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Involving consumers successfully in NHS research: a national survey

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Abstract

Objectives To investigate how far and in what way consumers are involved in NHS research.

Background There is guidance from the UK Department of Health on involving consumers in research, but it is not known how these policies have been implemented.

Design A national postal survey was conducted of 884 researchers selected randomly from the National Research Register, 16 researchers registered on the INVOLVE database and 15 consumers nominated by researchers who collaborated in the same research projects.

Setting The survey participants were drawn from diverse settings including NHS organizations and universities.

Participants Researchers and consumers collaborating in the same projects.

Main outcome measures Details of how consumers were involved and the number of projects that met previously developed consensus-derived indicators of successful consumer involvement in NHS research.

Results Of the 900 researchers who were sent a postal questionnaire, 518 responded, giving a response rate of 58%. Nine of the 15 consumers responded. Eighty-eight (17%) researchers reported involving consumers, mainly as members of a project steering group, designing research instruments and/or planning or designing the research methods. Most projects met between one and four indicators.

Conclusions This national survey revealed that only a small proportion of NHS researchers were actively involving consumers. This study provides a useful marker of how far the Department of Health's policy on consumer involvement in NHS research has been implemented and in what way.

Introduction

Consumer involvement in health research is becoming more widespread both nationally and internationally.[1–6] In the UK, the Department of Health has strengthened its policies on involving consumers in health research,[7–9] with current research strategy stating that 'patients and the public must be involved in all stages of the research process'.[7] Guidance is available for both researchers and consumers on effective ways of involving consumers in health and social care research.[10]

There are increasing numbers of reports in the academic literature of consumer involvement at every stage of the research process including: developing research policy, strategy and priorities, the design and conduct of research and dissemination of research findings. Consumers may be involved in any or all of these stages, with some research entirely consumer-led.[11–16]

Public involvement in scientific research is also emerging. By 'scientific research', we mean a wide range of research that includes basic research, such as molecular, physiological, nuclear and chemical research. The Medical Research Council established an Advisory Group on Public Involvement, formerly the Consumer Liaison Group in 2000.[17] Demos, a political think tank, called for 'upstream engagement'; the earlier involvement of non-specialists in setting scientific research priorities.[18] This was endorsed in an editorial in Nature [19] where it was noted that funding bodies, such as the USA National Institutes of Health, could benefit from public involvement to strengthen their endeavours to integrate a wider range of perspectives into their decision-making processes.

Given the burgeoning interest in and commitment to consumer involvement, it is of interest to find out how far, and in what way, consumers are involved. According to a national survey of consumer involvement in randomized controlled trials,[20] approximately one-third of the trials reported involving consumers, most frequently in reviewing information for patients, promoting recruitment and serving on steering committees. Investigators noted that collaborating with consumers had helped to refine research questions, improve the quality of patient information and make the trial more relevant to patients' needs. An in-depth examination of consumer involvement in 11 primary care research projects [21] revealed that most of the involvement concerned the development or refinement of research tools, the collection of data and occasionally the interpretation of data. It was concluded that the consumers had exerted a beneficial impact on the different research projects and that participants gained personal benefit from learning within the individual studies.

The influence and practical value of patients' input was investigated in 23 cases of research processes where patients had played a role.[22] In nine cases, there were clear examples of influence at different stages of the research process. These included suggestions for research topics or research questions that were subsequently incorporated into specific new research projects, national or international research programmes. Patients' hypotheses were also taken forward into new research questions.

The different ways in which consumers contribute to and influence the NHS' research and agenda-setting process have been described in a systematic study of the processes and outcomes of identification and prioritization in both national and regional R&D programmes.[11] Because of the absence of comparative studies, it was not possible to conclude that one method of involving consumers was more beneficial than another: 'The choice of approach to engagement and methods of interaction will depend on the researchers, the consumers, the research task, the funding body and the social context and values informing the research process'. The authors did, however, conclude that some approaches were associated with specific advantages and disadvantages, while recognizing the uncertainties of knowledge in this area: 'More success might be expected if research programmes embarking on collaborations approach well-networked consumers and provide them with information, resources and support to empower them in key roles for consulting their peers and prioritizing topics'.

It may be argued that research commissioners can shape the way that consumers are included in research processes. A recent postal questionnaire survey and in-depth interviews were conducted with UK funders of health-related research[23,24] to investigate whether, why and how they promote consumer involvement in research projects. Respondents mentioned the inclusion of consumers on advisory or steering groups most frequently, but stressed the importance of not being prescriptive about how consumers should influence the conduct of research. There was recognition that different models and methods of involvement may be appropriate for different types of research.

There is scope for misunderstanding and disagreements about the nature of consumer involvement. One study investigated the extent to which researchers publishing in four international medical journals were involving consumers in their research.[25] Two-fifths of the authors of randomly selected papers reported that they had involved consumers in the research process. Consumer involvement was said to be associated most often with identifying research topics and disseminating research findings. However, mismatches between researchers' perceptions of having involved consumers in their studies and an established definition of consumer involvement in research [26] were found in almost half of the examples given by researchers. The examples included descriptions of consumers participating in research by completing questionnaires.

Consumer involvement in health research is a complex issue, with little consensus about what it means to involve consumers successfully in research. In an endeavour to introduce more clarity, research was undertaken to see if it was feasible to reach agreement on principles of 'successful consumer involvement in NHS research'.[27] Using consensus methods, eight clear and valid principles, each with at least one clear and valid indicator, were derived with a consensus level of at least 85% (see Table 1).

It was not known how many research projects in the UK would meet the consensus-derived indicators of successful consumer involvement in NHS research, as there is a paucity of information on how consumers are involved in health research in the UK. The present study reports on a national postal survey of recently completed health research projects in the UK to provide information on: (i) how far and in what way consumers are currently involved in UK health research and (ii) the number and types of research projects that met the indicators of successful consumer involvement in NHS research.

Methods

Definitions of 'consumer' and 'consumer involvement'

For this study we used the following definitions: 'Consumer' – 'patients, carers, long-term users of services, organizations representing consumers' interests, and members of the public who are the targets of health promotion plans'. 'Consumer involvement in research' – 'Consumer involvement in research can be described as doing research with consumers rather than to, about, or for consumers'.[28]

The establishment of principles and indicators of successful consumer involvement in NHS research

Eight clear and valid principles of successful consumer involvement in NHS research, each of which has at least one clear and valid indicator (see Table 1), were derived through two formal consensus methods: (i) an expert workshop of consumers and researchers that employed the nominal group technique and (ii) a two-round postal Delphi process. Full details are available in the study by Telford *et al.* [27]and Boote *et al.*[29]

Consumer involvement in this study

Three people who provided a consumer perspective at the expert workshop agreed to join the Advisory Group after the workshop and were consulted at different stages of the research,

Table 1 Principles and indicators of successful consumer involvement in NHS research

P	Principle	Indicator(s)
1	The roles of consumers are agreed between the researchers and consumers involved in the research	**The roles of consumers in the research were documented**
2	Researchers budget appropriately for the costs of consumer involvement in research	**Researchers applied for funding to involve consumers in the research** **Consumers were reimbursed for their travel costs** **Consumers were reimbursed for their indirect costs (e.g. carer costs)**
3	Researchers respect the differing skills, knowledge and experience of consumers	**The contribution of consumers' skills, knowledge and experience was included in research reports and papers**
4	Consumers are offered training and personal support, to enable them to be involved in research	Consumers' training needs related to their involvement in the research were agreed between consumers and researchers **Consumers had access to training to facilitate their involvement in the research** Mentors were available to provide personal and technical support to consumers
5	Researchers ensure that they have the necessary skills to involve consumers in the research process	Researchers ensured that their own training needs were met in relation to involving consumers in the research
6	Consumers are involved in decisions about how participants are both recruited and kept informed about the progress of the research	Consumers gave advice to researchers on how to recruit participants to the research **Consumers gave advice to researchers on how to keep participants informed about the progress of the research**
7	Consumer involvement is described in research reports	**The involvement of consumers in the research reports and publications was acknowledged** **Details were given in the research reports and publications of how consumers were involved in the research process**
8	Research findings are available to consumers, in formats and in language they can easily understand	**Research findings were disseminated to consumers involved in the research in appropriate formats (e.g. large print, translations, audio, Braille)** The distribution of the research findings to relevant consumer groups was in appropriate formats and easily understandable language Consumers involved in the research gave their advice on the choice of methods used to distribute the research findings

Indicators in bold were embedded in the postal survey questionnaire.

influencing the methods and the interpretation of the results.

Survey method

A structured postal questionnaire was developed, with the indicators embedded within the questions, to investigate: (i) the types of health research, as classified by the Department of Health, that were most associated with consumer involvement (see Table 2), (ii) the nature of consumer involvement, (iii) how many recently completed NHS-research projects met the indicators of principles of successful consumer involvement in NHS research, (iv) the reasons for not involving consumers and (v) respondents' suggestions for improving consumer involvement in health research.

The questionnaire included ten of the 16 consensus-derived indicators (see Table 3). Those selected for inclusion in the questionnaire were the ones which achieved higher ratings on

Table 2 Reports from lead researchers ($n = 518$) and consumers ($n = 9$) on the different types of research that they had been involved in

Type of health research	Lead researchers' responses from the full sample ($n = 518$)	Lead researchers' responses from projects involving consumers ($n = 88$)	Responses from consumer participants ($n = 9$)
Health services research	150	37	4
Clinical trials	111	19	3
Biological and laboratory research	89	6	1
Population-based research	44	7	0
Other	37	8	0
Research on tissue/DNA samples	30	3	0
Behavioural research	28	7	1
Imaging and technology research	25	1	0
Missing	3	1	0

Table 3 Responses from 88 researchers on whether consensus-derived indicators of successful consumer involvement in NHS research were met by their research project

Indicator	Indicator met? Yes	Indicator met? No	Missing Data
The involvement of consumers in the research reports and publications was acknowledged	53	23	12
The roles of consumers in the research were documented	43	33	12
Details were given in the research reports and publications of how consumers were involved in the research process	41	30	17
Consumers were reimbursed for their travel costs	36	36	16
The contribution of consumers' skills, knowledge and experience was included in research reports and papers	34	36	18
Consumers gave advice to researchers on how to keep participants informed about the progress of the research	33	39	16
Research findings were disseminated to consumers involved in the research in appropriate formats (e.g. large print, translations, audio, Braille)	22	42	24
Researchers applied for funding to involve consumers in the research	21	53	14
Consumers had access to training to facilitate their involvement in the research	20	51	17
Consumers were reimbursed for their indirect costs (e.g. carer costs)	17	51	20

'feasibility', defined as 'the extent to which data for this indicator is, or could be made, available and consistently recorded by research teams'.[27] A copy of the questionnaire is available from the authors. The postal questionnaire survey was carried out between November 2002 and January 2003, with one reminder to non-respondents posted 3 weeks after the first posting.

Sampling frames

Two sampling frames were used for the survey: (i) The National Research Register, a database of ongoing and recently completed research projects funded by, or of interest to, the UK NHS.[30] It is, to our knowledge, the most comprehensive and up-to-date database on health research. One thousand research projects that were due to be completed by 2002 were randomly selected from 51 266 research projects. (ii) A project database of research involving consumers, which had then been newly established by the INVOLVE Support Unit.[10] This was used as it was thought to be the best available database of health research projects involving consumers. All 16 completed research projects that had involved a consumer and were due to be completed by 2002 were selected. All lead researchers contacted through the two databases were sent the questionnaire, and were asked to obtain written consent to provide contact details of at least one consumer who had also been actively involved in the research project, so that they too could be sent the same questionnaire.

Ethical approval

The study was registered with the Sheffield Health and Social Research Consortium and obtained ethical approval from the North Sheffield Local Research Ethics Committee.

Analysis of qualitative data

Lead researchers were asked on the postal questionnaire survey: 'What is the one improvement that you would like to see concerning consumer involvement in health research'? The 'framework' approach for the analysis of qualitative data was employed to analyse the responses.[31] This technique is recommended for use in applied policy research where research is undertaken in real world settings, by more than one researcher, within limited timescales, with the intention of generating practical outcomes and recommendations for both public policy and practitioners. Although an iterative dynamic process, the framework model has the following key stages: familiarization with the data, identifying a thematic framework, indexing and charting of the data using the thematic framework and then mapping an interpretation.

An initial framework of themes and categories was developed through negotiation among the research team, based on an analysis of a small number of questionnaire responses. After the initial framework was agreed, all the responses were analysed, with codes allocated to the text referring to a theme and category contained in the framework. Any additions to the framework during this indexing stage were discussed. Data were then extracted from within the original responses and charted in Word.

Results

Returned questionnaires

Of the 1016 projects initially identified, 116 were excluded for a number of practical reasons, including: the project had not started, had been delayed, or the researcher had moved on and no forwarding address could be found. Lead researchers from the remaining 900 projects were sent the questionnaire, and 518 (58%) responses were received. Of the 88 (17%) projects reporting that they had involved at least one consumer in their research, only 15 lead researchers gave the name of a consumer who had given written consent to be contacted by the research team. All 15 consumers were contacted and nine returned their questionnaire.

Description of participants

Most lead investigators described themselves as a 'researcher' ($n = 501$; 97%), with a small number ($n = 20$; 4%) describing themselves as 'researcher/consumer'. The nine responding consumers named by the lead investigator were asked to specify a particular consumer perspective that best described them, from a list of options. They gave the following responses: advocate/activist/consumer representative ($n = 3$), patient/service user ($n = 2$), other ($n = 2$), employee of an organization for consumers ($n = 1$) and carer ($n = 1$).

Types of health research

Lead investigators responding to the survey appeared to be mainly researching in the areas of health services research ($n = 150$), clinical trials (*n* = 111) and biological and laboratory research (*n* = 89) (see Table 2). Responses from those involving consumers and also from the nine consumers themselves appeared to show a similar pattern, but numbers were too small to make meaningful comparisons between the types of health research and the involvement of consumers in research.

Nature of consumer involvement

According to the lead researchers, consumers who had been involved in the 88 research projects were involved in the following way: as members of a steering group (*n* = 49), designing research instruments (*n* = 38), planning/designing research methods (*n* = 37), identifying/prioritizing research topic/question (*n* = 32), disseminating the research findings (*n* = 31), collecting the data (*n* = 26) and analysing and interpreting the data (*n* = 13). Agreement between the responses of researchers and consumers within the same project on the manner of involvement was not strong. Where both had responded to this question, there were 38 instances of agreement between researchers and consumers and 15 instances of disagreement.

A number of reasons for not involving consumers were offered and respondents were asked to tick an appropriate box, with no restrictions on the number of reasons endorsed. Lead researchers responded in the following way: it was considered inappropriate (*n* = 192; 37%); they never considered involving consumers (*n* = 167; 32%); no funding was available (*n* = 53; 10%); there was no time to engage with consumers (*n* = 52; 10%); they did not know how to involve consumers (*n* = 36; 7%) and no consumers were available (*n* = 12; 2%). Looking ahead to the possibility of future consumer involvement, lead researchers were asked: 'if the research project were to start now, would it benefit from the involvement of consumers'? Two hundred (39%) lead investigators said 'no', 172 (33%) said 'yes', and 143 (28%) were 'unsure'.

Indicators of successful consumer involvement in NHS research

An aim of this study was to find out how many recently completed NHS research projects met the consensus-derived indicators of successful consumer involvement in NHS research (see Table 1). Of the 518 lead researchers who responded to the survey, 88 reported that they had involved consumers in their research projects. Eighty research projects met at least one indicator, with most projects meeting between one and four indicators. Table 3 shows the number of research projects meeting each of the ten indicators. These ranged from 17 to 53 research projects, depending on the specific indicator. Research projects were most likely to meet those indicators that acknowledged and described consumer involvement in reports, what the roles were, and how consumers were involved in research. The indicators least likely to be met concerned reimbursing consumers for indirect costs, consumers having access to training, researchers applying for funds to involve consumers, and research findings disseminated to consumers in appropriate formats. There appeared to be reasonably good agreement between the responses from lead researchers and consumers within the same research projects on which indicators were met. Where data was available from both, there were 58 instances of agreement, with 10 instances of disagreement.

Qualitative analysis of suggested improvements to consumer involvement in health research

Lead researchers were asked: 'What is the one improvement that you would like to see concerning consumer involvement in health research'? and 175 researchers responded. Four themes emerged: consumer-specific issues, dimensions of support, research issues and value and/or ethical issues.

Consumer-specific issues

There were four sub-themes relating to consumer-specific issues: (i) access to consumers,

(ii) representativeness of consumers, (iii) motivation and expertise of consumers and (iv) communication between consumers, researchers and funders. Many responses concerning access to consumers indicated that some researchers had difficulty in finding consumers: 'To have a panel of consumers available for advice'. For other respondents, the issue of representativeness of consumers was important: 'Mechanism to identify appropriate consumer'. The engagement of consumers was brought up by some respondents within the sub-theme of motivation and expertise of consumers: 'More interest from consumers in getting involved, but recognizing their time is as precious as ours'. A small number of responses addressed issues relating to communication between consumers, researchers and funders: 'Better communication between the researcher/clinician or scientist and the general public to help them to understand the research that is ongoing – using simple explanations, limited use of technical jargon and being as open as possible'.

Dimensions of support

The most frequently mentioned improvement concerned dimensions of support and there were four sub-themes within this broad theme: (i) funding and support, (ii) time, (iii) education and training and (iv) guidance and/or information. The need for funding and support was felt to be important by many people: 'Better financial support by grant agencies to facilitate consumer involvement'. The sub-theme of time was commonly linked to the need for funding: 'Better understanding from funding bodies about what consumer involvement entails in reality (time and costs) and more funding to initiate changes based on what consumers say'. Respondents highlighted education and training for both researchers and consumers and this was sometimes linked to resources: 'More education for researchers about how to involve consumers in a meaningful way'; 'Better resources for training consumers for their roles in health research'. Many asked for guidance and/or information: 'A set of standard guidelines indicating when consumer involvement is advisable and how to achieve it'.

Research issues

This theme comprised three main sub-themes: (i) the early stages of research, (ii) dissemination and feedback to consumers and (iii) research methods. There was clear support for consumer involvement at the early stages of research, with suggestions addressing the prioritizing of research projects: 'Involvement in setting research agendas' as well as during the research process: 'Involvement of consumer in development of research question so that it is relevant to them and their peer group'. Some considered dissemination and feedback to consumers to be pertinent: 'Consumer involvement in dissemination of research findings'. Responses within research methods were mixed, and no coherent picture emerged. Suggestions included: 'Development of methods that are consumer friendly'.

Value and ethical issues

Responses relating to the theme of value and ethical issues concerned two sub-themes: (i) the value and/or appropriateness of consumer involvement in research and (ii) ethical issues. Strong support was expressed in relation to the value and/or appropriateness of consumer involvement in research: 'More use of consumers will help to properly address their issues and improve the validity of the research' However, a small number of respondents had clear reservations: 'I see little or no role for consumers in my kind of laboratory-based fundamental research'. A very few responses were measured: 'Active consumer participation is only beneficial for some kinds of research projects'. Comments relating to the sub-theme of ethical issues appeared to be concerned with elucidating the process of involving consumers: 'Clarification regarding need for ethics committee approval when involving users in research'. Other suggestions addressed the inclusion of consumers on Ethics Committees: 'Consumers having representation on ethics committees'; and the need to reduce bureaucracy: 'Make ethical approval easier'.

Discussion

This national postal survey of 518 UK health researchers had a response rate of 58% and revealed that few (88; 17%) health research projects involved consumers. Only projects ending in 2002 were included and many had been planned when policies on consumer involvement in health research were at an early stage of development. Nevertheless, the findings provide a useful marker on how far UK NHS policies on consumer involvement in heath research have been implemented.

Most consumers were involved in research as members of steering groups, designing research instruments and planning or designing the research. A number of frameworks have been proposed that describe various 'levels' of consumer involvement, such as consultation, collaboration or user control,[32,33] but caution has been recommended[23] against assuming that involvement at 'higher' levels is better, as the levels do not mirror all the dimensions of involvement that may be significant and they do not take into account the outcomes of involvement.

Where consumers had been involved in research, almost all projects met at least one indicator of successful consumer involvement in NHS research, and most met between one and four. These findings suggest that the consensus-derived principles and indicators of successful consumer involvement in NHS research are pertinent to health research, and may have utility in future efforts to evaluate and monitor the implementation of UK Department of Health research policies on consumer involvement in NHS research.

Clear recommendations emerged from lead researchers' suggestions for improving consumer involvement in health research, and there were striking similarities between these and the indicators of successful consumer involvement. Areas of overlap included: funding, training, the contribution of consumers' knowledge and experience, dissemination and feedback to consumers and clearer communication between researchers and consumers. Most of the suggestions for improvements were positive. However, a small number of lead researchers stated that consumer involvement was not relevant for their type of research and a few declared that decisions about the appropriateness of consumer involvement in research should be made on a case-by-case basis.

The indicators did not encompass all the main suggestions from lead researchers. Many respondents proposed that consumers should become involved in the early stages of research. Interestingly, this suggestion had emerged as a potential principle at the Expert Workshop during the first stage of the consensus study, but was not retained as it failed to meet consensus of 85% of the panel.[27] Some UK funders of health-related research have been reported to favour the early involvement of consumers in prioritizing research questions, to ensure that the design of research proposals is acceptable to consumers.[23,24]

A key issue to emerge from the suggestions for improvements in consumer involvement in health research concerned training and guidance for researchers and consumers, particularly for researchers. As most responders to this survey were researchers, this is not surprising, and suggests that researchers are seeking to become more knowledgeable and skilful about how to involve consumers in their research. INVOLVE[10] has produced publications on training and a database of training opportunities that are likely to be of interest to both consumers and researchers.

Other suggestions put forward appeared to relate to difficulties in accessing consumers. A few participants proposed panels of consumers who might be interested and available to become involved in research. This is consistent with recommendations referred to earlier in this paper, that more successful consumer involvement is more likely to occur when research programmes collaborate with well-networked consumers, and engage consumer groups directly and repeatedly in facilitated debate.[11] However, these and other authors suggest that the choice of methods for involving consumers should be negotiated with consumers themselves.[23,24]

Many researchers raised ethical issues as areas for improvement. Specific suggestions were made to include consumers on Ethics Committees, to have clear guidance on including consumers in research, and to reduce the bureaucracy. A recent Report of the Ad Hoc Advisory Group on the Operation of NHS Research Ethics Committees[34] has made recommendations that address some of these concerns. It advised that membership of Research Ethics Committees is drawn from a wider mix of society, and a number of proposals have been recommended to streamline Research Ethics Committee operating systems and procedures. Guidance is now available on the ethical conduct of research carried out by mental health service users and survivors.[35]

There did not appear to be a strong association between consumer involvement and the type of health research carried out, and numbers were too small for detailed analysis to be conducted. Comments from a few participants about consumer involvement and basic research raise questions about the value and appropriateness of consumer involvement in this type of research. Some consumer organizations, such as the Alzheimer's Society's Quality Research in Dementia (QRD)[36] initiative are closely involved in commissioning and monitoring basic as well as applied research. QRD members have highlighted the value of close links with researchers: as motivators, by reminding researchers of the possible benefits of their research; as supporters and as potential co-applicants for future research funding applications (S Nurock, personal communication). Members of the Medical Research Council Advisory Group on Public Involvement are also involved in providing advice on policy and strategy concerning research priorities which influence decisions about the funding of basic research.[17] Interviews with UK health-related research funders [23,24] revealed mixed views on the feasibility and/or desirability of consumer involvement in all types of research project.

When questioned about the benefits of future involvement of consumers in their research projects, a third of the lead researchers said it would benefit their research project, and this was twice the number of lead researchers who said they had involved consumers in their research projects. Some comments indicated that the survey itself might have suggested possibilities of involving consumers to researchers, for example, 'This study on consumers in health research is the first time I have seriously been prompted to think about involving consumers in the research process itself, rather than in a more traditional way'.

Previous authors have noted mismatches or variations between people's understanding of 'consumer involvement in research' and established definitions.[25] In this study, the terms 'consumer' and 'consumer involvement' may have confused some lead researchers, even though definitions were given with the questionnaire. In a few cases, comments written on the questionnaire suggested that some researchers thought that 'consumers' were 'research participants'. The missing data in responses to questions about the indicators in Table 3 could indicate that some researchers were unclear about the roles of the consumers in their research project.

It had been intended to capture the opinions of consumers to examine any divergences between their views and those of researchers. However, very few consumers participated, highlighting the difficulties of recruiting consumers through researchers. Lead researchers were not asked why so few of them had invited the consumers to take part in this survey, but some mentioned the following reasons on their returned questionnaires: it was not considered ethical, some consumers did not want to be named and researchers did not wish to ask any more of the consumers in their research projects. The limited information available suggested that there was good agreement between researchers and consumers on which indicators were met, with more divergence on how consumers were involved in the research.

We recognize that the generalizability of the findings of this survey is limited by the response rate of 58%. However, this is the largest survey of health researchers on consumer involvement in NHS research, as far as we are aware, in an area that is still under-researched.

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References

1 The Cochrane Consumer Network. http://www.cochrane.org/consumers/homepage.htm (accessed October 2006).
2 The Consumers' Health Forum of Australia. http://www.nhmrc.gov.au (accessed October 2006).
3 National Institutes of Health Director's Council of Public Representatives. http://www.copr.nih.gov (accessed October 2006).
4 Health Technology Assessment Programme http://www.ncchta.org (accessed October 2006).
5 National Cancer Research Institute. http://www.ncrn.org.uk (accessed October 2006).
6 National Forensic Mental Health R&D Programme. http://nfmhp.org.uk (accessed October 2006).
7 Department of Health. *Best Research for Best Health*. London: Department of Health, 2006.
8 Department of Health. *Research Governance Framework for Health and Social Care*. London: Department of Health, 2005.
9 Department of Health. *Research and Development for a First class service*. London: London: Department of Health, 1999.
10 INVOLVE. http://www.invo.org.uk (accessed October 2006).
11 Oliver S, Clarke-Jones L, Rees R *et al. Involving Consumers in Research and Development Agenda Setting for the NHS: Developing an Evidence-Based Approach*. Health Technology Assessment, 2004, **Vol 8**, number 15, http://www.ncchta.org (accessed October 2006).
12 Faulkner A, Layzell S. *Strategies for Living: The Research Report*. London: The Mental Health Foundation, 2000.
13 Andejeski Y, Bisceglio I, Dickersin K *et al.* Qualitative impact of including consumers in the scientific review of breast cancer research proposals. *Journal of Women's Health & Gender-Based Medicine*, 2002; **11:** 379–388.
14 Trivedi P, Wykes T. From passive subjects to equal partners: qualitative review of user involvement in research. *British Journal of Psychiatry*, 2002; **181:** 468–472.
15 Rhodes P, Nocon A, Booth M, Chowdrey MY *et al.* Service users' research advisory group from the perspectives of both service users and researchers. *Health and Social Care in the Community*, 2002; **10:** 402–409.
16 Patterson C. *Consumer Involvement in Research into Complementary and Alternative Therapies*. Bristol: MRC Health Services Research Collaboration, University of Bristol, 2003.
17 Medical Research Council. http://www.mrc.ac.uk (accessed October 2006).
18 Wilsdon J, Willis R. *See-Through Science*. London: Demos, 2004.
19 Editorial. Going Public. *Nature*, 2004; **431**(7011)**:** 883.
20 Hanley B, Truesdale A, King A, Elbourne D, Chalmers I. Involving consumers in designing, conducting and interpreting randomised controlled trials: questionnaire survey. *British Medical Journal*, 2001; **322:** 519–523.
21 Barnard A, Carter M, Britten N, Purtell R, Wyatt K, Ellis A. *An Evaluation of Consumer Involvement in the London Primary Care Studies Programme*. Eastleigh: INVOLVE, 2005.
22 Caron-Flinterman F. *A New Voice in Science (p32)*. Amsterdam: Vrije Universiteit Amsterdam, 2005.
23 O'Donnell M, Entwistle V. Consumer involvement in research projects: the activities of research funders. *Health Policy*, 2004; **69:** 229–238.
24 O'Donnell M, Entwistle V. Consumer involvement in decisions about what health-related research is funded. *Health Policy*, 2004; **70:** 281–290.
25 Chambers R, O'Brien LM, Linnell S, Sharp S. Why don't health researchers report consumer involvement?. *Quality in Primary Care*, 2004; **12:** 151–157.
26 Standing Advisory Group on Consumer Involvement in the NHS R&D Programme. *Research: What's in it for Consumers?*. London: Department of Health, 1998.
27 Telford R, Boote J, Cooper C. What does it mean to involve consumers successfully in NHS research? A consensus study. *Health Expectations*, 2004; **7:** 209–220.
28 Royle J, Steel R, Hanley B, Bradburn J. *Getting Involved in Research: a Guide for Consumers*. Winchester: Consumers in NHS Research Support Unit, 2001.
29 Boote J, Telford R, Cooper C. Principles and indicators of successful consumer involvement in NHS research: results of a consensus study and subgroup analysis. *Health Policy*, 2006; **3:** 280–297.

30 National Research Register. http://www.nrr.nhs.uk (accessed October 2006).

31 Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG (eds) *Analysing Qualitative Data Analysis*. London: Routledge, 1994.

32 Hanley B, Bradburn J, Barnes M *et al. Involving the Public in NHS, Public Health and Social Care Research: Briefing Notes for Researchers*, 2nd edn. Eastleigh: INVOLVE, 2004.

33 National Health and Medical Research Council and Consumers' Health Forum of Australia. *Statement on Consumer and Community Participation in Health and Medical Research*. Cranberra: AusInfo, 2001.

34 Department of Health. *Report of the Ad Hoc Advisory Group on the Operation of NHS Research Ethics Committees*. London: Department of Health, 2005.

35 Faulkner A. *The Ethics of Survivor Research*. Bristol: Published for the Joseph Rowntree Foundation by the Policy Press, 2004.

36 Alzheimer's Society. Quality research in dementia. http://www.qrd.alzheimers.org.uk (accessed October 2006).