



Consumer involvement in research projects: the activities of research funders

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Abstract

This paper reports findings from a postal questionnaire survey and in-depth interviews with UK funders of health-related research that explored whether, why and how they promote consumer involvement in research projects.

Many UK funders of health-related research are adopting a policy of promoting consumer involvement in research projects. Telephone interviews revealed they have several reasons for doing so, and that they vary in the ways they encourage and support researchers to involve consumers. For some, descriptions of consumer involvement in a research proposal are important for project funding decisions. They recognized a need for flexibility when assessing consumer involvement in different contexts.

We suggest that funders should continue to work to clarify what they consider to be the parameters of acceptability in terms of consumer involvement and ensure that 'flexible' criteria are fairly applied. Researchers should be aware of particular funders' views when applying for project funding.

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1. Introduction

Consumer involvement in health-related research is increasingly advocated. Reasons for this include beliefs that the 'public' have a right to influence the agenda for publicly funded research and that consumer involvement in research activities allows for greater transparency of the research process, makes funding organizations and researchers more account-

able for the research they carry out, and may lead to health-related research being more valued and trusted by members of the public. It has also been argued that people who have experienced particular health problems and used particular health services can improve the quality of research carried out by providing insights that can contribute to the development, conduct, interpretation and use of research relating to these health conditions and services [1–5].

Internationally, various government policy groups and public sector funding bodies have made commitments to increase the extent to which consumers are enabled to influence the scope, nature and use of health-related research [6–8]. Efforts have been made, for example, to involve consumers in the processes of

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setting research agendas and awarding project grants, to include consumers as members of clinical trial steering committees, and to engage consumers in assessing the outcomes of research [8–13].

This paper reports on a two-part study of organizations in the UK that fund health-related research. The first part involved a postal survey of funders to gain an initial overview of their consumer involvement activities and to facilitate the identification of a sample of organizations for a more in-depth investigation. The second part of the study involved semi-structured telephone interviews with a purposive sample of funders that reported involving consumers in their research activities to explore why and how they were doing this. This paper focuses on why and how funders promote consumer involvement in individual research projects.

2. Methods

In February 2002, we surveyed UK organizations that fund health-related research to identify which funding organizations were involving consumers in their research activities. We included public and voluntary sector organizations that award research grants through open competition and whose research expenditure is greater or equal to £100,000 per annum. Our survey included National Health Service Research and Development (NHS R&D) Programmes, the Medical Research Council (MRC), a health-focused Economic and Social Research Council (ESRC) programme, and research charities affiliated to the Association of Medical Research Charities (AMRC) [14].

We sent a structured questionnaire to 88 named contacts (senior staff with research management and/or consumer liaison responsibilities) in 81 organizations. For organizations with several substantial programmes of health-related research we sent separate questionnaires to each identified research programme manager. We sent a reminder letter and questionnaire to non-responders 2 weeks after the first mailing, and an e-mail message to those who had still not responded 2 weeks after the reminder. The e-mail message gave people the opportunity to quickly indicate if they did not involve consumers in the research they funded.

In the covering letter and on the questionnaire we defined consumers as including patients, carers, long-term and potential users of health services, and

organizations representing consumers' interests. We followed the Consumers in NHS Research group's definition of consumer involvement and explained that by involvement we meant some form of active partnership between consumers and researchers in the research process, rather than the use of consumers as the 'subjects' of research [15].

The questionnaire asked respondents whether and how their organizations involved consumers in various activities relating to the management of their research programme(s). It also asked whether and how they encouraged researchers applying for project funding to involve consumers in their research.

Following the postal survey we purposively selected 20 funders of different organizational types that varied in terms of the scope of research funded and had reported various forms of consumer involvement in their research activities. These included national NHS R&D programmes, the MRC, the ESRC's Innovative Health Technologies Programme, the Community Fund and 13 medical research charities.

We e-mailed people who responded to the postal questionnaire and asked if they would be willing to be interviewed by telephone about their consumer involvement activities. Those who agreed were sent a topic guide prior to the interview to allow them to consider the issues to be discussed. The interview questions varied slightly according to the responses given on the postal survey but in general information and opinions were sought on:

- Why and how their organization involved consumers in activities relating to identifying and prioritising research topics, and/or reviewing research proposals.
- Why and how their organization promoted consumer involvement in research projects and encouraged and supported researchers to involve consumers in research projects.
- Whether and how consumer involvement in individual projects was considered when making funding decisions.

The interviews were conducted by MO'D between August and November 2002. They were between 20 and 55 min long. We told respondents that we would not attribute personal views to named individuals or organizations.

The interviews were audiotaped and transcribed in full. Both authors read through the interview data and agreed upon a simple indexing structure that reflected the research questions asked and covered the main issues discussed in the responses. MO'D applied the index codes using NVivo software to help manage the data [16], and VE checked the coding. Both researchers examined the data under each index code and agreed the main findings during discussion.

During the analysis we clarified and supplemented information from the interviews with information from the organizations' websites, including information provided to researchers applying for project funding. In this paper, we report only the findings relating to the involvement of consumers in research projects.

3. Results of the postal survey

Of the 88 people contacted, 69 (78%) replied. One indicated that their organization no longer funded research. Four programme managers from one organization to whom we had sent separate questionnaires returned one questionnaire to cover all four programmes. In total, 68 of the 84 eligible respondents completed questionnaires giving an adjusted response rate of 81%.

Forty-two (62%) respondents indicated that their organizations currently tried to involve consumers in aspects of their research work and went on to answer further questions about this. Thirty-two of the forty-two respondents said they encouraged researchers who apply for funding to involve consumers in their research. The types of activities they encouraged researchers to involve consumers in are summarized in Table 1. Of the 10 respondents who said they did not currently encourage researchers to involve consumers in their research projects, one reported planning to do so in the future.

Ten respondents reported that their organizations included information about involving consumers in the guidance notes that they gave to researchers. Eleven said their organizations asked researchers to explain how they had involved consumers in the development of the grant application. Twelve said they asked researchers to explain how they would involve consumers in their proposed research. Another respondent indicated that their organization was in the pro-

Table 1

Types of research activities in which UK funders encourage researchers to involve consumers

Do you encourage researchers to involve consumers in	Proportion (%) of funding bodies indicating Yes <i>n</i> = 42
Managing research	25/42 (60)
Carrying out research (e.g. carrying out interviews)	15/42 (36)
Interpreting the results of research	15/42 (36)
'Other' ^a	9/42 (21)

^a All 'other' activities related to dissemination of research findings.

cess of adding these questions to funding application forms. The majority of the respondents who indicated that their organizations provided information about consumer involvement in guidance notes or asked researchers about consumer involvement on application forms were from the public rather than the voluntary sector.

4. Results of the in-depth semi-structured telephone interviews

Of the 20 funding organizations approached 17 agreed to take part. One medical research charity did not respond to several email requests and two declined because they did not think their current consumer involvement activities warranted a more detailed analysis.

The organizations approached varied in terms of their constitutions, missions and structures, the range of health conditions they covered, the types of research they funded (basic and/or applied) and their methods of funding (commissioned research and/or responsive funding). Over half of those interviewed had indicated that their organization asked researchers to explain how they had involved consumers in the development of research applications and/or how they planned to involve them in their proposed research.

4.1. Reasons for promoting consumer involvement in research projects

Most respondents gave several reasons for their organization's promotion of consumer involvement

in research projects. They varied in terms of the importance they appeared to attach to particular ones.

Some respondents saw it as a 'matter of principle' that researchers should take consumers' perspectives into consideration particularly if the research involved consumers as 'subjects' or participants and/or if it had potential to influence what health services are delivered and how. Several respondents from public sector funding bodies pointed out that it was 'policy' to involve consumers in research, referring to government and NHS policy commitments. Some highlighted the fact that consumer involvement in research is identified as an ethical requirement in the Research Governance Framework document [17].

Funding organizations also perceive consumers as useful sources of information and advice to researchers, for example on: what it is like to live with a particular health condition; how relevant particular research questions and/or research outcomes are to consumers; whether particular research methods would be acceptable to consumers; how to gain access to study populations; how to go about recruiting participants to a study; the content of information materials for research participants; and where to disseminate research results. Respondents who commented on consumers being a useful source of information and advice to researchers either explicitly or implicitly suggested that such involvement could in some sense improve the 'quality' of research.

One respondent noted that the potential impact that specific consumers might have as sources of information and advice to researchers might diminish over time. For example, as researchers become more in tune with consumers' perspectives it may be the case that consumers' comments on proposed research methods or research outcomes would simply confirm that those proposed by researchers were appropriate. The person who made this point also expressed caution about reverting back to a position where researchers assume they know what is appropriate for consumers without actually checking that this is the case.

A number of respondents commented that bringing researchers into contact with consumers on a research project could help motivate researchers if it made them more aware of how their work might improve the lives of people with a particular health condition. This rationale was particularly associated with contexts in which researchers would otherwise have very little contact

with the potential beneficiaries of their research—for example, laboratory-based researchers. As one respondent commented:

[Consumer involvement] also keeps researchers' eyes on the ball as it were, because we have a lot of basic science research and often the researchers involved have never met anybody with [the condition] or never had any contact with somebody who had cared for somebody with [the condition]. The important benefit we are seeing is that actually researchers are more motivated because they are meeting with consumers all the time and [researchers] actually understand the urgency and the importance of the project they are involved in. (08)

Consumer involvement in research projects was also perceived as a means of improving consumers' understanding of the research process and allowing consumers direct access to research findings which in turn might enhance consumers' abilities to influence policy.

Respondents from the medical research charities noted that consumer involvement in research projects could help raise awareness of and legitimise the research they were funding to their consumer members. This was particularly important to medical charities that raised money for research through members' fundraising activities: they hoped that greater awareness of ongoing research projects might indirectly lead to further research funds being generated.

There was little mention of any potential negative effects of consumer involvement, but a few respondents did express concern about the possibility that some consumers might take advantage of opportunities to influence research to 'hijack' projects to satisfy their own personal or political agendas rather than the needs of wider consumer groups.

The different rationales for involving consumers in research projects influenced the kinds of roles funding organizations envisaged for consumers. Other factors mentioned as being influential included considerations of costs, organizational capacity, types of research project, and the extent of consumer involvement at other stages of the research enterprise (for example in identifying and prioritising research topics). Several respondents stressed that consumer involvement policies and activities within their organizations were still under development, and that they might be mod-

ified as new 'evidence' about consumer involvement emerges.

4.2. Perceptions of consumers' roles in individual research projects

Respondents discussed a variety of roles that consumers had played or might play during the initiation, design, conduct and dissemination of research projects. Taken collectively, their comments suggest that funding organizations consider various forms of consumer involvement as potentially appropriate for at least some types of project. They do not have clear, fixed views about which particular forms of involvement are 'best'.

Some respondents explained that their organizations encouraged researchers to involve consumers during the development of a research proposal prior to submission in order to help ensure that the research questions asked were relevant and the proposed research methods were acceptable to consumers. Some expressed the view that 'early' involvement had more potential to improve the quality of research. For example:

The important thing is getting them involved as early as possible because then if the topic is the right one and if the question is the right one hopefully it makes for better research all the way down. (04)

The most frequently mentioned form of involvement was the inclusion of consumers on project advisory or steering groups. Some funders encourage researchers to include consumers on such groups, but acknowledge that this may sometimes be difficult because of the nature of the research topic, the scale or location of the project, and/or the amount of time and effort being asked of consumers. Some funders appoint consumers to project advisory or steering groups or, for smaller scale projects that might not warrant such groups, assign consumers as project 'buddies'.

The roles that respondents envisaged for consumers on project advisory or steering groups or on assignment to individual projects varied and apparently depended in part on the nature of the research and the reason(s) for involving consumers. For example, in basic research projects consumers could be perceived as acting as motivators to researchers. In more applied research projects, consumers were more likely to

be viewed as being able to offer advice (for example about the acceptability and practicalities of methods) and/or to play a more challenging role (for example by questioning researchers' initial interpretations of research findings).

Several respondents commented on the need to have more than one consumer on advisory or steering groups to ensure that a range of consumer interests were represented and/or to ensure that consumers have peer support. A few suggested that the inclusion of consumers on advisory or steering groups should be supplemented by other forms of consumer involvement during the course of the project.

Well, I think I would want to see that consumers have been actively involved and weren't just tagged on as a member on a steering group, it would be important to have them [involved] throughout ... (04)

Some respondents focused mainly on dissemination activities—either consumers' contributions to the dissemination of research findings or efforts to disseminate research findings to consumer audiences. Consumers who had been assigned to individual projects from the start of a project were seen as particularly well placed to contribute to dissemination activities because of their "*excellent inside knowledge of what the project has been all about*" (08). Efforts to disseminate research findings to consumer audiences could include open days at research sites and presentations of research projects to lay audiences at workshops, meetings or conferences.

Other roles that respondents suggested had been or might be appropriate for consumers included carrying out interviews, writing up research findings, and contributing to discussions about the interpretation and policy implications of research findings.

Some respondents thought that some type of consumer involvement was possible in all types of research projects. For example:

There is hardly any research that we could imagine where [consumer] involvement is impossible. (11)

I would like to argue that all research can have some consumer input. (04)

Others, however, seemed less strongly convinced about the feasibility and/or desirability of consumer

involvement in all types of project. Some explained that their organization placed more emphasis on involving consumers at other stages of the research enterprise, for example in identifying and prioritising research topics and/or reviewing research proposals.

All respondents made comments which indicated that they thought the appropriateness of a particular form of consumer involvement could vary across different types of research project. They also seemed to accept that different types of consumer might be appropriate for different forms of involvement and in different contexts. For example people with personal experience of a health condition were deemed appropriate to be involved on a project steering group for a clinical trial if their role was to provide researchers with useful advice on recruitment issues.

4.3. Steps taken to facilitate consumer involvement prior to submission of research applications

A number of respondents reported giving researchers information, advice and support relating to consumer involvement prior to the submission of grant applications. The types of information they provide include: what they mean by consumer involvement and why they consider it important; the appropriateness of different types of consumers and consumer involvement activities; suggestions about how to identify appropriate consumers; and potential barriers to consumer involvement and how to overcome them. Some funding organizations encourage researchers to consider and budget for the time and costs associated with consumer involvement activities in a project.

Funders supply information and advice about consumer involvement to researchers in various contexts, including: guidelines about applying for research funding; briefing sessions with potential research applicants; commissioning briefs for particular projects; and in response to researchers' enquiries. Several respondents mentioned providing or directing researchers to information from the Consumers in NHS Research group (now called INVOLVE) [18].

Respondents stressed that their organizations tried to avoid being prescriptive in the advice that they gave to researchers because they recognized that the appropriateness of particular forms of consumer involvement was dependent on a number of issues. Rather they were keen to encourage researchers to consider

carefully whether and what types of consumer involvement might be appropriate for their particular projects.

4.4. Approaches used to address consumer issues and perspectives in research proposals

From respondents' comments we identified four main ways in which funding organizations encourage researchers to address consumer issues and perspectives in their proposals (see examples in Box 1). They ask researchers to:

- explain the relevance and importance of the research to consumers, for example by identifying how it will address consumers' research priorities or meet consumers' needs (this is often asked in the context of broader questions about the benefits of the research to the NHS or other stakeholders);
- describe how consumers have been involved during the development of the proposal;
- describe how consumers will be involved once the project has begun;
- provide a lay summary of the research proposal.

Although it is not widely viewed as a way of actively engaging consumers in project development, some respondents saw asking researchers to provide a lay summary of their research proposal as a way of addressing consumer issues in a research proposal. Some funders use the lay summaries during their assessment of proposals, asking consumers to comment on the relevance or appropriateness of proposed research. Lay summaries are also used to inform consumer audiences about ongoing research.

4.5. The use of descriptions of consumer involvement for the assessment of research proposals

Our interview data revealed variations across and within funding organizations in terms of how much importance was attached to researchers' descriptions of consumer involvement when funding decisions were being made about particular proposals.

From respondents' comments we identified three groups:

- those that make consumer involvement a condition of funding;

Example 1

“How will the proposed research meet the needs of users, patients and carers?”
(NHS New and Emerging Applications of Technology Programme)

Example 2

“Consumer-led research priority this proposal will address:”
(Alzheimer’s Society)

Example 3

How will your research benefit those with a primary immunodeficiency?
(Primary Immunodeficiency Association)

Example 4

How do you know there is a need for your project? Include details of how users or potential users were involved in identifying the need.
(Community Fund)

Example 5

“Please outline your proposals for the involvement of stakeholders throughout the project (both prior to the project starting, e.g. during the development of the proposal and after the project has begun, e.g. as participants in the research). This should include services users, and those who plan, manage and deliver services.”
(NHS Service Delivery and Organization R&D Programme)

Example 6

Consumer involvement
“... Research teams wishing to involve consumers should include in their application: the aims of active involvement in this project; a description of the consumers (to be) involved; a description of the methods of involvement; a budget for consumer involvement ...”
(NHS Health Technology Assessment Programme: Commissioning Brief 02/35)

Example 7

How will you make sure that the people or organizations who will benefit from your project are involved in developing, managing, monitoring and evaluating it?
(Community Fund)

Example 8

Plain language summary of the research proposal: in no more than 300 words please summarise your proposal in non-scientific language, using words and terms that can be easily understood by non-research communities. Do not use acronyms or abbreviations. Your summary must include a clear statement of the purpose of your research, how it will build on existing evidence where available, and its intended benefits to patients and the public. It must also describe how the research will be conducted and how patients and the public will be involved.
(NHS Service Delivery and Organization R&D Programme)

Example 9

Please give a short description (no more than 500 words) describing your project in ‘lay’ terms, and explaining how it will help those with a primary immunodeficiency. This may be used for publication by the PiA at any time and forms an implicit part of your application.
(Primary Immunodeficiency Association)

- those who do not explicitly consider consumer involvement at all when making funding decisions; and
- those who consider researchers' descriptions of consumer involvement as one of several criteria when assessing applications for funding.

Within the latter group there is variation in terms of the importance they attach to consumer involvement relative to other criteria (such as the 'feasibility' of proposed research or the robustness of methods), and the stage at which they consider it during the review process. Some respondents appeared to consider consumer involvement as an integral part of the quality of a research proposal while others perceived it as something separate from the more narrowly conceived 'scientific' quality of a research proposal.

Some respondents suggested that if a research proposal was weak in terms of proposed consumer involvement but strong in other respects, the development of consumer involvement activities could be negotiated with researchers as a condition of funding or as the project progressed. For example, if funders thought that researchers could improve the way they disseminated research findings to consumer audiences, they might advise researchers about this once the project was under way.

A few noted that the significance of consumer involvement in a research proposal in terms of funding success might depend on the nature of the research and who happened to assess the applications. For example, assessors with a particular interest in consumer involvement would tend to place more emphasis on this.

4.6. *Perceived indicators of 'good' descriptions of consumer involvement*

When asked what makes for good consumer involvement in research projects, a number of respondents focused on the need for consumers to be able to influence the conduct of the research. For example:

Consumers should make a difference (011),

Consumers should have some real power in the whole process (08) and

That [consumers'] opinions and thoughts on the application of the technology would be reflected in the research so that the research process might be altered according to the consumers' responses. (02)

However, they acknowledged the difficulty of assessing consumer involvement against such ideals, especially on the basis of descriptions in research proposals.

In practice, reviewers' and funders' judgements were or could be made on the basis of:

- the types and numbers of consumers involved in different research activities;
- whether the proposed descriptions of consumer involvement were 'credible' or 'feasible';
- whether consumers were named as co-applicants on research proposals;
- whether researchers demonstrated in their proposals that they had already made initial contact with consumers;
- details of training, personal and financial support for consumers; and
- costing and appropriateness of costing of activities associated with consumer involvement.

However, concerns were expressed about whether researchers would actually do what they proposed to do and whether consumers who were named co-applicants or had been contacted by researchers during proposal development would be guaranteed 'real' involvement in a project.

Consistent with the view that judgments about the appropriateness of different forms of consumer involvement should take into account the type and context of research, respondents recognized a need for flexibility when considering descriptions of consumer involvement in a proposal. Some expressed a need for guidance to enable those assessing research proposals to assess the quality of descriptions of consumer involvement appropriately and consistently.

4.7. *Approaches to monitoring consumer involvement in research projects*

Some organizations attempt to monitor consumer involvement in the projects they fund. They do this either by seeking feedback from consumers who serve as project 'buddies' or advisory or steering group mem-

bers, or by asking research teams to discuss their consumer involvement activities in interim reports or during progress update meetings. Some funders use feedback from researchers as an opportunity to offer advice on consumer involvement issues.

Some respondents recognized that during the course of a project, research teams might come across unforeseen barriers to the forms of consumer involvement they propose and/or identify other consumer involvement opportunities of which they had been unaware when writing the proposal. Our general perception was that funders tend to be flexible and encouraging rather than rigid and punitive when monitoring consumer involvement.

5. Discussion

Our postal survey provided us with an initial overview of the current practices of consumer involvement among funders of health-related research in the UK. Nearly two-thirds of respondents reported involving consumers in some aspects of their research work or planning to do so in the near future. Those who indicated that they didn't involve consumers in their research work were not asked why this was so. We suspect that non-respondents to our study were perhaps less likely than respondents to involve consumers.

The semi-structured telephone interviews with staff from funding organizations who reported involving consumers in their research work gave us greater insight into why and how different funders encourage researchers to involve consumers in research projects and whether and how consumer involvement is considered in project funding decisions. The individual accounts that we obtained might not reflect the views of all members of funding organizations.

Funding organizations varied in their reasons for promoting consumer involvement in research projects and in the emphasis they placed on particular reasons. Consumer involvement was perceived as a policy requirement and/or something that could benefit researchers, the quality and impact of research, consumers themselves, and the profile of the research enterprise more generally. Respondents' rationales for encouraging researchers to involve consumers in re-

search projects reflect those outlined in the academic literature and policy documents.

Between them, funding organizations envisage various types of people being involved in different ways in a range of project-related activities. While a number are striving to promote active partnerships between researchers and consumers, there is no clear consensus across or within funding organizations about what consumer involvement in any particular research project should ideally entail or achieve. Most funders seem to accept that the importance of consumer involvement and the appropriateness of particular forms of consumer involvement may vary across projects and contexts. One of the contextual factors that some funders take into account is the extent to which consumers are involved in the setting of research priorities and the development of commissioning briefs. Strong consumer involvement in these activities may lessen the perceived necessity for particular forms of consumer involvement in specific projects.

Concerns were expressed about the possibility that consumers will inappropriately dominate particular projects, perhaps in the service of hidden agendas. Certainly the possibility that consumer groups may be unduly influenced by the pharmaceutical companies that offer them resources has been highlighted recently [19]. However, such concerns do not necessarily support an argument against consumer involvement per se. Rather, they point to a need to look critically at the views and underlying values of people who seek to contribute to research as consumers, which is similar to the need to look critically at the views and underlying values of other contributors.

Given the lack of research evidence about the effects of consumer involvement in research projects, and uncertainties about the relationships between different forms of consumer involvement and the 'quality' of research delivered, it is not surprising that there is no clear consensus among funding organizations about whether and how researchers' proposals for consumer involvement should influence decisions about which projects are funded. Most organizations are currently adopting flexible approaches to the promotion and assessment of consumer involvement in specific projects. However, 'flexibility' does not have to mean 'anything goes'. Questions do need to be asked about the boundaries of what is acceptable in terms of consumer involvement in projects, and about what kinds of con-

textual considerations are important for assessing particular forms. Also fairness requires that care is taken to ensure that a 'flexible' approach is consistently applied by those involved in assessing research proposals and making decisions about funding.

Research teams seeking project funding need to be aware of the variations in attitudes and practices relating to consumer involvement amongst and within funding organizations. Researchers who are unclear how significant consumer involvement might be in the assessment of research proposals should seek further advice and information from the organizations they seek funding from.

6. Conclusions

Many UK research funders of health-related research are adopting a policy of encouraging researchers to involve consumers in research projects. Most acknowledge that different forms of consumer involvement will be appropriate for different types of research project and that uncertainties remain about how best to judge the quality of consumer involvement in research proposals. Funders should continue to work to clarify what they consider to be the parameters of acceptability in terms of consumer involvement and ensure that 'flexible' criteria are fairly applied when assessing it. Researchers should be aware of funders' views about the appropriateness of different forms of consumer involvement in individual research projects when applying for project funding.

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