Health researchers' attitudes towards public involvement in health research

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Abstract

Objective To investigate health researchers' attitudes to involving the public in research.

Background Public involvement in research is encouraged by the Department of Health in the UK. Despite this, the number of health researchers actively involving the public in research appears to be limited. There is little research specifically addressing the attitudes of health researchers towards involving the public: how they interpret the policy, what motivates and de-motivates them and what their experiences have been to date.

Design A qualitative research design, using semi-structured telephone interviews.

Setting and participants Fifteen purposively sampled UK-based University health researchers were the participants. Interviews were conducted over the telephone.

Findings The participants suggested varying constructions of public involvement in research. Arguments based on moral and political principles and consequentialist arguments for involving the public in research were offered and most participants highlighted the potential benefits of involving the public. However, feelings of apprehension expressed by some participants imply that a number of researchers may still be uncomfortable with involving the public, as it presents a different way of working.

Introduction

Involving patients and the public in health research forms part of an established movement in the UK towards creating a 'patient-led' health service[1] and a renewal of civic society.[2] As part of the New Labour modernization agenda, participatory governance is intended to increase professional accountability and strengthen public trust in the health service, including health research.[3,4]

'The public' is a portmanteau phrase used to encapsulate the many different types of stakeholder who may be involved in health research including patients, service users and carers. Whilst recognizing that this term may not be acceptable to everyone, because of its lack of precision, we chose to endorse the INVOLVE[5] definition in order to promote continuity and consistency.

Involving the public in research is about readjusting the balance of power between the researcher and the research participant.[6] It is about engaging with users of health services in such a way that their 'experiential expertise'[7] of illness and services is afforded greater consideration alongside professionally defined expertise. In England, the Department of Health[8] has formalized its support for involving the public in research stating that 'relevant service users and carers or their representative groups should be involved wherever possible in the design, conduct, analysis and reporting of research'. Attempts at putting this policy statement into practice have been made within the formal structures of the research environment. Some funding organizations, such as the National Institute for Health Research, provide detailed information on ways to involve the public as well as feedback to applicants on good practice and weaknesses concerning public involvement in research proposals. In Wales, formal support for public involvement in research is more recent, with the establishment of 'Involving People'[9] as part of the Welsh Clinical Research Collaboration, which aims to promote the involvement of the public in 'the strategy, development and implementation of health and social care research in Wales'.[9]

However, despite strong philosophical and political underpinnings, public involvement in health research appears to be making relatively small inroads, is fragmented and is often concentrated within particular groups or geographical areas.[10]

Benefits and challenges of involving the public in research

There are numerous reasons why the public should be involved in health research. These can be categorized, although not exclusively, into arguments based on moral and political principles and consequentialist arguments. Moral and political arguments incorporate ideas concerning rights, citizenship and power distribution. As part of this, a commonly cited argument is that as citizens and taxpayers, members of the public have the right to influence research that is funded through public monies.[11,12] Consequentialist arguments are concerned with the actual contribution that the public can make towards research and its wider acceptability. Authors have commented on the increased relevance and credibility of research, the impact on recruitment and improvement in overall research quality, attributable to involving the public in research.[13–15] More broadly, involving the public in research can be viewed as a way of promoting greater societal acceptance of research by developing public understanding of science.

The challenges of involving the public are well-documented. There are difficulties in obtaining adequate funding to involve the public meaningfully in the initial formulation stages of research. The costs, in both time and money, appear to be key concerns.[15,16] The lack of skills, of both researchers in involving the public and members of the public in carrying out research, have been reported.[17] Unfamiliar research language and jargon have also been cited as potential barriers. Both researchers and members of the public highlight the need for more training in this area.[17]

Alongside the practical challenges, ideological barriers can pose difficulties. The idea of involving the public is not uncontested.[18] An important challenge arises from the lack of an evidence base on the impact of public involvement in research. In response, increasing calls have been made to produce the evidence that will support the case for public involvement.[15,19]

Health researchers' attitudes

An understanding of health researchers' attitudes towards involving the public may help us to appreciate the apparent mismatch between the rhetoric of public involvement and the reality. Positive staff attitudes have been identified as a key component of successful working partnerships between professionals and the public in health- and social-care services.[20,21] Negative attitudes held by researchers could lead to them making tokenistic attempts to involve the public in order to meet policy requirements. Health professionals' failure to involve the public meaningfully may result in an unsuccessful attempt at collaboration that could lead to disillusionment amongst researchers and the public. Whilst there is limited knowledge of researchers' attitudes to involving the public, it has been suggested that some health professionals are unresponsive to involving the public, maintaining professional paternalism.[20,22] One author writing about service user involvement in mental health service development noted 'resistance to non-expert views'.[23] A study investigating public involvement on Primary Care Group boards found 'unwillingness and fear amongst professionals'.[24] Authors researching collaborative working in social work observed that many professionals are 'uncomfortable with the idea of working in partnership with service users'.[25]

Actively involving the public as part of a research team can present a new way of working for health researchers. With the increasing requirements from funding organizations, research governance bodies and ethics committees to involve the public, researchers may find that they have to adapt if they want to obtain research funding. To our knowledge, there has been no research specifically addressing researchers' attitudes towards involving the public in research. We therefore have scant appreciation of how researchers understand and interpret the Department of Health[8] policies, what motivates or de-motivates them to involve the public in research and what researchers' experiences have been to date. The present paper aims to begin to address this gap in the knowledge by reporting on findings from an exploratory study of health researchers' attitudes to public involvement in health research.

Methodology

The study was an exploration of university health researchers' attitudes and opinions towards public involvement in health research. A constructivist framework using a qualitative approach to data collection was used. This was considered to be the most appropriate approach to explore people's attitudes, experiences and personal accounts, given the rich and detailed descriptive accounts that were expected to emanate from the in-depth interviews.[26]

Qualitative interviews were selected as the data collection method as they present participants with the opportunity to develop their own ideas and opinions. They also provide the flexibility required to consider ideas that had previously not been contemplated.[27] The lead author of this paper conducted the interviews to explore participants' understanding of public involvement policy and the meanings that the participants attached to it. The interviews also provided an opportunity to discuss and interpret the participants' experiences and feelings towards public involvement in research. This research is informed by a constructivist paradigm as the aim of the interviews was to understand the multiple realities of the research participants and their personal knowledge of, and beliefs about, public involvement in research.[28] The interview dialogue was a shared construct between the participant and the researcher.[28]

Participants

The sample population for the study were university health researchers in England and Wales. University health researchers, rather than researchers within NHS trusts, were chosen to avoid possible time delays to the project whilst applying for NHS research governance from multiple sites.[29] Eighteen university departments were selected to reflect the diversity in geographical location and the type of health research, comprising biomedical- and laboratory-based research, health service research (both qualitative and quantitative) and clinical trials. Information about the study, a consent form and a demographic detail request form were emailed to each University department's administrator with a request for them to forward the information to all researchers within their department.

In total, we received 22 responses from University researchers willing to participate in the study, which covered 10 of the 18 Universities sampled. Those willing to participate were predominantly from health service researchers. Fifteen researchers were then purposively selected in order to maximize diversity and to address the categories of our sampling frame (Table 1). Data collection ceased after 15 interviews because it was believed that data saturation had occurred, with no new themes emerging from the interviews.

Data collection

The data were collected through semi-structured telephone interviews conducted between November 2005 and May 2006. The length of each interview ranged from 20 min to just over an hour, with an average length of approximately 35 min. A broad topic guide derived from a comprehensive review of the literature was endorsed by the research team and was used to guide the interview. The topic guide aimed to cover the three components of attitude: cognitive (what an individual believes about public involvement in research); affective (how an individual feels about public involvement in research); and behavioural (how an individual behaves towards public involvement in research).[30] The topic guide covered the following areas:

- Thoughts on the key purpose of public involvement in research.
- Reasons or arguments in favour of and against public involvement in research.

Table 1 Details of participants

Participant number	Gender	Research background	Academic grade
1	Female	Health service research	Research Fellow
2	Female	Health service research	Senior Research Fellow
3	Female	Clinical trials	Clinical Trials Manager
4	Male	Health service research	Professor
5	Male	Health service research	Principal Clinical Lecturer
6	Male	Health service research	Professor
7	Female	Health service research	Research Associate
8	Female	Biomedical/laboratory	Research Officer
9	Male	Health service research	Research Fellow
10	Female	Biomedical/laboratory-based	Lecturer
11	Female	Clinical trials	Research Fellow
12	Female	Health service research	Research Associate
13	Female	Health service research	Senior Lecturer
14	Male	Biomedical/laboratory-based	Reader
15	Female	Health service research	Lecturer

- The scope and limitations of public involvement in research.
- An exploration of positive and negative experiences of public involvement in research.
- Positive and negative impacts on the research team and the research when members of the public are involved in research.
- An exploration of what would make an individual more or less likely to involve the public in research.

Throughout the interview, the participants were asked to provide practical examples of any experiences they had in order to illustrate their thoughts and opinions. The constant comparative method was used whereby emerging themes and findings from previous interviews were used to inform subsequent interviews. This allowed the researcher to repeatedly explore new and emerging ideas.[31]

Data analysis

The interviews were tape-recorded and transcribed verbatim. The transcribed data were managed using the NVivo qualitative data analysis software (QSR International Pty Ltd, version 7, 2006, Melbourne, Australia). A broad interpretive thematic approach to analysis was chosen.[32] The data analysis was loosely guided by the principles of grounded theory. The transcripts were openly coded line by line, followed by more selective coding and categorization. Links and relationships between the categories were explored and themes were developed. An iterative process was used to derive the codes and themes, which were then compared with the literature.[33] The transcripts were analysed separately by JT and PW. Any emerging differences in codes and themes were compared and discussed as part of the analysis process.

Findings

The main findings from this study relate to the differing constructions of public involvement in health research, the motivating factors and feelings of apprehension about involving the

public in health research. It is hoped that these findings may help to illuminate researchers' current views on public involvement and stimulate discussion and reflection on the future of public involvement in research.

Competing constructions of public involvement in research

The researcher conducting the interviews gave the same definition of active public involvement in research at the beginning of each interview, 'doing research *with* the public, rather than *to, about* or *for* the public'.[34] However, there was no consensus between participants on the construction of public involvement in research, indicating the varying ways in which the policy Department of Health's policy[8] is interpreted.

Various conceptual perspectives on public involvement were offered by the participants. These ranged from 'partnerships in research', 'offering the public information about research', through to involvement viewed as 'participation in a clinical trial'. The constructions offered by participants and presented here illustrate the complex and multifaceted nature of public involvement in research.

Public involvement was constructed by some participants in terms of partnership and collaboration. Participants frequently referred to members of the public as an essential component of the research team who could actively contribute to all parts of the research process. Here members of the public were often constructed as 'co-researchers'. One author states that this form of public involvement in research '…implies equality and mutual respect between participants'.[35] This suggests a rebalancing of the relationship between researcher and research participant, with the public moving from a role often associated with passivity to one of active involvement. The following quote, given in response to a question about the key purpose of public involvement in research, illustrates this:

> I'm not sure how to sum it up in one sentence, but I think the key purpose is to take the viewpoint of the people you are researching, and to not use them as

subjects but as equal partners in the research, as far as you can, because I think there's far too many times when research is done to people and they haven't been able to inform it, and their views should be taken on board and are very valid. So essentially I think it's about power relations in research, it's about respecting the people that you're researching because I don't think you can just come at it from one angle when you're not in the shoes of the people that you're researching. (Participant 1)

A few participants felt very strongly that whilst involving the public in research may be of benefit, the way in which the public are involved and the overall control of the research should remain in the researcher's hands. This suggests a resistance to transferring and sharing power and a construction of public involvement that is professionally defined:

> …we the researchers have to lead it and that's when I think that there can be a danger if we go too far overboard then the agenda, the research agenda, to such an extent, becomes unworkable. (Participant 7)

Public involvement was also the phrase used by a small number of participants when talking about what is commonly understood as public engagement. Public engagement usually refers to professionals working with the local community to inform them about science and research – for instance, holding public debates about science – rather than the public becoming actively involved in the research process.[36] Participants holding this view of public involvement spoke of the importance of public information, consultation and engagement with society about science. This type of involvement often sees the public engaged as a 'sounding board' in the research process. The participants who constructed public involvement in this way were mainly, although not exclusively, from biomedical and laboratory research backgrounds. The following quote illustrates an example of public engagement:

> …increasingly we are doing stuff and I think public involvement in science is building…We get quite a bit of our money obviously through the government, the research councils, and they sort of impose on us, not exactly a duty but certainly an expectation that we will engage in various, you know, public perception of science, or

understanding sciences isn't a word that is used so much anymore… So they [post graduate students] go and spend a week or so working with a local school and doing sort of science projects with school children and things like that. (Participant 14)

A further construction of public involvement was given by participants who believed that having patients as participants on a clinical trial meant that they were involving the public in research. Some participants spoke about how they 'involved the public' by keeping them updated and informed about a clinical trial and their individual progress within it, with one participant stating that this had the benefit of making the public 'more compliant'.

The construction of public involvement in research as participation in clinical trials was given in response to a question about the participant's personal experience (if any) of active public involvement in research:

> We do have meetings for research but they would be notified, they do get a letter at the end explaining what the results were and they are always very interested finding out what their erm participation has helped to do, because obviously people do want to take part in research, they like to know that their contribution has found something rather than not. (Participant 8)

One participant, a researcher and a GP, believed that because they engaged with their patients on a daily basis, involving the public in research was less relevant for them. They saw public involvement playing a greater role for those researchers that have little or no face-to-face contact with patients. This suggests a construction of public involvement based on the impact that it will have on the researcher, and perhaps on the research, rather than accounting for redistribution of power and a greater voice for the public in research:

> Well I mean I'm a GP so I am sitting and listening to what patients are telling me every day. So it is less relevant I think to me. I think it is much more relevant to the non-clinical researchers actually. And especially the non-qualitative, non-clinical researchers, you know, some of our epidemiologists and perhaps statisticians and health care service people. (Participant 9)

Moral, political and consequentialist motivations

Despite the varying constructions given by the participants, all provided a rationale for involving the public, with perhaps the exception of one participant who saw compliance as the main impetus. We have themed the arguments for involvement given by the participants into moral, political and pragmatic categories; however, the authors recognize that these are not mutually exclusive with some arguments falling into more than one group.

Arguments based on moral and political principles

One of the most significant motivating factors identified by participants for involving the public in research appeared to be the political imperative, a common theme related to the culture of working in an academic research department. Short-term contracts and deadlines for funding left some researchers querying their ability to involve the public in a meaningful way. 'I mean obviously we are always, everybody's always under pressure of time aren't they?' (Participant 3). Public involvement was often seen as an additional pressure in a highly competitive environment. Many research funding, research governance and ethics application forms now require researchers to state how the public will be involved in their research projects. This requirement was viewed as an impetus to include members of the public where appropriate. However, there was also some indication that this could inadvertently lead to a 'tick box' mentality with little consideration given to how the public could be meaningfully involved:

> I think it's a very big undertaking and you know I think because of this I suspect there is a lot of lip service paid to it rather than genuine attempts to involve the public. (Participant 14).

Questions about public involvement were sometimes viewed as another hurdle for researchers attempting to gain the relevant approval in order to begin conducting their research. The following quote was given in response to a question about how well the participant felt that public involvement is embedded in the research culture:

> Well it sort of, it forms part of most grant proposals now doesn't it? But I wonder whether sometimes when you read proposals, because we have had a few, the sort of the extent of their user involvement is like a token one individual or a token or, my concern would be that it's tokenism. (Participant 10)

A case was made that it is ethically and morally right to involve the public in research. First, it was argued that because the public effectively fund research through money paid in taxes, research is publicly owned and therefore the public should have some stake in this. '…it's their money in terms of taxes or whatever…' (Participant 4). Secondly, other participants spoke of 'discourses of empowerment' (Participant 6) and the importance of power redistribution within research relationships, '…the opportunity to be in complete control and direction and to have the power I think it's very important that that's there.' (Participant 2).

Consequentialist arguments

The majority of participants gave examples of the impact that they felt involving the public in research had made, including a common consequentialist argument that centred on the 'validation effect'. This was a reflection on how involving key stakeholders in the research process gave the research a 'seal of approval', and improved its credibility and worth. Involving the public in research was said to make the process 'more real' (Participant 3), and 'more relevant and sensitive to public need' (Participant 15). Reference was frequently made to the 'unique point of view' that the public can bring to the research process and the impact that this makes by improving the documentation, question formulation and data collection processes:

> Interviewer: And having them on board, I mean, what does that do for your, you know, research project?

Participant: It makes it better because they could get information from people that we couldn't nearly so easily. And from our point of view it's much more efficient to work with them because they can do that job so much better and more efficiently than we could. (Participant 5)

Arguments concerning societal acceptance of research and creating greater awareness of research amongst the public were less commonly given by the participants. Perhaps it is of little surprise that these types of argument were generally used by biomedical- and laboratory-based researchers in their construction of public engagement with science. Social acceptance arguments also tended to reflect a belief amongst a small number of participants that involving the public in research would help to create a flourishing research culture, whereby the public felt more compelled to take part in trials, thus having an effect on recruitment and participation rates:

So to sort of set the agenda and henceforth if they set the agenda then that hopefully will then promote awareness of, you know, research and increase participation in research and get to the results quicker. (Participant 3)

Feelings of apprehension

It was interesting that whilst participants put forward arguments in favour of involving the public in research, a number of them also professed feelings of apprehension, giving indications of a potential attitudinal barrier to involvement. Involving the public in health research could be seen as presenting a challenge to traditional scientific knowledge production and acquisition. It suggests a move away from the positivist paradigm towards research that is driven by and grounded in experience.[15,37] The primary source of apprehension amongst the participants appeared to arise from a fear of the unknown, uncertainty about new ways of working and exposure of one's working practice to the outside world: 'It's a different way of working it's uncomfortable to move out of your set ways' (Participant 6). This apprehension could be seen as a natural response to change

and could reflect the need for clearer and more accessible information for researchers about the wider aspects of involving the public in research.

A secondary source of apprehension was that increasing public involvement in research might undermine professional skills and academic knowledge, leading to a sense of de-professionalization. This suggests a tension between knowledge acquired through lived experience and knowledge acquired through professional expertise. This notion forms part of a wider transformation in the society as claims to legitimate knowledge are increasingly contested and as the boundaries between what is understood to be 'expert knowledge' and what is 'lay knowledge' continually shift.[38] In an information age, where the general population is able to access information, which was previously privy to only a small group of appointed experts, the boundaries that had defined both 'lay' and 'expert' status are no longer static.[39] As McClean and Shaw[40] note '…changes to the public status of science and medicine have fundamental implications for the legitimacy of knowledge in the postmodern era'. The identification of a threat to professional skills and knowledge could also highlight a desire by some researchers to maintain a distance between themselves and the public and, consequently, a divide between those with specialist knowledge and those without:

My boss is, I wouldn't say she is anti service user, she is not anti it, but she holds reservations and I think her reservations are the fact that she spent years training and studying to be a researcher and to really get to grips with the whole kind of research process and these people have been bobbing around taking pills and whatever for, and claiming incapacity benefit for 5 years and they are coming in and suddenly they are the experts and they have done no studying, no qualifications and I think she feels a bit kind of like that's not right, 'their experience cannot outweigh my academic qualifications and knowledge'. (Participant 12)

Discussion

The findings presented in this study illustrate that whilst there were multiple constructions of public involvement in research given by

researchers, the majority of participants identified some potential benefit in involving the public in research, including those who expressed feelings of apprehension towards involvement.

The findings highlight the varying and complex attitudes that university health researchers revealed towards public involvement in research. Not all participants shared the same understanding of the meaning of public involvement. Whilst some participants viewed the public as potential co-researchers, others preferred to retain overall control. Public involvement was occasionally interpreted as communicating more closely with research participants and sometimes appeared to be understood as researchers taking part in activities to disseminate, interpret and communicate their findings to the public. Other writers have also commented on the complexities of public involvement and the different ways in which it has been interpreted and/or misunderstood by researchers.[41] The varying constructions are perhaps indicative of the complex and diverse nature of the development of public involvement in health research, reflecting consumerist and emancipatory ideals. It could be argued that constructions of partnership working suggest a greater degree of power sharing and are perhaps more aligned with the principles of empowerment and enhanced citizenship rights.[37] Constructions of public involvement with a focus on public understanding of research perhaps fall within the consumerist ideology of enhanced information and choice. The ethical and moral rationales for involvement were generally located in interviews with those participants who spoke of 'partnership working' and tended to reflect the participants' research interests, for example an emphasis on qualitative research methods and socially excluded groups. In contrast, constructions of involvement based on public understanding of science, or public engagement with research were mostly coupled with arguments for enhanced social acceptance of research. These constructions and associated views reflect the research interests and backgrounds of the participants concerned, in this case they were chiefly biomedical- and labora-tory-based. It could be that the dominant model of public involvement found within health services research may not be appropriate for biomedical- and laboratory-based research. This may indicate the need for further research in order to develop appropriate methods of involvement for different research areas.

The academic research culture is fundamentally project-driven. Researchers are frequently hired on short-term contracts to undertake research projects within tightly defined deadlines. The preparatory work that is needed before a research proposal can be submitted for funding is considerable and there is a lack of funding available for involving the public in the initial ideas generation and project design. Despite this, these research findings suggest that some researchers are finding ways in which to include the public and recognize the value that the public can bring.

It was apparent that some participants felt apprehensive about involving the public, and were concerned that their knowledge and skills may be challenged. This could indicate confusion about the different roles that the public might be expected to bring to the research process. It is also possible that this exploratory study has highlighted a more fundamental issue around challenges to epistemology and the ways in which professional and public 'expertise' can work together. This corresponds with other bodies of work including 'claims to expertise' and 'knowledgeable narratives'.[42–44]

For many participants, a key driving force behind involving the public in research appeared to be the research governance imperative. This raises questions about how far researchers are convinced of the rationales for involving the public in research. If researchers are involving the public through a sense of requirement without a clear appreciation of the value that they could bring to a study, a tokenistic situation could develop rather than the encouragement of a positive culture change.[37] A study of public involvement in complementary and alternative therapy research showed that when involvement took place, it was usually because of a stipulation by the funding body, or because

the public had taken a lead in the research.[45] This 'requirement' or 'driving force' can be linked to Foucault's construction of governmentality.[46] Using this analysis, research governance represents a discourse that attempts to regulate researcher behaviour so that individuals feel compelled to show that they are following the rules.

However, the research governance impetus for involving the public should not necessarily be viewed in a negative light. It demonstrates that whilst public involvement may be new to some researchers, attempts are being made to comply with these new requirements. In a longitudinal study of health service staff attitudes to community involvement in services, Nathan *et al.*[20] found that staff became more receptive to community involvement over time. Initial anxiety and negative attitudes diminished once staff had experienced working with community representatives. Perhaps in a similar vain, although initially viewed as a requirement, once researchers have experience of working collaboratively with the public, involvement could become part of their research philosophy.

Limitations of this study

The findings presented in this study reflect the views of a small number of purposively sampled researchers. Whilst a large sample of participants was initially contacted and invited to take part in the research, we received a limited response. We are mindful of the fact that the team conducting the research may be known as a group who are pro-public involvement because of previous work conducted. Due to this, and the political impetus associated with public involvement, we must consider the possibility that participants felt limited in their ability to express their feelings in an attempt to answer in a socially desirable manner. It could also be assumed that only those who are enthusiastic about public involvement in research, or perhaps those who have had a negative experience, might have agreed to be interviewed. However, the data captured provide a range of attitudes and opinions, which reflects an attempt to sample for deviant cases and is a potential strength of our study.

Conclusions

The present study has explored the different ways in which researchers interpret the current policy on public involvement in research in the UK. It illustrates the competing constructions of public involvement in research and the motivating factors for involving the public. This study highlights the need for a greater understanding of the realities of public involvement, perhaps through education and training for researchers. Like any major change in working practice, researchers need the time to adjust. The value of involving the public is increasingly recognized by researchers. Although we may be encouraging lip service to public involvement, there is also reason to be hopeful that for some researchers who initially 'tick the box', their experience will lead to a greater appreciation of the benefits of involving the public in research. Small steps are been made by researchers towards involving the public, but they represent a whole new way of working for many. With greater institutional support structures, researchers will be better placed to involve the public meaningfully and develop good working practices and relationships.

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