assessed, with the reviews, by the Scientific Advisory Committee. The Committee assesses each project qualitatively according to: • novelty (i.e. how similar it is to research done elsewhere) • the fit of the project with Ataxia UK's strategy and priorities • the time that will elapse until worthwhile results might be achieved • how directly the project might benefit people affected by ataxia • the number of people who might benefit. The Scientific Advisory Committee advises the Trustees on whether specific research proposals should be funded. The Trustees make the final decisions, based on the Scientific Advisory Committee's advice and the funds available.
PPI	The Scientific Advisory Committee includes lay members.

BackCare

www.backcare.org.uk/

Funding available	£50k in 2006.
Type of research funded	Patient-oriented research into the causes and management of back pain.
Health conditions covered	Back pain.
Methods of funding	Project grants.
Prioritise or commission research	The Research Committee (researchers and clinicians) discussed setting priorities and decided that because the charity has a limited research budget and covers a wide area of research, it would be better not to prioritise.
How funding decisions are made	Applications are judged by the Research Committee with additional expert reviews if appropriate. Applicants can decide to submit a brief application for consideration of the Research Committee before submitting a full application or can decide to submit a full application straight away.
PPI	None mentioned on website.

BioMed HTC

www.biomedhtc.org.uk/

Funding available	Not available on website.
Type of research funded	The BioMed Health Technology Co-operative (HTC) was set up in April 2005 with funding from the Department of Health's Health Technology Devices (HTD) Programme. Its purpose is to accelerate the development and adoption of new technologies, treatments and devices for patients with urinary incontinence.
	The HTD funding provides infrastructure support towards an initial three year programme of research and innovation. This will include studies on the needs and abilities of patients with long term indwelling catheters and the development of tools to compare cost effectiveness and quality of life. There is an ongoing programme designing and developing new products and testing them. Patients are then given the opportunity to try new devices through a clinical trial.
Health conditions covered	Intractable urinary incontinence.
Methods of funding	BioMed HTC provides a research resource for clinical trials, a microbiology research laboratory, education and training facilities, access to a range of experts for advice and consultancy and a specialist clinic for people with long-term indwelling catheters.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	Not mentioned on website.
PPI	Industry, patient/carer user groups, universities, NHS and government organisations are listed as partners.

Breakthrough Breast Cancer
www.breakthrough.org.uk

Funding available	£8 million.
Type of research funded	Basic and clinical.
Health conditions covered	Breast cancer.
Methods of funding	BBC funds three Research Units in Edinburgh, Manchester and London, each of which focuses on a specific area of breast cancer research. A new Clinical Researcher Programme started in 2007 aiming to support clinical researchers in carrying out translational research. Programme, project, equipment and capital grants and clinical and non-clinical research fellowships and postgraduate studentships are available to researchers in the Units.
Prioritise or commission research	Their research strategy was developed in partnership with multiple stakeholders including women affected by breast cancer. This sets the global areas of research in the three units.
How funding decisions are made	The Scientific Advisory Committee peer reviews all applications for funding and also all progress reports. Applications are funded on the basis of excellence.
PPI	New research strategy makes commitment to user involvement to inform and influence research.

British Heart Foundation
www.bhf.org.uk/

Funding available	In 2006/07: grants awarded = £50 million.
Type of research funded	Research into cause, prevention, diagnosis and treatment – basic and clinical science.
Health conditions covered	Diseases of the heart and circulation.
Methods of funding	Project and programme grants, professorships, clinical and non-clinical fellowships and studentships. Rolling programme – mostly responsive.
Prioritise or commission research	Some calls for proposals e.g. joint call for proposal with the MRC.
How funding decisions are made	The BHF has three research grant committees which meet four or more times a year. The members of each committee are experts in various aspects of basic and clinical cardiovascular research. • Project Grants Committee • Fellowships Committee (Personal awards) • Chairs & Programme Grants Committee Applications are sent to independent reviewers before being assessed by the committee. Judgements are made on factors such as scientific merit, relevance to cardiovascular disease, timeliness, relationship to other work in the field and value for money.
PPI	None described on website.

British Lung Foundation

www.lunguk.org/

Funding available	£250k in 2006/07.
Type of research funded	Basic, clinical and epidemiology.
Health conditions covered	All forms of lung disease and respiratory illness.
Methods of funding	Project grants and fellowships. Joint studentships with the MRC. Trevor Clay Memorial Grants - available for practical research, the results of which should be immediately applicable and beneficial to people with a lung disease.
Prioritise or commission research	In support of "Priorities for Respiratory Research in the UK" published in Thorax January 2007, the Foundation is inviting preliminary applications for large project grants to be awarded in November 2008 – focusing on COPD and respiratory infections.
How funding decisions are made	Following short-listing of successful pre-applicants by the Foundation's Scientific Committee, full applications are evaluated by an external peer review process that involves leading respiratory experts from the UK and worldwide. The peer review comments are considered by the Scientific Committee who award the grants.
PPI	The Scientific Committee has two lay members. The 'lay sections' of full grant applications are evaluated by a selection of non-scientists from the Foundation's Board of Trustees. Their job is to assess how well the applicant can communicate the importance of their proposed study for people living with lung disease. This also allows the Foundation to evaluate the applicant's ability to explain their ideas to a non-scientist and helps to fund scientists who are able to communicate about their research.

British Occupational Health Research Foundation

www.bohrf.org.uk/

Funding available	£200k.
Type of research funded	• Biomedical • Psychosocial • Ageing workforce • Performance/productivity • HR domain provided it relates significantly to occupational health e.g. diversity, dignity at work
Health conditions covered	Research that has outcomes that have direct practical application at work.
Methods of funding	Project grants.
Prioritise or commission research	The BOHRF strategy is to: ⇒ identify which practical questions need evidence based answers according to employers and their professional advisers in both private and public sectors ⇒ approach two research centres of excellence on the topic and request proposals designed to provide evidence based answers to the questions. They are also willing to receive bids from other research teams.
How funding decisions are made	BOHRF has set up an independent Research Committee that acts as a peer review committee. Additionally all grant applications are sent to two independent peer reviewers: one being a researcher/academic working in the relevant field; the other being a professional working "at the sharp end" in the field. All applications received by the Research Committee are reviewed by the Board of Trustees.
PPI	None mentioned on website.

British Skin Foundation

www.britishskinfoundation.org.uk/

Funding available	£500k
Type of research funded	Basic and clinical.
Health conditions covered	All skin diseases.
Methods of funding	Project grants, fellowships, studentships and in 2007 a clinical trial award.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	The British Skin Foundation invites applications for funding each year. Each application is examined by the Foundation's Grants Advisory Committee which consists of five dermatologists and a medical research specialist. Each application is also sent to two external referees for review, the proposed project being matched to the referee's field of expertise. A decision on which projects will receive support is made at a final meeting of the committee.
PPI	None mentioned on website.

The BUPA Foundation

www.bupafoundation.com/

Funding available	£1.5 million per year on medical research.
Type of research funded	Clinical.
Health conditions covered	Priorities identified as areas where deficiencies in UK funding: • surgery • preventive health • information and communication • mental health in older people • health at work
Methods of funding	Project grants.
Prioritise or commission research	See above.
How funding decisions are made	Applications received are sent to the BUPA Foundation governors for scoring on a scale of zero (poor) to ten (excellent) based on the following criteria: • the originality of the research proposal • quality of the study design/methods • the long-term implications of the research proposal and the likelihood of success • the proposed statistical analysis (where appropriate) • relevance to clinical practice • relevance to public health • priority for funding Shortlisted applications are sent for external peer review. Finally, the BUPA Foundation board decides which projects to support.
PPI	None mentioned on website.

Cancer Research UK
http://science.cancerresearchuk.org/

Funding available	Research budget 2006/2007: £325 million.
Type of research funded	Three potentially relevant funding streams: • Basic Biology, Clinical and Translational Research Funding - Covers all areas of basic biology, clinical, and translational research • Clinical Trials Funding - Covers pre-clinical, early and late phase clinical trials. • Population and Behavioural Science Funding - Covers all areas of population and behavioral sciences, including public health epidemiology, and behavioural and psychosocial research
Health conditions covered	All cancers.
Methods of funding	They support over 500 research group leaders throughout the UK, through a variety of funding mechanisms including research institutes, clinical centres, programme and project grants as well as personal awards (fellowships, PhDs and masters) for scientists and clinicians. Strategic and responsive mode funding managed by committees.
Prioritise or commission research	See below.
How funding decisions are made	Applications undergo peer review and funding decisions made by committees. There are 10 committees including: **Clinical Trials Advisory & Awards Committee** – funds phase 3 trials. Assessment criteria include: • Clinical importance of the research question • Expected interest/appeal to patients and likelihood of adequate accrual **Clinical and Translational Research Committee** - funds a comprehensive portfolio of cancer clinical trials in treatment, screening and prevention as well as the infrastructure to support them. **Population and Behavioural Sciences Committee** – funds research in cancer prevention and control and in behavioural research relevant to cancer. Has identified priority areas as: prevention, professional education and training, statistical and epidemiological modeling, Public understanding and education, The role of primary care, palliative care. **Science Funding Committee** - funds awards for research Programmes and Projects, Clinical Chairs and Centers in the Universities and medical schools. Strategic oversight of all Committee activities is taken by the Scientific Executive Board.
PPI	**Population and Behavioural Sciences Committee** state they encourage applications with user involvement. No other PPI is mentioned on website.

Chest, Heart and Stroke Scotland

www.chss.org.uk/

Funding available	£600k per year.
Type of research funded	Basic and clinical research.
Health conditions covered	Chest, heart or stroke illness.
Methods of funding	Project grants, fellowships, small awards and action research.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	Decisions on external reviews taken on individual basis by lead assessor from Research Committee.
PPI	None mentioned on website.

Children with Leukaemia

www.leukaemia.org/

Funding available	£3.8 million in 2006.
Type of research funded	Basic and clinical research – treatment, causes and prevention.
Health conditions covered	Childhood leukaemia.
Methods of funding	Project, programme and capital grants.
Prioritise or commission research	The organisation's research strategy identifies key areas of research that are a priority.
How funding decisions are made	Researchers are invited to submit grant applications, either as part of an annual grants round or on an ad hoc basis in areas of particular interest. Grants are made following peer review involving internal scientific advisers as well as external reviewers. A specialist panel is convened to review the applications received.
PPI	Not mentioned on website.

Children's Liver Disease Foundation

www.childliverdisease.org/

Funding available	£80k per year.
Type of research funded	Basic and translational, nursing and social research.
Health conditions covered	Diseases of the liver and biliary system in children.
Methods of funding	Studentship, fellowships, project grants, small grants.
Prioritise or commission research	Occasionally they invite applications on a particular topic.
How funding decisions are made	CLDF assigns a member of its Scientific Committee to act as lead reviewer on each application. The lead internal reviewer puts forward names for CLDF to approach to provide a review of the application. Following peer review, applicants receive anonymised reviewer comments and can respond by email prior to the grants review meeting. The Scientific Committee then makes recommendations for funding to the board of trustees for their final decision.
PPI	Not mentioned on website.

The Cochrane Collaboration
www.cochrane.org/

Funding available	No funding for research. 52 different review groups provide support to help researchers undertake systematic reviews on a voluntary basis. Thousands of people work with the Cochrane Collaboration from all across the world.
Type of research funded	Systematic reviews.
Health conditions covered	All health conditions.
Methods of funding	A small staff provide training, guidance and support in undertaking a review in each country. Findings are published in The Cochrane Library. The UK Cochrane Centre is in Oxford.
Prioritise or commission research	As Cochrane Review Groups depend on the time and commitment of unpaid reviewers it seems that the general approach has been to allow priorities for reviews to be determined by the reviewers themselves. Two papers on the Cochrane website from 1999 discuss the need to ask clinicians and consumers as end user of reviews to identify their priorities. The Cochrane Heart Group stated that they would develop a model to do this.
How funding decisions are made	Not described on website.
PPI	The Cochrane consumer network is taking part in an online survey. The aim is to identify priority Cochrane reviews for consumers and the public. The main objective is to develop a database prioritising Cochrane Reviews of greatest relevance to consumers. This project will also identify the useful and relevant criteria for prioritising reviews.

Cystic Fibrosis Trust
www.cftrust.org.uk/

Funding available	£4 million – a quarter is directed at improving current clinical care.
Type of research funded	Basic, translational and clinical – focus on gene therapy.
Health conditions covered	Cystic fibrosis
Methods of funding	Project grants, innovative awards (small projects) and PhD studentships. Also funding a Clinical Research Training Fellowship in collaboration with the Medical Research Council.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	Stage 1 outline applications are reviewed by the CF Trust's Research Advisory Committee. Successful applicants at Stage 1 are invited to submit a full Stage 2 application. These are peer reviewed by external and internal referees and discussed in detail by the Cystic Fibrosis Trust's Research Advisory Committee, which makes recommendations for funding to the Trustees of the CF Trust.
PPI	None mentioned on website.

Deafness Research UK

www.deafnessresearch.org.uk/

Funding available	£690k in 2006.
Type of research funded	Basic and clinical.
Health conditions covered	Deafness
Methods of funding	Project grants, research fellowships, postgraduate studentships.
Prioritise or commission research	Grants are concentrated on the following priority areas: • Fundamental molecular, cellular and developmental research leading ultimately to prevention and medical treatments for hearing loss • Early detection of deafness and hearing rehabilitation programmes • Causes and treatment of conductive hearing loss • Genetics of deafness • Improving benefit from hearing aids • Improving benefit from cochlear implants • Central auditory processing • Causes and treatment of tinnitus
How funding decisions are made	The charity has a panel of eight scientific and medical experts who advise on research strategy and have responsibility for the review and monitoring of applications and grants. The research advisers, assisted by the external reviewers, assess not just the scientific merit of an application but its chances of yielding clear, applicable results, and its urgency and appropriateness. Small grants up to £15k – decision made by adviser with external review if necessary. Large grants £15k+ - review involved the following steps: • Preliminary proposal reviewed by research adviser • If successful, researcher asked to submit full aplication • Assessment by DR(UK) adviser and external referees • Revisions /comments invited, as appropriate • Final scoring and recommendation by adviser • Consideration by Research Sub-committee • Final decision by Board of Trustees
PPI	None mentioned on website.

DEBRA

www.debra.org.uk/

Funding available	£1.2 million in 2006.
Type of research funded	Basic and clinical.
Health conditions covered	Epidermolysis bullosa.
Methods of funding	Project grants and training fellowships.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	DebRA UK is the largest provider of EB research funds of all of the national DebRAs around the world and also manages a centralised research grant assessment process on behalf of all of the member groups of DebRA International. On receipt of the applications, suggestions are sought from the Chair and other members of the International Medical and Scientific Advisory Panel (see below) for external referees. Each application is

	sent to 3 external referees. The external referees' reports, together with the applications are submitted to the International Medical and Scientific Advisory Panel. The Panel meets twice a year to consider grant applications. The recommendations of the Panel are then conveyed directly to the applicant and, in the case of referred applications, to the national groups to whom the application has been made. The final decision on whether to fund a particular project rests with the Board of the national group to whom the application has been made.
PPI	None mentioned on website.

Diabetes Research & Wellness Foundation
www.drwf.org.uk/

Funding available	£600k in 2006.
Type of research funded	Basic and clinical – focus on a cure.
Health conditions covered	Diabetes.
Methods of funding	Project grants and exchange fellowships (especially between UK and USA).
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	Research Advisory Board carries out a rigorous peer review process for the assessment of research applications. Involves 2 stages and interviews where appropriate.
PPI	None mentioned on website.

Diabetes UK
www.diabetes.org.uk

Funding available	£6.6 million in 2006.
Type of research funded	Basic and clinical.
Health conditions covered	Diabetes.
Methods of funding	Project grants, small grants, fellowships and studentships.
Prioritise or commission research	The Diabetes UK Research Strategy (2006 -11) was developed in consultation with people with diabetes and their carers, healthcare professionals, researchers and other interested parties. The strategy focuses on research opportunities, not on research priorities. It states: "*There is no question that research opportunities exist across a broad range of topic areas. By contrast, research priorities are debatable and will vary depending on an individual's views and their own particular circumstances at any given point in time. It is also important to bear in mind that we cannot predict where the next research breakthrough will occur. Therefore the strategy allows for flexibility as well as 'acting swiftly and proactively' to commission research when there is urgent need for research in a given area*". Diabetes UK will continue to fund most of its research in responsive mode. Up to 20 per cent of their annual uncommitted research budget may be used to support proactively commissioned research.
How funding decisions are made	Studentship applications are sent to a remote Panel. They are not peer reviewed. The remote Panel will score all applications and make recommendations for funding. Fellowships, project grants and small grant applications are all sent out to peer review. A specialist panel makes recommendations for shortlisting for fellowships. Shortlisted candidates are invited to attend an interview at

	Diabetes UK. The Diabetes UK staff make decisions about small grants and the Research Committee makes recommendations on project grant funding to the Board of Trustees.
PPI	None mentioned on website.

Epilepsy Research UK
www.epilepsyresearch.org.uk/

Funding available	£500 k in 2006.
Type of research funded	Basic and clinical.
Health conditions covered	Epilepsy.
Methods of funding	Project grants and fellowships.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	Applicants send in a preliminary application. These are reviewed by the Scientific Advisory Committee. At this stage the SAC are only interested in the quality of the science to be undertaken. Each member of the SAC independently assigns a score to each application. At a meeting, all applications and their average scores are discussed. The most promising proposals are shortlisted, and a full application is requested. For each of these applications, the SAC selects two independent reviewers. At this stage of the process, the SAC consider factors other than pure science including patient benefit. Taking into account the expert reviews, the SAC again independently assign scores to each application. At their final meeting, they decide which projects will be selected for funding.
PPI	The SAC consists of eight epilepsy researchers from a variety of scientific backgrounds and two lay people.

Fight for Sight
www.fightforsight.org.uk/htm/home.html

Funding available	Currently committed to funding over £5 million to projects.
Type of research funded	Not known – research strategy pages unavailable.
Health conditions covered	Eye disease.
Methods of funding	Programme and project grants, studentships and fellowships.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	The grants allocation panel: • assess and score abstract grant applications for shortlisting • suggest suitable external peer reviewers for full applications • meet and assess full grant applications which have been externally peer reviewed • make recommendations to the Trustees of Fight for Sight concerning the scientific merit of applications
PPI	None mentioned on website.

Heart Research UK

www.heartresearch.org.uk/

Funding available	£900k
Type of research funded	Surgical, clinical and basic science.
Health conditions covered	Heart disease and related disorders.
Methods of funding	In clinical research – project grants and studentships.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	Review undertaken by Medical Review Panel. Each panel member is allocated specific applications for review (2 per application) and has access to all the applications for comment. The panel meets twice a year to make recommendations to the Trustees. External review is sought where extreme difference of opinion is unresolved.
PPI	None mentioned on website.

Inspire Foundation

www.inspire-foundation.org.uk

Funding available	£76k in 2006.
Type of research funded	Research into and the development of electronic, mechanical and medical aids to assist the mobility and enablement of those suffering from spinal cord paralysis.
Health conditions covered	Spinal cord injury.
Methods of funding	Pump priming of the early stages of research.
Prioritise or commission research	INSPIRE's members recently agreed the following list of priorities. a. Bladder function b. Bowel function c. Pain management d. Pressure sores e. Enablement for Tetraplegics f. Mobility for paraplegics g. Sexual function
How funding decisions are made	The organisation has a Scientific Committee which includes users as well as specialist clinicians, and a User Committee. All applications seeking an INSPIRE grant are first subject to review by the User Committee. Shortlisted applications are then reviewed by the Scientific Committee. The final decision rests with the Board of Trustees.
PPI	As above.

Kidney Research UK

www.nkrf.org.uk/

Funding available	Approx £9 million invested per year in over 120 active grants.
Type of research funded	Research into causes, prevention and treatment of kidney disease.
Health conditions covered	Diseases of the kidney and urinary tract.
Methods of funding	• Research Project Grants • Innovation Grants • Senior Non-Clinical Fellowships • Training Fellowships • Career Development Fellowships
Prioritise or commission research	Mostly responsive funding – but the charity also aims to support special projects of research in areas where a specific need is identified, often in partnership with other organisations. Have also carried out a survey of people affected by kidney disease to identify research topics and rank them. Report published Sept 2007.
How funding decisions are made	Applications are peer reviewed by members of the charity's Research Grants Committee and external reviewers. The Committee considers these comments in making decisions about which applications should get funded.
PPI	People affected by kidney disease act as lay reviewers. There are two lay-members of the Research Grants Committee but they are non-voting members. Their role is to comment on any applications and the overall process. A patient representative is also asked to sit on the individual committees overseeing special projects.

Medical Research Council

www.mrc.ac.uk/

Funding available	2005/2006 total research spend = £503.6 million
Type of research funded	The MRC funds a broad range of research – from basic molecular science to applied research. This research is divided into five broad scientific areas, each of which is represented by an MRC research board. The relevant areas that include clinical research are: • Health Services and Public Health Research • Infections and Immunity • Neurosciences and Mental Health • Physiological Systems and Clinical Sciences High level strategic priorities have been identified as: • Clinical and public health research • Infections and vaccine research • Global health • Biomarkers • Ageing-related research • Sustaining capability in areas of strategic importance
Health conditions covered	All health conditions.
Methods of funding	Grants available for research projects and programmes, clinical trials, new investigators, fellowships and studentships. Also funding provided to scientific centres – which include 15 centres, 3 institutes and 29 MRC Units.

Prioritise or commission research	Priorities are identified in response to a broad clinical or scientific need e.g. funding the first UK research in AIDS, establishing a unit to research prion disease, providing the infrastructure to pursue a particular area of research such as a population based genetics, or providing training to develop research capacity. The MRC have always relied on expert advice from the clinical and scientific communities to decide on priorities. The MRC puts out calls for proposals across all areas. Many are initiated by research boards. They also publicise highlight notices that alert researchers to areas of biomedical science that are currently a high priority for the MRC. These topics are broad to allow the best research to come forward. This forms a very small proportion of the research that the MRC funds.
How funding decisions are made	The MRC's funding decisions are made by the five Research Boards, after the proposals they receive have been assessed by external reviewers. They hold their own research budgets, and review and manage scientific activity within their specialist areas. External reviewers comment on applications and those which are unlikley to be funded are rejected at this stage. Short-listed applications are then considered by the research board. External reviewers and research boards/panels assess proposals against the following three core criteria: • **Importance:** how important are the questions, or gaps in knowledge, that are being addressed? • **Scientific potential:** what are the prospects for good scientific progress? • **Resources requested:** are the funds requested essential for the work, and do the importance and scientific potential justify funding on the scale requested? They are then asked to give each proposal an overall score based on their general assessment. Board members are asked to consider issues of quality, importance and likely impact.
PPI	The MRC has recently established a public panel. Details of roles still being established. In the past members of the public have been involved in reviewing and scoring applications as part of a steering group allocating a ring-fenced amount of funding for projects. There is no lay involvement in research boards.

Medical Research Scotland
www.medicalresearchscotland.org.uk/

Funding available	£375k in 2006.
Type of research funded	Basic and clinical.
Health conditions covered	All health conditions.
Methods of funding	Project grants and Fellowships. Focus is on pump-priming innovative proposals from applicants at the start of a research career, to enable the applicants to proceed subsequently to mainstream funding.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	Applicants have first to submit an Outline Application which will be peer-reviewed by national and international experts in the field and a peer review committee of the Trust itself. Up to 30 of these will then be invited to submit

	Full Applications, which will also be subjected to comprehensive peer review. Before final funding decisions are reached, the Full Applications are considered in detail by all the Members of Medical Research Scotland (lay and scientific), who take into account the views of all the external referees. Applications for the Tyson Research Fellowship are similarly subjected to international expert peer review and scrutiny by the scientific Members. A short list of applicants is then invited for interview by a small group, comprising both scientific and lay Members of Medical Research Scotland, who decide whether or not to make an award.
PPI	As above.

Meningitis Research Foundation
www.meningitis.org

Funding available	£82k in 2006.
Type of research funded	Clinical, laboratory based, or epidemiological.
Health conditions covered	Meningitis – especially group B.
Methods of funding	Project grant.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	Full applications are assessed by peer review. A minimum of two independent external referees provide detailed written comments and an overall score on each application. The Scientific Advisory Panel then meets to decide which proposal to recommend, with reference to referee reviews. Final decisions are made by the Foundation's Trustees on applications recommended by the Panel.
PPI	None mentioned on website.

Motor Neurone Disease Association
www.mndassociation.org/

Funding available	Funds spent on research 2006/07 = £736k.
Type of research funded	Basic and clinical science – cause and treatment – but mostly laboratory science.
Health conditions covered	MND
Methods of funding	Project grants, PhD Studentships, Clinical Research Fellowships.
Prioritise or commission research	The MND Association is piloting a Health and Social Care research programme with the aim of creating an evidence base to support gaps in their Clinical Guidelines, which in turn will improve quality of care for people affected by MND.

Funding priorities for the pilot round were:

• Palliative management of respiratory distress (with particular reference to management of patients undergoing voluntary withdrawal of non-invasive ventilation).

• Assessment of the impact of cough assist techniques on respiratory function, survival and quality of life.

• Factors influencing patient decision-making on gastrostomy and/or non-invasive ventilation. |
| How funding decisions are made | • Biomedical Research Advisory Panel members (3 per application) review summary applications. |

	• Full applications are requested from short-listed applicants. • Full applications undergo external review by independent experts. • Proposal and referee comments considered by full panel – one panel member leads on each proposal. • Board of trustees make final funding decisions based on recommendations of the Panel.
PPI	Lay members on panel comment on whether proposals reflect the interests of people affected by MND but do not offer a detailed critique of proposals. Difficult to get users involved as many are terminally ill and may die soon after being diagnosed. But they have managed to involve users and carers in peer review via a web-based virtual advisory board. All reviewers (researchers included) use the same chat room to discuss applications.

Multiple Sclerosis Society
www.mssociety.org.uk/

Funding available	£2.5 million per year.
Type of research funded	Basic and clinical and health services development.
Health conditions covered	MS.
Methods of funding	Project grants, innovative awards, PhD studentships. Highlight notice with MRC – providing career development award and clinical fellowship.
Prioritise or commission research	Research Network members were involved in prioritising projects and funding decisions. In response to views of Research network the Society has begun a new initiative to raise money to fund research into symptom relief.
How funding decisions are made	There are two grant review panels – one for basic and clinical research and one for applied research. Each Panel includes experts within the field of MS research, members of the Society's Research Network (people affected by MS) and members of the Executive. Each Grant Review Panel first reviews outline applications. Shortlisted applicants are then invited to submit a full application. Full applications are subject to peer review and applied applications are also reviewed by people affected by MS. The relevant Grant Review Panel then evaluates the scientific merit and relevance to MS of all applications, in light of reviewers' comments and their own expertise. The Grant Review Panels then make recommendations for funding to the Society's Strategic Advisers Group.
PPI	Research Network members involved throughout.

Muscular dystrophy campaign
www.muscular-dystrophy.org/

Funding available	£1.3million on new and existing grants per year.
Type of research funded	Basic and clinical.
Health conditions covered	60 different forms of muscular dystrophy and allied disorders.
Methods of funding	Project grants (3 years) and PhD studentships.
Prioritise or commission research	MDC have developed a research strategy, influenced by scientists and clinicians. The objective of the research strategy is to increase understanding of muscular dystrophy and allied disorders and to support research into and evaluation of potential management and treatment strategies. It states that the focus of research should be:

	1. To further understanding of the basis of normal and abnormal muscle function with the long-term aim of identifying candidate treatments or management strategies for muscular dystrophies 2. To fast-track promising treatments when they are close to clinical trials to ensure a rapid transition from the laboratory into the clinic 3. To progress safe and effective treatments through clinical development to the marketplace in the shortest time
How funding decisions are made	Applicants send in outline proposals which are reviewed by the Medical Research Committee. Successful applicants are invited to complete a full application form. These are sent to experts world-wide for peer-review and finally considered by the Medical Research Committee. At their annual meeting, each member grades applications and the average score for each application is calculated. The highest ranking applications are funded within the limits of the available budget.
PPI	Plans for PPI are under development. There is some concern that patients will always prioritise applied research at the cost of basic science, although they are aware that other charities have had a different experience. It is difficult for their members to agree priorities when they are variously affected by over 40 types of different neuromuscular condition and research is at a different stage in the development for a treatment for the various conditions.

National Association for Colitis and Crohn's Disease
www.nacc.org.uk/content/home.asp

Funding available	£300-£500k per year.
Type of research funding	Basic and clinical research. Two separate funding programmes, one for Medical Awards and one for Social, Psychological or Health Services Awards.
Health conditions covered	Colitis and Crohn's Disease
Methods of funding	Projects and occasionally PhD students.
Prioritise or commission research	Mostly responsive funding but some projects and reports have been commissioned.
How funding decisions are made	Grant applications are reviewed by the Medical Advisory Committee that includes 3 lay members, six researchers and 3 medical professionals. Lay and scientific reviewers assess and grade applications using identical scoring systems, which are recorded separately (to allow differences to be recognised and discussed) but given equal weighting in the final grant awards meeting. Final decisions are made by the Board of Trustees who consider the opinions of all the committee members.
PPI	As above.

National Institute for Clinical Excellence
www.nice.org.uk

Funding available	No funding for research available.
Type of research funded	The Department of Health commissions NICE to develop clinical guidelines, guidance on public health and technology appraisals.
Health conditions covered	All health conditions.
Methods of funding	N/A

Prioritise or commission research	The topics NICE considers come from a number of sources:
	• clinical and public health professionals, patients, carers and the general public
	• the Department of Health's national clinical directors and policy teams
	• the National Horizon Scanning Centre (they suggest new and emerging health technologies that might need to be assessed)
	• suggestions from within NICE itself
How funding decisions are made	NICE reviews each of the suggestions received to ensure they are appropriate and to check whether they are already included in its work. The suggestions are then filtered according to a check list based on the Department of Health's selection criteria. The DH selection criteria were developed in July 2006 in response to the public consultation on the new process for selecting topics for referral to NICE. The suggestions are then reviewed by consideration panels composed of experts in the topic area, generalists with a good knowledge of the health service, public health and the public sector, and patient and carer representatives. The panels' recommendations go to the Department of Health and a health Minister makes the final decision on which topics are referred to NICE for guidance to be produced. The selection criteria take into account:
	• burden of disease (population affected, morbidity, mortality)
	• resource impact (i.e. the cost impact on the NHS or the public sector)
	• policy importance (i.e. whether the topic falls within a government priority area)
	• whether there is inappropriate variation in practice across the country
	• factors affecting the timeliness or urgency for guidance to be produced.
PPI	The Department of Health carried out a public consultation on the topic selection process from March - June 2006. As a result NICE was asked to manage the administration of the early stages of the topic selection process on behalf of the Department of Health. Anyone can suggest a topic for NICE to develop guidance on by completing a form online or writing to them.

National Institute for Health Research
www.nihr.ac.uk/

Funding available	DH accounts 2005-2006 do not provide details of research budget because R&D activity hard to separate from patient care. 2007 Pre-budget report and Comprehensive Spending Review states that by 2010-11, the single fund for health research will rise to £1.7 billion which includes ring-fenced funding for the National Institute for Health Research through the Department of Health.
Type of research funded	NIHR commissions and funds NHS and social care research that is essential for delivering public health and personal social services. The existing research programmes are being expanded and new funding streams are being introduced. Relevant funding streams include:
	• **Programme Grants for Applied Research** - directed towards leading researchers who can demonstrate an impressive track-record of achievement in applied health research. Addresses areas of priority or need for the NHS.
	• **Research for Patient Benefit (RfPB) Programme** – this national response-mode programme is for high quality investigator-led research projects that address issues of importance to the NHS. Funds will be available on a population basis. Applications will be assessed and processed by a regional committee. Committees covering each of the ten Government Office regions have been established.
	• **Invention for Innovation Research Programme** - a new Programme

	that brings together the work of several smaller programmes with a new investment stream. The Programme will help accelerate the take-up and use of proven new treatments and devices by the NHS.
	• **Research for Innovation, Speculation and Creativity (RISC) Programme.** This programme, provides small, discrete grants for new speculative and radical health research proposals that could lead to a step change in the care and management of patients. RISC awards are intended particularly for speculative, novel proposals that are unlikely to gain support during traditional peer review processes. • **The Health Technology Assessment (HTA) programme.** The HTA programme ensures that people who use, manage or provide care in the NHS have the best and latest information on the costs, effectiveness and impact of health technology developments.
Health conditions covered	All health conditions.
Methods of funding	Funds research networks, infrastructure, NIHR faculty, projects and programmes and research units.
Prioritise or commission research	Each programme has a different remit and will take a different approach to deciding what they should be funding and how determine their priorities. As they are mostly operating in responsive mode, 'prioritisation' involves deciding which applications to fund. Some programmes put out calls for proposals which can be very broad are quite specific. These are worked up by individual programmes using their expertise. The Central Commissioning Facility (CCF) manages the research for a number of the NIHR and Department of Health research programmes. They do not set policy or priorities but support the processing of applications.
How funding decisions are made	There is not one simple process. NIHR is a complex set of different funding streams each of which has different decision-making mechanisms and is managed by different agents. Typically the process involves peer review and decision-making panels.
PPI	The CCF will have public involvement on all their commissioning panels. The Programme Commissioning Panels are advisory groups consisting of 15-20 clinical and academic experts. Their role is to assess grant applications for excellence in the quality of the research to be funded, and the focus on clinical relevance to the NHS. Two members of the public will be recruited to each panel.

NIHR Health Technology Assessment Programme
www.hta.nhsweb.nhs.uk/

Funding available	In 2006, the HTA's annual budget increased by £27 million, from £13 million to £40 million by 2009, to support more HTA clinical trials.
Type of research funded	The HTA programme commissions research in three different ways: • by advertising standard calls for research proposals that address specific topics • by advertising special calls for research proposals that address themed areas • by funding HTA Clinical Trials that are proposed directly by researchers.
Health conditions covered	All health conditions.
Methods of funding	Funding awarded for projects – responsive mode and commissioned research.

Prioritise or commission research	HTA receives many suggestions for research projects via many different routes, including via their website. However the majority of project ideas come from targeted academic research. The process of prioritisation involves a number of stages: 1. Initial suggestions are considered by one of the four expert advisory panels (each one is made up NHS staff and 3 lay members) that cover: • Diagnostic technologies and screening • Pharmaceuticals • Therapeutic procedures • Disease prevention 2. They discuss and vote on which topics are most important for the NHS, based on established criteria. They then identify 8 topics to go to the next meeting. Detailed briefing papers (vignettes) are prepared on the 8 topics. The advisory panels then assesses each one in more depth applying the following criteria: • Benefits in terms of reduced uncertainty – outcomes for patients, cost-effectiveness to the NHS and targeting of services • Length of time before benefits are realised • Value for money • Importance of an early assessment • Policy, social and ethical concerns 3. The panel then agrees which topic should go through to the final stage. Research priorities from all four panels are reviewed and agreed by the Prioritisation Strategy Group, made up of the Chair of each panel, the Programme Director and the Chair of Commissioning Board. The agreed priorities are then taken on by the commissioning team who advertise for research teams to carry out the work.
How funding decisions are made	Research proposals submitted in response to calls are considered by the HTA Commissioning Board, made up of around 20 senior academics, which assesses the scientific merit, feasibility and value for money of the proposals. Primary research submissions are first made in outline, with shortlisted research teams invited to submit more detailed full proposals for consideration by the Board. Outline proposals for HTA Clinical Trials are accepted on an ongoing basis and considered by the HTA Clinical Trials Board, made up of around 20 senior academics. The Board shortlists applicants to submit a full research proposal. Full proposals are then externally peer reviewed before being considered by the Board. Proposals are assessed for importance to patients and the NHS. The Prioritisation Strategy Group is responsible for making the ultimate funding decisions based on the recommendations it receives from the two Boards.
PPI	Members of the public are involved in the prioritisation process in a number of ways by: • Commenting on vignettes • Taking part in the peer review of research proposals • Acting as members of advisory panels The HTA are in the process of developing a 'topic identification strategy' that will involve identifying stakeholders and establishing more formal links with them. This will include patient groups and networks.

National Osteoporosis Society

www.nos.org.uk

Funding available	£235 k per year.
Type of research funded	Basic and clinical.
Health conditions covered	Osteoporosis.
Methods of funding	Project grants, innovative awards, fellowships and PhD studentships.
Prioritise or commission research	They fund both reactively and proactively. They report on call for a clinical trial in response to members' interest in a treatment.
	Users and professionals were consulted about developing the research strategy for 2006-2009.
How funding decisions are made	Funding decisions involve peer review. Experts from all over the world are asked to comment upon the research proposal and a committee of medical and scientific experts, the Research Grants Committee, will take these reports into consideration when judging the overall quality of and importance to the NOS research strategy. The NOS Board of Trustees finally approve funding.
PPI	Non health professional representatives are included on the Research Grants Committee and their views are given equal weight to those of the scientific members of the committee.

Northern Ireland Chest, Heart and Stroke Association

www.nichsa.com/html/index.php

Funding available	£250 k in 2007.
Type of research funded	Scientific programme - basic and clinical research.
Health conditions covered	Chest disease, heart disease and stroke.
Methods of funding	Project grants.
Prioritise or commission research	Every third year commission research in relation to (a) chest, (b) heart and (c) stroke illness.
How funding decisions are made	A short application form is completed in the first instance which is scrutinised by the Scientific Research Grants Committee. Successful applicants are invited to submit a full application which is subject to extensive peer review. Reviews are anonymised and sent to the applicants with an opportunity to respond within a fortnight. The Reviews along with the applicants' responses are sent to the SGRC two weeks before their meeting when they decide which projects should be funded.
PPI	None mentioned on website.

Novo Nordisk UK Research Foundation

www.novonordiskfoundation.org.uk/documents/home_page/document/index.asp

Funding available	£250k in 2006.
Type of research funded	Clinical research.
Health conditions covered	Diabetes.
Methods of funding	Fellowships for health professionals.

Prioritise or commission research	Not mentioned on website.
How funding decisions are made	Applications are reviewed and shortlisted by the Research Selection Committee. The shortlisted applicants are invited to submit a full application which is then sent out to external reviewers.
PPI	None on website.

Parkinson's Disease Society

www.parkinsons.org.uk/

Funding available	Research budget 2006: just under £4 million.
Type of research funded	Basic and clinical science.
Health conditions covered	Parkinson's Disease.
Methods of funding	Project grants, fast-track grants, career-development awards (fellowships and studentships).
Prioritise or commission research	Mostly reactive mode of funding but now also asking for research to address priority topics. The Society's priorities are: • slowing or halting the progression of Parkinson's • the establishment of guidelines for the clinical management of Parkinson's • treatment of non-motor symptoms • role of, and support for, Carers • evaluation of "classical" (e.g. physiotherapy, speech therapy) and complementary therapies These key research topics were agreed by members of the Society and form the PDS programme of research for the period 2005-2009. The Research Agenda itself was generated following input from a number of different groups of people. These included the Society's Board of Trustees, experts in the field of Parkinson's, people with Parkinson's and their carers, the Special Parkinson's Research Interest Group of the PDS (SPRING), physicians, other members of the Society, and PDS staff.
How funding decisions are made	Applications for funding undergo external peer review. These comments are considered by the Research Advisory Panel which has 4 lay members from the Research Network. Each application is assigned to two panel members – one research and one lay expert. The decision as to whether to fund an application or not is made by all panel members.
PPI	PDS have a research network of about 45 volunteers – people affected by Parkinson's. Members play diverse roles, reviewing grant applications, members of research Steering Groups and carry out site visits to PDS funded institutions.

The PBC Foundation (UK) Ltd

www.pbcfoundation.org.uk/

Funding available	£72k in 2007.
Type of research funded	Basic and clinical.
Health conditions covered	Primary Biliary Cirrhosis
Methods of funding	Project grants.
Prioritise or commission research	Not mentioned on website.
How funding	Application assessed by the Research Committee. High quality applications

decisions are made	are sent for review by at least two independent external referees. The applications are then re-considered by the Committee and recommendations made to the Trustees.
PPI	None mentioned on website.

Prostate Cancer Research Foundation

www.prostateresearch.org.uk/

Funding available	£330k in 2006.
Type of research funded	Basic and clinical.
Health conditions covered	Prostate cancer.
Methods of funding	Project grants.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	External peer review followed by consideration by the volunteer scientific and clinical advisory committee.
PPI	None mentioned on website.

Psoriasis Association

www.psoriasis-association.org.uk

Funding available	In 2007, £20,000 for project grants and £75,000 for a studentship.
Type of research funded	Basic and clinical research.
Health conditions covered	Psoriasis
Methods of funding	Project grants and studentships.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	All applications are considered by the Association's Research Committee chaired by the Chief Executive. Decisions are based on scientific merit. Projects approved for funding are listed in priority order and presented for final approval to the National Council of the Association.
PPI	No mention on website.

Remedi

www.remedi.org.uk

Funding available	£70k in 2006.
Type of research funded	Focus on clinical but will fund basic research.
Health conditions covered	All health conditions with focus on rehabilitation to help people with an illness or disability improve their quality of life.
Methods of funding	Project grants.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	Initial outline applications are considered by the Chairman to see if they fit with the remit of the organisation. Successful applicants are invited to submit

	a full application. Each application is then be reviewed by at least two independent referees and applicants may be asked to respond to their comments. The Scientific Advisory Committee meets to consider the applications that have been successful in the previous stages. The SAC shortlists these applications and recommends them in order of priority, for the Trustees to consider for grants.
PPI	None mentioned on website.

Research into Ageing
www.helptheaged.org.uk/research/

Funding available	£2million per year.
Type of research funded	Basic, clinical and epidemiological research.
Health conditions covered	All aspects of ageing – but not usually cancer.
Methods of funding	Project grants, fellowships and studentships, small incontinence awards.
Prioritise or commission research	Commission social research and operate responsive funding for biomedical research.
How funding decisions are made	Outline proposals are evaluated by the charity's Research Advisory Council on the basis of scientific merit and relevance to Research Into Ageing's mission. Full applications are reviewed by at least 3 independent referees before being reviewed by the Research Advisory Council. Applications for Research Fellowships are shortlisted by the RAC. Shortlisted candidates are invited for interview.
PPI	Not mentioned on website.

Sir Jules Thorn Charitable Trust
www.julesthorntrust.org.uk

Funding available	£1.3 million in 2006.
Type of research funded	Focus on translational research having a good possibility of achieving improvements in clinical management within 5 years.
Health conditions	All health conditions.
Methods of funding	Project grants.
Prioritise or commission research	At the Trustees' discretion, funds are allocated annually to one charitable Special Project linked to a theme determined by the Trustees. This programme is not available for unsolicited bids. Applications may be submitted only upon specific invitation from the Trust.
How funding decisions are made	All applications are assessed by the Medical Advisory Committee supplemented by appropriate external referees. For the Trust's main grant programme (The Sir Jules Thorn Award for Biomedical Research) a panel comprising the Committee and external referees makes site visits to discuss shortlisted applications with investigators, collaborators, etc.
PPI	None mentioned on website.

SPARKS - The Children's Medical Research Charity
www.sparks.org.uk/

Funding available	£2 million in 2006.
Type of research funded	Only research which is likely to have a clear clinical application in the near future – next ten years.
Health conditions	Conditions affecting babies and young children

covered	
Methods of funding	Project grants.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	All applicants are required to complete an outline application form. These are reviewed by the Medical Research Adviser. Applicants with suitable research projects are invited to submit a full application. All complete applications are assessed by full peer review, firstly by independent external referees and then by the SPARKS Medical Advisory Committee.
PPI	None mentioned on website.

The Stroke Association
www.stroke.org.uk

Funding available	£2 million in 2006.
Type of research funded	Research into prevention, treatment, rehabilitation and long-term care – basic and clinical.
Health conditions covered	Stroke.
Methods of funding	Project grants and fellowships.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	All Research Project Grants are reviewed by 2 external reviewers and the Research Awards Committee (RAC). Clinical Fellowships are reviewed by the RAC. The Committee makes recommendations to the Council as to which projects to fund.
PPI	Developed research strategy with extensive consultation of stroke survivors and their carers and other stakeholders. Have been developing user involvement in peer review of applications.

Tuberous Sclerosis Association
www.tuberous-sclerosis.org/

Funding available	£135k in 2006
Type of research funded	Basic and clinical
Health conditions covered	Tuberous Sclerosis
Methods of funding	Project grants.
Prioritise or commission research	Have identified priority areas for research and produced an extensive list – which is all encompassing. Their website states the following on setting priorities: *Outlined below are the areas the TSA believes are priorities for research over the next three years to produce the effective treatments which often arise from understanding the molecular mechanisms. It is not possible to be categorical about which areas should receive funding first, since such decisions often depend upon opportunistic factors. These include recent developments in research, the interest and expertise of individual research groups, and which areas are most likely to be funded by agencies outside the TSA. Nevertheless the TSA's role will be to stimulate interest and pump-prime with grants those areas that it feels relevant to the treatment of TSC or that will provide the missing building blocks in understanding of the disease.*

How funding decisions are made	Completed forms are sent to 3 experts for peer review. Peer Review Committee comment on scientific merit of proposal. Research Sub-committee of Trust Board comment on whether conforms to TSA strategy and finances. Trust Board ratifies grant.
PPI	Not mentioned on website.

Wellbeing of Women

www.wellbeingofwomen.org.uk/

Funding available	£1.1 million in 2007.
Type of research funded	Basic clinical and translational research.
Health conditions covered	1. Gynaecological Cancers 2. Pregnancy and Birth; including pre-term birth, miscarriage and fertility 3. Quality of Life issues; including menopause, incontinence and prolapse, sexual health, menstrual disorders and endometriosis
Methods of funding	Project grants, fellowships, scholarships for medical students.
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	Following assessment, the RCOG/WoW Research Advisory Committee recommends awards to be funded and agreement is obtained from the Board of Trustees.
PPI	None mentioned on website.

WellChild

www.wellchild.org.uk

Funding available	£300k in 2006.
Type of research funded	Clinical - All applications should be able to show potential for clear tangible patient benefit and innovation for children and young people's health within five years.
Health conditions covered	Children's health.
Methods of funding	Project grants
Prioritise or commission research	Not mentioned on website.
How funding decisions are made	Two stage process - preliminary applications are assessed and successful candidates invited to submit full applications. Applications undergo peer review and decisions made by the Medical Advisory Committee.
PPI	None mentioned on website.

Wellcome Trust

www.wellcome.ac.uk/

Funding available	Expected budget: £450 million each year 2005-2010.
Type of research funded	Four relevant funding streams: • **Immunology and Infectious Disease** - covers all aspects of immunology and infectious disease in humans and animals and includes basic, epidemiological, clinical studies.

	- **Populations and Public Health** - supports research to improve understanding of the determinants of disease and quality of life in populations and to provide a sound evidence base to inform decisions in public health and healthcare delivery. - **Neuroscience and Mental Health** - invites applications investigating the function of the nervous system in health and disease and includes cellular and cognitive neuroscience, as well as clinically oriented proposals investigating common neurological, ophthalmologic and psychiatric conditions. - **Physiological Sciences** - covers basic and clinical research relevant to the understanding of biological processes at the cell, organ, system and whole-animal level in health and disease and includes clinical trials.
Health conditions covered	All health conditions.
Methods of funding	Grants awarded for programmes, projects, studentships and fellowships.
Prioritise or commission research	Funding priorities and highlighted research areas are decided by stream strategy committees.
How funding decisions are made	Assessment of grant applications is based on peer review. External referees' comments are sought on applications and are considered by the Trust's funding committees (one for each stream), which decide whether or not to fund the application. In the case of some very large grants, the committee makes a recommendation to the Board of Governors, which makes the final decision. Applications are judged on the merits of the proposal put forward.
PPI	Public engagement activities funded – but no mention of public involvement on website.

Appendix 2: Findings from the telephone interviews with staff in organisations that identify priorities for research.

Alzheimer's Society

Why were priorities identified?	Harry Cayton established the QRD Consumer Network when he was Chief Executive at the Society. Network members are involved in all aspects of the Society's research programme, including setting research priorities. This ensures that the Society only funds research that is of direct benefit to its members and is likely to produce results in a short timeframe.
How are priorities identified?	Every two years, a questionnaire is sent to all 180 members of the QRD Network asking them for their top three topics for research. These topics are collated into a long list and then all QRD members asked to vote for their top 10. The topics receiving the highest scores then become the QRD research priorities for the next 2 years. These are listed on the Society's website. The topics vary in number each time. Some are very focused and others include broadly themed areas e.g. stem cells. Staff also ensure that the list of priorities is balanced across the three areas of cause, cure and care.
Link with funding decisions	When researchers submit an application they are asked to state which priority they are addressing. If they do not address one of the priorities, their application is not considered.

Network members also score applications and sit on grant panels. At both stages they are asked to bear in mind the relevance of the applications to the stated priorities. |
| Future plans | It is a challenge to summarise all the ideas that come from network members in a way that captures all the nuances of what a large number of people have said. The research staff are thinking about how to improve the way this is done. |

Arthritis Research Campaign

Why were priorities identified?	The ARC appointed a new medical director in 2007, who has been leading on developing their research strategy. Identifying priorities formed part of this development work.
How were priorities identified?	The medical director has organised a series of meetings with the medical and scientific communities to identify priorities for research.

Link with funding decisions	Having identified priorities, ARC will put out calls for proposals. They are also setting up a committee of patients and professionals – end-users of research – who will look at applications and comment on how well they reflect their needs. It has not yet been decided how funding of commissioned research will sit alongside funding of research in a responsive mode.
Future plans	ARC are still developing their strategy and defining procedures.

Association for Spina Bifida and Hydrocephalus

Why were priorities identified?	The organisation became aware of an issue affecting their members via ASBAH local advisers. Two projects were recently commissioned as a result. These are researching the impact of hydrocephalus on (1) children and (2) adults.
How were priorities identified?	The organisation heard a number of concerns from parents of children with hydrocephalus about behavioural problems at school.
Link with funding decisions	The Medical Advisory Committee (MAC) were asked whether these topics should be identified as a research priority. They agreed that they should and recommended that the Board of Trustees release funds for this purpose. They also identified researchers who could potentially carry out this work. ASBAH then wrote to these researchers inviting applications along with estimates of costs. The MAC made recommendations as to which proposals should be funded, while the Board made the final decision about how much money should be made available. This process was separate from the responsive mode of funding.

Asthma UK

Why were priorities identified?	Asthma UK currently has two research strategies – one basic and one clinical. The clinical research strategy was developed in 2004 and identified priorities for clinical research. The strategies were developed to advise grant applicants of the key research topics that Asthma UK were interested in funding. At the same time, it also fulfilled a recommendation from the AMRC regarding the importance of a research strategy.

| How were priorities identified? | The clinical strategy was based on work carried out by the British Thoracic Society and SIGN to develop evidence-based guidelines for asthma. Three working groups made up of relevant experts considered the three major topics derived from the guidelines. Each group developed a list of research questions in their area based on the gaps in research evidence. They also discussed any new and ongoing research and then identified and prioritised research topics that would fill the gaps. The outcomes of the working groups were brought together in a plenary session, which included representatives from other funding bodies. Through further discussion, the participants reached a consensus on the key areas of research that should be a priority for funding. Within each of these seven priority areas, they not only identified the major research questions, but also, where possible, the best approaches to address them.

More recently Asthma UK worked with the JLA to identify the research priorities of a working partnership of people with asthma and clinicians. |
|---|---|
| Link with funding decisions | All research projects are funded in responsive mode. Applicants are asked to explain how their proposal relates to the identified priorities. Applications which do not address a priority topic are still considered for funding, but only if they are good quality and directly benefit people with asthma. Such applicants are asked to explain why the research is novel and how it is relevant. However, most proposals do fit with the priorities as they are quite broad.

All applications are peer-reviewed. Peer reviewers give each application a final score. One of the criteria they consider is how well the proposal addresses the research priorities. |
| Future plans | The basic research strategy was updated in 2005/06. The clinical strategy still needs reviewing and both may soon be amalgamated into a single strategy outlining all of Asthma UK's research priorities. The development of the new strategy will involve much more PPI to ensure that the priorities of people with asthma are fully reflected in the research the organisation funds. The research priorities identified with the help of the JLA will be integrated into the new strategy. There are currently no plans to ring-fence funds to address priority topics. Asthma UK will continue to fund good quality research that addresses any of the priorities. They may consider commissioning research as a way to encourage more innovative applications in specific areas, diversify their research portfolio and address unmet needs. |

Ataxia UK

Why were priorities identified?	Ataxia UK rarely commissions research and mostly operates in responsive mode.
How were priorities identified?	They rely on informal communication with members – e.g. emails and helpline queries which occasionally identify topics of potential interest. If they are unable to answer a query, they ask their scientific committee if the topic might be a useful area to research. They may then put out a call for proposals. The committee includes lay and professional members.
Link with funding decisions	All proposals including commissioned proposals go through the same process of evaluation (peer review) and are assessed for the scientific quality against a standard set of criteria. The Scientific Committee then recommends which ones are funded. They are likely to give higher priority to those sent in response to a call for proposals. To date, as a small charity, there has not been a problem with competition for resources – they only receive small numbers of applications. They also commissioned an epidemiological research project in Scotland to make use of funds provided by a Scottish Trust.
Future Plans	They are considering developing a more proactive approach to research funding in future – because they are aware of a new area of relevant research that is becoming more active.

Breakthrough Breast Cancer

| Why were priorities identified? | Breakthrough Breast Cancer was originally established to raise £15 million to fund a dedicated research centre. From the outset, advocates have been involved as members of Breakthrough's Board of Trustees, and more recently on other committee's responsible for the progress of Breakthrough's research, including Breakthrough's second flagship project - the Breakthrough Generations Study.

In 2006 Breakthrough published a new research strategy, which describes the ways in which the charity will deliver funding in the next 5-10 years. The main driver for this was that the Breakthrough Research Centre had reached maximum capacity. It has led to the launch of two major collaborative programmes. |

How were priorities identified?	The main way that priorities were identified was through a one day expert workshop involving a range of stakeholders, including scientists, clinicians, policymakers, health professionals, pharmaceutical industry representatives and people affected by breast cancer. Of 80 delegates, 10 were Breakthrough supporters. They received lay documents and a briefing in addition to the meeting documents. The day was structured to ensure there was maximum opportunity for discussion and debate amongst all stakeholders present. At least one supporter attended each table. In addition, Breakthrough sent out a lay version of a questionnaire to over 100 supporters, including campaigners and fundraisers, posing questions about a large range of research priorities and funding models, asking them to rank the level of priority using a 10 point scale. The questionnaire included free-space, to ensure users could add comments, questions, and information to explain their scores. All of the above views informed the final decision, which resulted in the establishment of the new Breakthrough Research Units and the Breakthrough Clinical Researcher Programme.
Link with funding decisions	A committee was established to make funding recommendations to Breakthrough's Board of Trustees regarding which units should be appointed. An advocate was recruited to join the committee, and a range of support mechanisms, including lay briefings and a pre-meetings were provided to ensure that the advocate felt able to represent the needs and interests of people affected by breast cancer, and confidently participate in decision-making.

British Lung Foundation (BLF)

Why were priorities identified?	BLF hosted a joint conference with other relevant charities and the main funders of biomedical research (e.g. the MRC, the Wellcome Trust and the DH) and the respiratory research community to raise awareness of the importance of lung research. The feedback from the DH was that it would be important to identify research priorities.
How were priorities identified?	The BLF therefore held a further 3 meetings with the scientific community and other charities to identify research priorities. Task groups also worked on developing more detailed descriptions of what would need to be covered in each area. These priorities were published in the journal Thorax. This was thought to be a

	good process as the charities and the scientific community could all sign up to this list. Patients were not involved because charity staff were there to advocate patient views.
Link with funding decisions	BLF has adopted these priorities but will still consider applications outside of these areas. They have modified their application forms to ask researchers to identify which priority area they are addressing. If they are not researching a priority topic, they are asked to justify why BLF should consider funding their proposal. The BLF decided not to stipulate that all applications should address the priorities in case an application was put forward for ground-breaking research in an area they hadn't considered. In practice probably 100% of the applications address the priority topics as they are quite broad. Peer reviewers are asked to give a single final score to applications based on a wide range of criteria – one of which is whether the project addresses a priority topic. There is no ranking of the priority research areas – so addressing any one of them is considered to be of merit. So it is unclear how much weight is given to this issue in reviewers' scores.
Future plans	The BLF Scientific Committee, which has two patient members, reviews the research strategy on an annual basis. They will consider whether the priorities are still relevant each year and may decide to change them over time.

British Occupational Health Research Foundation (BOHRF)

Why were priorities identified?	In 2001, BOHRF took a decision to become more proactive about funding research and at the same time adopted a strategy of only funding research of direct relevance to work. The main drivers for this change were: - The vast majority of applications that were being submitted to the BOHRF were failing to recognise employers' concerns and only reflecting researchers' interests. As a result BOHRF were declining applications at a high rate. - BOHRF's corporate sponsors were concerned that too much of the research being funded was blue-skies research, which made it difficult for them to justify their sponsorship as they weren't getting a return for their investment. - Many employers were expressing concern that occupational health professionals were unwilling to give advice or take

How were priorities identified?	BOHRF run 'brainstorm evenings' as and when they are needed to identify new research questions. These are attended by occupational health medics, HR directors and health and safety professionals, mostly from private sector organisations. The ideas for research projects are then reviewed with corporate sponsors to determine if any of the ideas are worth funding, should be rejected or worth further development. Topics for research are also identified via the continual informal discussions with employers, CEOS and HR Directors that form part of the wider work carried out by BOHRF. The prioritised topics are 'worked up' which involves translating the practical questions into proper research questions. This is sometimes a challenge as it can be difficult to develop a robust piece of research that will still address the original question. The final research ideas are then sent out as calls for proposals. Usually this involves approaching two centres of excellence with an invitation to bid for funding.
Link with funding decisions	BOHRF continue to fund applications in responsive mode, but only if they fit with the goals of the organisation. All applications (commissioned and responsive mode) go through an independent research committee and a process of peer review with independent experts. The BOHRF Board then makes the final decisions about funding based on the recommendations of the research committee. There is no separate funding stream for commissioned research. However, if a particular project receives funding from a partner organisation, then those funds will be ring-fenced for that specific project.

BUPA Foundation

Why were priorities identified?	As a small charity the BUPA Foundation wanted to make sure it would add value through its research funding and have therefore targeted areas of clinical research that are generally under-funded. The Foundation's funding of research likely to make a difference to clinical practice in the short to medium term was effectively demonstrated by the recent report "From Donation to Innovation: An analysis of health research funded by medium and

	smaller sized medical research charities" published by the UK Clinical Research Collaboration (UKCRC) and AMRC in October 2007.
How were priorities identified?	The Board identify priority areas for research. The Board is made up of professionals, some of whom do not have a clinical research background. The Board also identifies a specialist topic for commissioned research each year. In judging applications, for both specialist and medical research grants, governors employ a shortlisting scoring system in the initial stage, followed by rigorous peer review.
Link with funding decisions	Part of the budget is ring-fenced for funding research on the specialist topic, usually to the amount of £750 000. However, this amount has been exceeded on several occasions owing to the Board's decision to fund additional high quality clinical projects. The remainder is used to fund research addressing any aspect of the priority areas.

Cancer Research UK (CRUK)

Why were priorities identified?	CRUK has identified a set of ten goals they want to achieve by 2020. They realised they needed a research strategy to enable them to work towards these goals. Therefore about three years ago, they began an extensive piece of work to develop a research strategy. This strategy aims to provide a framework for decision-making around funding. It will provide clarity for the organisation, the research community and potential partners as to which areas CRUK is willing to support.
How were priorities identified?	CRUK undertook an in-depth analysis of their whole research portfolio, considering 23 different topics, e.g. drug discovery, support for institutes etc. They consulted a wide range of stakeholders including UK and international researchers, other funders and umbrella organisations like NCRI. Patients were consulted on the disease specific reviews. They have since drawn up a set of recommendations that will inform an organisational strategy to be published late 2008 - early 2009.
Link with funding decisions	When the research strategy is in place it will clearly state which areas CRUK wishes to be involved in and which areas it does not wish to fund. They will then only accept applications that address

	the topics of interest. It is likely these will be broad and encompass a wide range of projects. Applications that are accepted will be assessed for scientific quality by peer review.
Future plans	They are interested in commissioning research in future, but this is likely to be the exception rather than the rule.

Chief Scientist's Office, Scotland

Why were priorities identified?	Research priorities were identified as cancer, cardiovascular disease, mental health and public health, as well as 'other important areas'. They invite portfolio and programme grant bids in these areas, as well as smaller grant applications across all areas.
How were priorities identified?	Priorities were identified via a consultation process. There was some effort to engage patients and the public through the Chief Scientist's Public Involvement Group. They also contacted the AMRC, some larger AMRC members and some larger Scottish charities.
Link with funding decisions	Funding is not limited to priority areas as capacity building is another priority, which means funding other topics. They have set up 4 'portfolio strategy groups' that cover each priority area. These groups advise on where specific investment might go, and advise on bids. There is PPI in these groups.
Future plans	Their research strategy is currently being rewritten. They are likely to write to a range of charities to ask them what their research priorities are and how these were reached.

The Cochrane Collaboration

Why were priorities identified?	Historically, topics for Cochrane systematic reviews have been suggested by researchers wishing to prepare a review and approved by the relevant Cochrane Review Group (CRG). However, the increasing workload since the Collaboration was first established in 1993, has led some CRGs to become much more selective in the new reviews they take on. The Collaboration also has a longstanding aim to update all reviews at least every two years. The CRGs therefore have to think about prioritising

	both new reviews and the updating of existing ones to be able to manage their workload.
How were priorities identified?	Some CRGs collect ideas as to what reviews are important, but they do not set the agenda. The topics for review are still identified to a large extent by the people volunteering to do the work, and although they may be asked to amend their proposals to be more in line with identified priority areas, the ultimate decision on whether they work on a review is taken by the authors. Some CRGs highlight reviews they believe are a priority in their newsletters and invite researchers to address these topics. However it can be difficult for CRGs to agree on priorities for reviews with a potential global audience. Many issues need to be considered (e.g. burden of disease, commonness of treatment, likely impact on current practice) and the views of a very wide range of stakeholders need to be taken on board. A review that might be a priority for the UK, for example, may not be relevant to other countries.
Link with funding decisions	There are no formal, centrally agreed processes for CRGs to make decisions about which review topics to take forward. But all CRGs are thinking about how to balance the importance of the topic with how much work is likely to be involved in supporting the review. For example, they may choose to do more reviews that require less support from the CRG, rather than conduct one review needing a lot of support, even if the topic is a higher priority.
Future plans	As one of the priortisation projects funded centrally by The Cochrane Collaboration, the Cochrane Consumer Network have carried out an online consultation asking people to prioritise amongst the topics of all the CRGs. This will be completed towards the end of 2008.

Diabetes UK

Why were priorities identified?	Priorities were identified as part of the development of a new research strategy launched in 2005. Historically, the majority of funding had been in responsive mode and the research grants were predominantly in basic science. In order to balance their portfolio, Diabetes UK launched two calls for clinical research. They also plan to commission research as part of the research strategy, and up to 20% of the research budget has

How were priorities identified?	Diabetes UK members and other interested stakeholders were consulted on research priorities via the web and the customer services department. They were asked to identify their top ten topics for research and also to rank some broad research areas. Although the response rate was low, the results did reveal four clear priority areas: a cure for Type I and Type II diabetes, prevention of diabetes, prevention of the complications of diabetes and improving the day to day management of diabetes. This involved grouping together a number of topics under broad themes.
Link with funding decisions	The prioritised themes have been addressed in different ways. The organisation put out two calls for proposals, one addressing day-to-day management of diabetes and one addressing the complications of diabetes.

In order to identify what research is needed in 'preventing Type 2 diabetes', Diabetes UK is hosting a meeting with a range of stakeholders, including people with Type 2 diabetes and people at risk. The aims are to (1) identify topics/ themes to inform future calls for research and (2) engage other funders and encourage them to address this agenda. If the research cannot be taken forward within the Diabetes UK research budget, they will seek to fund the work in partnership with other organisations.

They also plan to hold a meeting about research into 'cures'. This is expected to address the current problem of a lack of research in this area in the UK and consider how best to increase research capacity. |

(Note: the top row continues text "been set aside for this purpose." above the "How were priorities identified?" row.)

INSPIRE

Why were priorities identified?	A new member of staff (the only one in the organisation) decided to update existing priorities.
How were priorities identified?	A survey was carried out with 600 members. Members were asked to prioritise existing research topics and to add any further ideas. This led to a change in the order of research priorities and three new topics were added.
Link with funding decisions	The priorities have limited impact. The research committee that makes decisions about funding does take note of the priorities. However, because there are few researchers in the field of spinal cord injury, and these researchers have well-established areas of

	interest that tend to overlap with the priority topics anyway, in practice, they make very little difference.

Kidney Research UK

Why were priorities identified?	Kidney Research UK wanted to ensure that their research portfolio addressed issues of importance to patients – they were aware that there were gaps because some topics rarely came through in responsive mode e.g. research on dialysis.
How were priorities identified?	They carried out a postal survey of kidney patients in 2007 to ask what research questions they wanted answered. At the same time the Renal Association (a professional body) carried out a survey of researchers' interests. The results seemed to overlap considerably – and included both basic and clinical research. They would like to repeat the surveys to get greater clarity as to where there are overlaps and a greater understanding of the purpose of the research being carried out (e.g. immunological research could be relevant to preventing disease progression (scarring) and improving/finding new treatments (graft survival). They also plan to look at their current portfolio of funded projects and identify gaps. They might potentially put out a call for proposals to address specific research gaps.
Link with funding decisions	Previously when research priorities have been identified, Kidney Research UK has worked in partnership to fund these research areas (e.g. with other funding bodies, government or industry). Once funding was secured they put out an open call for proposals, followed by normal stringent peer review. Users were invited onto the steering groups overseeing these projects.

Macmillan Cancer Support

Why were priorities identified?	Most of what Macmillan spends on R&D relates to improving and developing their own services and charitable activities. This research has to be commissioned to ensure it provides the specific answers Macmillan needs. In order to influence the UK cancer research agenda and to promote research that will make a difference to people affected by cancer, Macmillan have identified research priorities based on the views of users and carers and professional stakeholders.

How were priorities identified?	Initially a series of workshops were held with a wide range of stakeholders to develop a list of research priorities. However, these research areas were broad and covered more than could be achieved within their small research budget. They therefore commissioned 'The Listening Study' which involved carrying out a large number of focus groups with people affected by cancer across the UK. This project developed a consensus opinion on more detailed research priorities. Users have also been involved in a subsequent review of the literature to find out what research has already been done and what still needs doing to address the top priority topic. This has helped identify specific research areas that need to be addressed. Macmillan is using these findings to influence the external research agenda.
Link with funding decisions	Macmillan aims to promote research addressing the priority areas in three ways: 1. A responsive funding stream invites researchers to submit proposals addressing specific research areas, and requires user involvement in the research design and implementation. A panel of staff and people affected by cancer review outline applications. Successful applicants are then invited to submit full applications. Following peer review the panel makes the final decision as to which projects should be funded. 2. Macmillan provides core funding for two research units. The research carried out in these units is being more tightly focused on the new research priorities. 3. Macmillan is also working to persuade other funders to fund research addressing these themes.

Motor Neuron Disease Association

Why were priorities identified?	Research priorities have been identified as part of a programme of work that aims to fill the gaps in the evidence in the MND Association clinical guidelines. Priorities have only been set for health and social care (H&SC) research. None have been set for basic science (which operates in a responsive-mode based on broader strategic themes).
How were priorities identified?	Patients and carers identified priority subjects for guideline development. Researchers at Oxford University then carried out systematic reviews to find the evidence to write the guidelines in

	consultation with a review committee comprising lay members and clinical/healthcare specialists. They also identified gaps in the evidence base. The MND Association research department consulted researchers to find out which of these gaps should be addressed first through further research. These research priorities have been checked with patient groups and clinicians who are broadly in agreement.
Link with funding decisions	There is a separate budget for H&SC research. The organisation applies strict criteria in reviewing applications: only proposals that address priority topics are considered. In developing a process fro commissioning research the Association has found that: • they didn't get many proposals of sufficient quality • their financial limit of £45k per annum was too low
Future plans	They plan to continue using this approach because the research they now fund directly benefits their members and helps to improve people's quality of life.

Multiple Sclerosis Society

Why were priorities identified?	Research priorities have been identified as part of a new 5 year research strategy that was launched in January 2008. Work began on a new strategy because the old strategy had come to an end plus advances in research and new government policies meant the strategy needed to fit with the new context.
How were priorities identified?	The new strategy was developed via extensive consultation with a wide range of stakeholders including open forums with researchers and people with MS. A draft version was presented at regional chairs' meetings and finally approved through an open ballot at the AGM. The priorities for research are quite broad. Therefore a Research Strategy Working Group has developed 10 recommendations to deliver the new strategy. Smaller working groups will in future consider the gaps and agree what further research could be done to make the most difference in the short term. There will be an ongoing Advisory Group to monitor implementation and progress, but also to ensure that the research is needs-based. A working group approach has already been taken to develop the theme of 'Research into the social and economic impact of living

	with MS'. Following further consultation, the group's conclusions will be presented to the Board as a set of priorities to underpin the strategy.
Link with funding decisions	Budgets have been ring-fenced for particular themes e.g. £2.8m has been allocated for symptom relief research over the next 3 years. The MSS will put out calls for proposals and applications will be peer-reviewed. As part of the review process, applications will be assessed in terms of how well they meet the priority themes and given a high, medium or low priority tag. These will be considered by members of the relevant review panel alongside an assessment of each project's scientific quality. The Review Panel will then make recommendations as to which applications should be funded to inform the final decision of the Board. The responsive mode continues in parallel with commissioned research so that innovative and important research can still come forward and the Society can choose to respond quickly if necessary. This involves a similar process of peer review and consideration by a review panel. If there are more high quality applications than funds available, then applications will undergo a strategic review. The applications that best fit with the new research strategy will be given priority for funding.
Future plans	The MSS plans to develop a commissioning framework for research addressing the 'social and economic impact of MS' theme as a way to kick start small and medium sized projects in this area.

National Association for Colitis and Crohn's Disease (NACCD)

Why were priorities identified?	There is very little health services research on Inflammatory Bowel Disease (IBD). The NACCD prioritise the research needed to achieve their objectives for improving NHS services and commission accordingly. The brief is worked up with the researchers. They only commission health services research. Other research - medical and social and psychological - is funded in responsive mode.
How were priorities identified?	Recommendations about IBD health services research are made by the IBD Health Services Committee, comprised of patients,

	carers and NACC staff with individual health professionals invited as necessary. Final decisions are made by the Trustees which is again a mix of patients, carers and co-opted health professionals.
Link with funding decisions	Up until now the health services research has been funded via general funds not research funds but this is changing in 2008. They will be looking to collaborate with researchers to write applications and will seek funding for this research from other funding bodies.

National Institute for Health and Clinical Excellence (NICE)

Why were priorities identified?	NICE budgets set a limit on how many pieces of guidance will be produced each year. Therefore the organisation needs to decide which topics will be given priority. They also have to ensure there is a manageable workload for all the advisory committees and working groups who develop the guidance, and for the staff who support these groups.
How were priorities identified?	Ideas for topics come in via a number of sources. Patients, clinicians and members of the public can submit ideas via the website. They are asked to fill out a form with details of the suggested topic and an explanation of why it is important. If necessary, the Information Services department at NICE will also carry out further research to generate the background information needed for informed decision making. Some topics are picked up by the National Horizon Scanning Centre in Birmingham, who mainly identify new technologies that NICE might need to look at.
Link with funding decisions	The topic selection process is supported by a small secretariat. The decisions are made by seven area-specific Consideration Panels which include lay members. The panels meet every 4 months to review the topics being proposed.
	Initially a questionnaire is sent to key patient groups relevant to the topics under consideration. This questionnaire asks people to indicate whether each topic is high, medium or low priority and how well the topic meets the agreed Department of Health (DH) evaluation criteria. If a topic is thought to be a low priority, the respondent is asked which topic they would rather see addressed.
	The responses are collated and summarised for the Consideration Panel. The panel considers these views as well as

| | the advice from a Clinical Adviser. They then produce a list of all the suggested topics in rank order.

An oversight committee of senior staff reviews the lists from all 7 panels to ensure there is a balance across subject areas. There is no patient involvement at this level. The final decision is made by the DH.

Technology appraisals go through an additional stage of review. Once the topics have been ranked as above, the DH produces a list to be 'provisionally referred' (the number of topics varies each time). These are then scoped in more detail and debated at a multi-stakeholder workshop. This process ensures the appraisal is tightly focused on a question that is appropriate and relevant, and also that the final appraisal will go ahead at the best time.

The outputs of this process are then fed back to the DH for assessment. The DH then chooses the topics that will become full technology appraisals (this list is the 'final referral' to NICE).

The biggest challenge is the lack of time which means consulting patient groups within very short timescales and asking them to stick to tight deadlines. There is not always enough time for people to respond. |
|---|---|

National Osteoporosis Society

Why were priorities identified?	Broad research priorities were identified during the development of the research strategy. The Society has limited funds available for research and needed to ensure that they considered the views of their membership when determining their strategy.
How were priorities identified?	Professional and non-professional members and volunteers were consulted during the development of the strategy. The strategy directs research funding decisions to projects that are likely to provide benefits to people with or at risk of osteoporosis in the short, medium or long term.

The Society is aware of some research priorities through their members' boards and fora and through feedback via their member publications.

The Society rarely commissions research. Ten years ago they commissioned a clinical trial of a complementary therapy that was being heavily marketed to their members. It showed no benefit – |

	so it was very useful. They may do more of this in future.
Link with funding decisions	All funding decisions are made in responsive mode. There is some concern about commissioning research, as they have relatively small funds, and there is a risk of not attracting high quality applications.

Parkinson's Disease Society

Why were priorities identified?	The PDS have established a research network of users and carers. Setting research priorities was one of the activities within a wider programme that aimed to ensure the research funded by the PDS would reflect the interests and needs of their members.
How were priorities identified?	Research priorities are identified in a number of ways: - surveys of members - deliberations of the Research Strategy Group - helpline enquiries - continuous informal channels of communication with research network members and the wider membership
Link with funding decisions	Having identified priorities, the PDS then commission research by developing a spec and advertising on their website. Applications go through a two stage process - firstly to shortlist candidates who are then invited to submit full applications. Proposals are peer reviewed at both stages. However, the bulk of research funding is allocated in responsive mode. There is a separate funding stream for projects addressing prioritised themes.
Future plans	They will be incorporating systematic reviews to determine what research they should fund to address specific priorities.

Appendix 3: Findings from the literature review - Reflections on peer review.

1. Peer review is universally accepted as the best method for making decisions about which research applications to fund. However there has been very little research into the effectiveness of this process, as confirmed by a recent Cochrane Review *'Peer review for improving the quality of grant applications*'[1]. Only ten studies were found to be relevant for inclusion in this review and these have only focused on a single or limited aspect of the peer review process. There have been no studies to assess the direct impact of peer review on the quality and results of funded research.

2. There are also a number of concerns about peer review which will now be discussed in turn.

It is resource intensive

3. Both researchers and grant giving organisations have expressed concern about the amount of time spent writing and reviewing research proposals. For this reason an early study carried out in 1983, compared a simplified assessment procedure with the standard peer review process[1]. As part of the study 113 grant applications to the Canadian Arthritis Society were initially reviewed on the basis of a brief outline application by internal reviewers. The same applications were then reviewed in more detail using additional external experts. The extra details and the external referees' reports had little impact on the final rating of the applications, suggesting that a simplified assessment process would be much more efficient.

4. More recently, Research Councils UK undertook a project in 2006 with the aim of increasing the efficiency and effectiveness of peer review[2]. They estimated the total cost to the UK of preparing and reviewing proposals (as well as producing progress reports) for Research Council funding to be £196 million per year. The direct costs for the Research Councils themselves were estimated to be approximately £9.8 million.

5. As part of this project, Research Councils UK also undertook a benchmarking exercise with a small number of other grant-giving organisations. This showed that basic peer review procedures vary very little between organisations. It also confirmed that the UK Research Councils' administration costs, as a proportion of total budget (4%), are low when compared to most other organisations included in the study.

6. The project also examined a wide range of options for changes to the peer review system that could help increase overall efficiency. 'Commissioning research projects' was one of the options considered, but was thought to offer little

improvement to the status quo. This was because of a concern that commissioning would *'require detailed specification of the research outcome which could hinder creativity and innovation in the research base and would need to restrict eligibility to ensure effect on costs'.* Therefore this option was not developed in any detail.

7.   In the final report, Research Councils UK concluded that[2]:

"These results provide a strong endorsement of the effectiveness of Research Councils' peer review processes in allocating funds wisely and fairly, and show they enjoy the confidence of the research community. Overall the project validated the continued use of peer review as the basis for funding decisions whilst noting the potential for further improvements, for example with respect to speed of decision-making, referee selection, supporting high risk research and with feedback processes".

It has the potential to introduce bias

8.   *Gender bias*: A 1997 investigation by the Swedish Medical Research Council reported that female applicants had to be 2.5 times more productive than their male colleagues to get the same peer-review rating[3]. However, separate investigations by the Wellcome Trust and the MRC in the UK found no evidence of gender bias: grant award rates and publication records were about the same for men and women. However, fewer women apply for funding than might be expected from the gender balance of biomedical researchers.

9.   *Institutional bias*: Some studies suggest that reviewers favour submissions from researchers at prestigious institutions[3].

It is highly subjective and potentially inconsistent

10.   A study in 1981 reported the results of an experiment in which 150 proposals submitted to the National Science Foundation were re-evaluated independently by a new set of reviewers[1]. The degree of disagreement between the two sets of reviewers was high, suggesting that the possibility of getting a research grant depended to a significant extent on chance.

11.   In contrast other studies have shown that there is a good deal of agreement between reviewers in judging the theoretical and methodological quality of the proposals, as well as in evaluating the appropriateness of the budget and also in the final recommendations[1].

The process is opaque

12.   The process of peer reviewing often involves assessing research proposals against a list of criteria including:

- The scientific quality of the proposal
- Its originality

- The appropriateness of the methods used
- The calibre of the applicant(s)
- The relevance of the research to people affected by the health condition under investigation

13. An example of a list of criteria given to peer reviewers can be found in Box 1. After assessing how well a proposal meets these criteria, the reviewer is usually asked to give each proposal a final score - often simply a mark out of five or ten. It is unclear how much weight is given to the different criteria and this is likely to vary between reviewers.

14. The scores and comments are then considered by an advisory committee (that may include lay members). Decision-making is then a complex social process with sensitive dynamics between researchers, reviewers (professional and patient) and funding organisation representatives. It would be difficult to determine the precise influences on any final decision.

It preserves the status quo

15. It has been suggested that peer review is '*an inherently conservative process, that encourages the emergence of self-serving cliques of reviewers, who are more likely to review each other's grant proposals and publications favourably than those submitted by researchers from outside the group*'[3]. This could have a number of consequences. For example, it could[3]:

- Discourage researchers from moving into new fields in which they have no track record

- Make it difficult for junior researchers to obtain grants or publish their research

- Present difficulties for multidisciplinary work, since peer review committees that do not contain individuals qualified to judge all aspects of a proposal may be less likely to approve funding

- Result in the funding/publication of 'safe' research that fits neatly into the conventional wisdom and work against innovative 'risky' or unconventional ideas.

16. **In spite of these well-recognised concerns about peer review, the general consensus is that there is no other alternative**. The recent Research Councils UK project did not question the validity of peer review. Instead they adopted the conclusions of an earlier study published in 1989 (The Boden Report), which stated that there is '*no practical alternative to peer review for the assessment of basic research*'. The Royal Society reached a similar conclusion in 1995.

17. Many patient organisations also appear to support this conclusion. For example Epilepsy Research UK says the following on its website:

Peer review has obvious flaws. It can be difficult for people in one scientific discipline to appreciate the importance of another, leading to bias. Peer review relies at all stages on scientists' behaving honourably, not borrowing ideas, being overly enthusiastic about friends' projects or overly negative about rivals'. It can be very incestuous in small research communities, where everybody is commenting on each other's work. It's quite a secretive process. It tends to focus on the negative points of studies rather than the positive ones. The quality of review and exact standards being applied can very hugely between reviewers.

However there is no obviously better system.

Does involving patients in peer review make a difference to funding decisions?

18. A small number of studies have investigated the impact of involving patients in peer review on final decision-making. In 1998, the National Cancer Institute of Canada (NCIC) undertook a survey of the 24 lay and 126 scientist panelists who had participated in the NCIC's grant review process in the previous year[4]. The survey asked about selecting lay members, the lay member role and suggestions for improving the process. The lay members generally concluded that their role needed to be better defined whilst the scientists expressed mixed views on whether patient involvement was worthwhile[4]. One lay panel member said that she felt the scientists had listened to her and that in a few cases the lay contributions had changed "the course of events"[4].

19. More recently, an evaluation was undertaken of the involvement of breast cancer survivors in the US Army's Breast Cancer Research Programme to assess the impact of patients on proposal scoring and the scientific review process[5,6]. Some of the scientists were concerned that involving patients would 'dilute the scientific rigor'. They thought that patients would require simpler explanations as opposed to fully scientific ones, and that their commitment to other patients might compromise their perspective. They also were concerned that patients would not 'realistically balance clinical versus basic scientific proposals'.

20. However, the study showed that patients' votes had a minimal effect on final proposal scores and therefore minimal impact on funding decisions[5,6]. This was because there were only two patients on each panel, and their proposal scores were very similar to those of the scientists. When the final score was affected, the difference was almost always small and more likely to be in the direction of increased scientific merit than decreased scientist merit.

21. It is not known whether patients' presentations or comments during the panel discussions had any effect on the scientists' voting[5,6]. Most scientists reported that the patients did not affect the overall scoring. However, many also reported that patients added an important perspective to the review process. One of the scientists commented that just having patients at the table led him to consider more carefully the potential impact of each proposal on patient with breast cancer.

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5. Andejeski Y et al. (2002) Quantitative impact of including consumers in the scientific review of breast cancer research proposals. *Journal of Women's Health & Gender-based Medicine* 11 (4): 379-388.

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Box1: An example of a checklist given to peer reviewers

Instructions for reviewers: Reviewers are asked to assess grant applications and give their score and comments based on the checklist below. Please make your comments as full as possible and give extra justification for exceptionally high or low scores.

THE AREA OF RESEARCH
Level of activity in the area internationally
Level of UK activity in the area and its international standing
The importance of the application to the advancement of biomedical science/clinical practice and to wealth creation or quality of life

SCIENTIFIC MERIT OF THE PROPOSALS
Are the objectives clear and sound?
Is the plan of investigation likely to yield decisive results and, if so, on what time scale?
Is the proposal novel, timely and original?
What is the likely significance to the field?
Comment on the suitability of method/ techniques proposed.

APPLICABILITY
How applicable is the work likely to be to people with condition X, now or in the future?

SPECIAL CONSIDERATIONS
Referees should mention any crucial considerations that argue for or against support.

STRATEGIC CONSIDERATIONS
Referees should also comment on how the work fits in with the strategic aims and needs of the charity. These could include the likelihood of high impact publications arising from the work, the possible appeal of the work to the general public and potential donors and other PR issues relevant to the type of work or the subject area.

Funding from the charity is guided by the following principles:

- Excellence and originality of science
- Relevance to those affected by condition X
- Short, medium and long term impact on those affected by condition X
- Financial need – no other obvious or more appropriate source of funding

RESOURCES
Are the resources requested justified and appropriate in terms of:
(a) Staff
(b) Running Expenses
(c) Equipment

Scoring
Please indicate how you would score this proposal – giving a score of 1-5 to reflect scientific merit and a grade A-E to reflect its importance and applicability to patients.