Exploring the meaning and impact of public involvement in health research

Thesis submitted for the degree of Doctor of Philosophy by publication

The University of Sheffield

School of Health and Related Research

Rosemary Barber (formerly Telford)

January 2014

Acknowledgements

I am indebted to Paul Bissell for his expert supervising of this thesis. He and others have been an immense source of inspiration, learning, challenge and support, and I should like to thank them all very warmly:

Brian Barber

Peter Beresford

Jonathan Boote

Cindy Cooper

Alison Faulkner

Liddy Goyder

Allen Hutchinson

Maxine Johnson

Glenys Parry

Lyn Russell

Marie Claire Shankland

John Wright

ABSTRACT

There is growing acknowledgement of the value and utility of public involvement in health research in both the UK and internationally. Health policies have highlighted the potential benefits of public involvement to enhance the quality as well as the democratic accountability of publically funded research. Yet it is not always clear who to involve, when and how. There are uncertainties about the meaning of public involvement and there is much to learn about the impact.

The six publications presented in this thesis are drawn from a programme of research that used both qualitative and quantitative methods to explore two questions:

- What does it mean to involve the public in health research?
- What is the impact of public involvement on research processes, outcomes and on key stakeholders?

Consensus methods, employed in two studies, show agreement between researchers and the public on what it means to involve the public successfully in research, and that it is feasible to evaluate the impact of public involvement on five impact issues: identifying topics to research, prioritising topics, disseminating the findings, members of the public involved in the research, and researchers.

A UK survey of researchers clarifies how researchers interpreted health policies and included the public in their research, while a qualitative prospective case study reveals the different ways in which public involvement had impact. Two critical reviews explore the meaning and impact of public involvement.

The thesis discusses how my research has added to knowledge in this field and where ambiguities, challenges and questions continue. Public involvement is contested by some, and while my publications have contributed to deepening understanding about epistemological, conceptual and practical aspects, many uncertainties remain.

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1. INTRODUCTION

Aim of the thesis

The aim of this thesis is to present, discuss and critically evaluate six publications from studies I have conducted on public involvement in health research. All have been peer-reviewed. I have carried out a coherent programme of research that has contributed to learning in this relatively new field by exploring the meaning and impact of public involvement.

Section 1 sets out the background and context. I give a brief summary of what was known about public involvement in health research, and highlight the lack of knowledge in particular areas that prompted me to initiate research to address specific deficits in the evidence base.

In section 2, I set out summaries of my included publications. Section 3 discusses my role in the research and associated publications, while section 4 explores the impact and limitations of my included publications. Section 5 describes how I have integrated the two themes of the meaning and impact of public involvement, presenting a conceptual framework. In section 6, I reflect on my personal development as a researcher. I discuss the contribution that my research has made, and suggest recommendations for future research in section 7. Section 8 concludes this thesis.

General introduction

There have been substantial developments in public involvement in health research during the past decade, in the UK and also internationally (Staley, 2009; Consumers' Health Forum of Australia, 2012; National Institutes of Health Director's Council of Public Representatives, 2012). There is now greater recognition of what it means to involve the public, and how members of the public can influence research processes and outcomes (Staley, 2009; Brett et al, 2010). Whilst considerable progress has been made in implementing UK health policies, expansion has been uneven (Tarpey, 2011), with some dissension and even hostility "Let us not display unthinking subservience to the principle of participation" (Taverne, 2004).

When I began a research programme on this topic in 2000, knowledge and understanding about public involvement in health research were limited. The language of involvement was imprecise, and studies were characterised by observational accounts lacking detail and generalisability. Research on the impact was absent. I therefore decided to focus my research on attempting to understand the meaning and impact of public involvement in health research, and the six included publications presented in this thesis reflect these two themes.

The opportunity to carry out this research on a part-time basis arose through my work as an NHS clinical psychologist. I was asked to investigate the topic on behalf of the Research Directorate within the NHS Trust where I was working. Although aware of the benefits of public involvement in health services, the concept of public involvement in research was new to me.

In this introductory section I describe the background to my research, presenting a brief history of public involvement, identifying relevant health policies, conceptual and theoretical approaches, outlining early work that explored the meaning and impact of public involvement. I explain how ‘public involvement’ is defined in this thesis and also give details of my wider research in public involvement to provide the context for the included publications.

Brief history of public involvement

Although public involvement is a relatively new concept for health researchers, it reflects ideas drawn from a longer tradition, particularly in disability and mental health services (Beresford 2005; Barnes & Cotterell, 2012).

Dissatisfaction with services, characterised by paternalistic, and sometimes oppressive attitudes, led activists from different condition groups to question the legitimacy of people in authority to speak for them and make important decisions about their lives. Examples of challenges that have changed policy and practice include the disabled people’s movement which initiated a social model of disability that changed the focus from individual impairments to disabling environments. The phrase “nothing about us without us” is a powerful expression of this achievement and further aspirations.

In my own field of mental health, service user groups such as ‘Survivors Speak Out’ campaigned for a stronger voice and more democratic services. Their limited success has been partly attributed to the reluctance of doctors and other health professionals to embrace the values and ideals of public involvement (Crawford, 2001; Rutter et al, 2004).

Service user-led research became more visible during the past decade, taking control of research agenda setting, prioritising, carrying out, interpreting and disseminating the research (Rose, 2011). These developments have not been welcomed by all: “There is a real danger that the engine of user initiatives in mental health services, although positive in principle, will accelerate out of control and drive mental health research into the sand.” (Tyrer, 2002). Whilst the volume of service user-led mental health research is small relative to researcher-led research, it is growing in influence, and a service user researcher was recently appointed editor of a major academic mental health journal (Rose, 2011).

My research was initiated from within an academic department of Public Health. Early work by Popay and Williams (1996) in public health research presented the case for greater recognition of the contribution that members of the public could bring. They highlighted the importance of lay knowledge, defined as “the meanings health, illness, disability, and risk have for people”, and suggested that it is “different from but equal to that of professionals in the public health field.” They gave examples of members of the public predicting later health problems from observations, and suggested that the public be involved in developing research questions and becoming active in research processes. The authors did not underestimate the possible tensions that changing the power dynamics could bring.

Health policies on public involvement in research

The increase in public involvement in health services and research has been linked to the growth of consumerist ideas in the 1980s and the development of an internal market in health and social care in the 1990s, which were associated with a greater emphasis on choice of and satisfaction with services (Beresford, 2002a; Barnes & Cotterell, 2012). The consumer voice was encouraged to drive up quality and value for money. Opposing views to the consumerist approach questioned the reality of choice within NHS services and highlighted the political right of citizens and taxpayers to have a greater say in their health services, and associated research. Entwistle et al (1998) observed: “the aim of bringing politics into the health care arena ... is to change the balance of power by challenging the decision-making monopoly of service providers.”

In England, Department of Health policies began to focus on the importance of involving the public in different aspect of health service developments, including research (DH, 1999), promoting involvement of the public at every stage of research, where appropriate (DH, 2005). An advisory group, now called INVOLVE (INVOLVE, 2013) was established in 1996 to ensure that public involvement improved the way that research was prioritised, commissioned, undertaken and disseminated. Currently, applicants for research funding from the National Institute of Health Research (NIHR, 2013) are required to say how they are going to involve the public in their research.

What is public involvement in health research?

When I began my research programme on public involvement in research, there was little understanding about what public involvement meant and how to do it, despite Department of Health policies, and early guidance from INVOLVE. Researchers appeared to have limited understanding of the concept (Dixon, 1999), sometimes stating that they were unsure whether or not they had involved the public in their research (Buckland & Gorin, 2001).

While conducting a scoping study of public involvement in one health region (Telford et al, 2002), I encountered conceptual and practical difficulties facing researchers: what exactly does it mean to involve the public in research? Who should be involved, when, how and why? The term ‘involvement’ was often mistaken for ‘participation’ (where members of the public are the subjects of research), or ‘engagement’ (which implies a less active and more educative process). Chambers et al (2004) examined how researchers had involved the public in studies published by medical journals. Only half of the authors described involving the public in ways that met the INVOLVE definition that was current at the time.

My early scoping study prompted me to initiate studies to explore the meaning of public involvement in research, and three of the included publications in this thesis have addressed this theme.

I used the INVOLVE definitions of public involvement: “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.” The term ‘public’ includes “patients, potential patients, carers and people who use health and social care services.” (INVOLVE, 2013).

The language used to describe people who are involved in research is an added complexity (Ross et al, 2005). Diverse terms have been utilized including: consumers, lay people, lay experts and service users (Boote et al, 2002; Telford et al, 2002), and more recently, PPI [patient and public involvement] agents.

This is a highly contested area, with strong feelings expressed about specific descriptors. In my scoping study (Telford et al, 2002), researchers gave their opinions about the different terms. The expression ‘lay’ was thought to be inappropriate, as it implies *“a passive, non-expert person”*, while *‘user’* was said to be associated with substance misuse. One researcher remarked that *“the word ‘consumer’ implies the doctor is running a supermarket’*, while another acknowledged that although this term was not ideal, it crossed *“the divide between sickness and health.”*

Initially I used the term ‘consumer’ to be consistent with the terminology in UK health policy documents and international organisations such as the Cochrane Collaboration (Cochrane Collaboration, 2013). This later changed to ‘public’ in line with the language change in UK health policy documents, and in response to the growing unpopularity of the word ‘consumer’. At the request of service user advisers, I used the phrase ‘service user’ in some of my studies, hence my included publications refer to all three descriptors. In this thesis I mainly use the term ‘public’ to promote clarity and fluency.

The language of public involvement can reflect underlying theoretical approaches that may not be explicit. The term ‘consumer’ is associated with a market approach to health, with an emphasis on choice, while ‘citizen’ is linked to empowerment issues and citizens’ rights (Beresford, 2002a; Boote et al, 2002; Telford et al, 2002). Bastian (1994) observed: “there is no universal agreement about the words meant to specify the people who use, or are meant to be served by, health care … the debate is fuelled by the fact that this is not just an argument about words, but about ways of seeing and portraying people and their relationships with the health care system”.

Why involve the public in health research?

Pragmatic, ethical and political reasons for public involvement have been articulated. (Chalmers, 1995; Entwistle et al, 1998; Ramon, 2001; Ross et al, 2005). It is said to lead to “better research, clearer outcomes, and faster uptake of new evidence” (NIHR, 2013).

Ramon et al (2001) suggest that one form of interview bias; self-censorship based on social desirability, can be reduced when interviews are carried out by people with the same condition as the interviewees, while Ross et al (2005) propose that public involvement in interpreting the research data adds insights that enhance the quality of the research.

Examples are available of the beneficial effects of public involvement in identifying and prioritising research topics, recommending outcome measures, conducting research, analysing and interpreting the data, and disseminating the findings. It is important to note that some deleterious effects have also been reported, such as members of the public becoming distressed when involved in research about their condition (Staley, 2009).

Ethical arguments have been expressed, for example, the National Health and Medical Research Council in Australia (2002) asserted that public debate and scrutiny contributed to increasing the accountability and integrity of research.

In the political arena, the Council of Europe (2000) recommended that the right of the public to be included in decision-making procedures concerning health care should be an essential part of a democratic society.

Dissenting voices

A number of concerns have been raised, including the time and cost of an initiative with little evidence of its effectiveness. Some question the representativeness of those who become involved in research, the value of contributions from ‘professional’ members of the public, and their ability to engage in meaningful research debates, given their lack of research training (Ives et al, 2013). Some researchers have expressed unease about their research skills being perceived to be devalued (Thompson et al, 2009).

Theoretical models of public involvement in health research

Theoretical approaches and conceptual frameworks can increase understanding by presenting a wider context. This can be especially helpful for researchers, who involve the public because it is a political imperative, to become aware of how their research fits into a broader setting.

There are few theoretical models of public involvement in research, with little attempt to test systematically those that are available (Oliver et al, 2008; Brett et al, 2010). Most theoretical approaches address issues relating to power, empowerment and control of research prossess.

The most well-known model is Arnstein’s ladder of citizen participation (Arnstein, 1969), which equates participation with the power of citizens to make decisions. The higher the rungs of the ladder, the stronger the degrees of citizen power. Tritter and McCallum (2006) have questioned the usefulness of this one-dimensional model which lacks acknowledgement of the diversity of knowledge that members of the public bring, their individual aims of involvement and the value that the process of involvement may have for them.

Drawing on Arnstein’s ideas, Hanley et al (2000a) presented an influential conceptual framework of three levels of involvement on a continuum: *consultation, collaboration and user-led*. While this lacks complexity, it has been widely used as a pragmatic way of highlighting different approaches to public involvement. I drew on this model for my research, acknowledging the limitations.

Whilst the different levels imply a hierarchy, this is not necessarily the case, and particular levels will be more appropriate for specific research activities. Members of the public may be involved as both consultants and collaborators at different stages of the same research project (Telford et al, 2002). Smith et al (2008) suggest that conceptualising public involvement as a continuum or hierarchy overlooks the multiple levels of decision making that may be happening simultaneously.

A number of theoretical frameworks varying in complexity have been developed more recently, but have yet to be systematically evaluated, some of these are briefly presented below.

Oliver et al (2008) presented a model of public involvement that took into account three dimensions: *the degree to which members of the public were involved, researchers' degree of engagement* and *whether members of the public were involved as individuals or groups*. The authors suggest that this matrix could be used to distinguish models of involvement that appear to be more successful than others.

A conceptual model of public involvement described by Brett and colleagues (2010) considered the impact within the *context* and also the *process* of public involvement, with both said to influence the impact. I drew on this model and expanded it to develop a conceptual framework that is presented in section 5.

Morrow and colleagues (2010) identified a need for "more critical and consistent assessment of what constitutes quality involvement". A range of social theories of power informed the development of a model (Quality Involvement Framework) and questionnaire that could be used for researchers and the public to reflect on the experiences of working together, addressing issues relating to *research relationships, ways of carrying out research* and also *research structures*. The authors showed how social theories of power can provide new insights into understanding public involvement, and I discuss this in more detail later in this section.

A recent four dimensional theoretical framework, which also drew on social theories, has been described by Gibson et al (2012): *(Pluralism – Monism, Strong Public – Weak Public, Instrumental – Expressive and Conservation - Change).* This model is intended to be used theoretically and practically to analyse the nature of public involvement, and reflect on current methods of involvement and future possibilities.

Empancipatory research

Two of the advisers who contributed public perspectives to my studies brought the paradigm of emancipatory research, which embraces the values of user-led research. Emancipatory research has been described as "the changing of the social relations of research production – the placing of control in the hands of the researched, not the researcher" (Oliver, 1997). It is closely linked to empowerment, where the aim is to conduct research that is empowering for the people being researched. Brett et al (2010) observed: "At its heart, PPI is about empowering individuals and communities, in order that they can play a greater role in shaping health and social care research."

A number of authors have found Foucauldian ideas of power relations helpful in conceptualising issues that underpin models of empowerment, illuminating tensions between researchers and the public involved in research and reflecting on knowledge production (Pease, 2002; Rose, 2004; Thompson, 2009; Morrow et al, 2010). I discuss some of these ideas below, focussing on Foucauld's ideas of productive power.

Foucauldian ideas of productive power

Foucault asserted that power and knowledge are inextricably linked. It is therefore useful to discuss notions of knowledge production before considering his ideas of power relations. I use examples from my own field of mental health to illustrate these ideas.

Foucault held a relativist view of knowledge. In other words, no particular statements or set of discourses about a specific subject can claim absolute reality. Certain views shape accepted thinking on a topic and can become the dominant discourse, which is subsequently viewed as regimes of truth, or accepted knowledge.

Bracken and Thomas (2001) suggest that modern psychiatry is a product of the European Enlightenment movement, which promoted truth and knowledge through science and rationality, and caution that "science can silence as well as liberate." It has been argued that mainstream mental health research has predominantly reflected the perspectives of clinicians and researchers, and marginalised those who use mental health services (Rose, 2009).

Faulkner and Thomas (2002) proposed that "madness came to be accounted for by the scientific and rational narratives of psychiatry, through the medical technologies of diagnosis and treatment", with treatment decisions based on an "objective understanding of a universal reality. " This is in contrast to service user defined frameworks for understanding their experiences that are not based on professional models of illness. Rose (2009) writes that Foucault (1967) claims psychiatry has created "a monologue of reason *about* madness", which has stifled the voices of people deemed to be mad by defining them as non-rational. Foucault referred to the way in which certain perspectives are denigrated as the power/knowledge axis, and I discuss his ideas about power, very briefly, below.

Foucault rejected notions of the polarisation of ‘powerful’ and ‘powerless’, maintaining that power is ubiquitous and relational, influenced by specific contexts, such as institutions,. People exercise power within these contexts and are able to challenge current knowledge and prevailing discourses: “where there is power, there is resistance” (Foucault, 1978). This allows the questioning of knowledges and what defines them, giving people the chance to explore and develop alternatives. Ryan et al (2004) point out that “the power that operates within society to govern our behaviours is not necessarily (or simply) oppressive or repressive, but instead is productive.”

Rose (2008) gives an illustration of this in a commentary entitled “madness strikes back”. Noting that the term ‘service user researcher’ can itself be problematic, when ‘madness’ is associated with the antithesis of reason, the author described user-led research on the perceived effects of electro convulsive therapy (ECT). This research demonstrated that people given ECT complained of permanent memory loss, in stark contrast to conclusions from psychiatric research (a meta-analysis of trials on the effectiveness and safety of ECT) that memory loss was not a significant problem.

Using user-focussed methods, Rose (2008) elicited important findings that successfully challenged mainstream psychiatric research, which was later found to be flawed. The outcome was productive, NICE guidelines were changed (NICE, 2013) to reflect the likelihood of permanent memory loss associated with ECT. This example exposed tensions and underlying power dynamics that can often be present between research communities and the public, and illustrates the possibilities of productive power within collaborative research.

The utility of theoretical ideas and models lies not only in their ability to describe phenomena clearly, but in their usefulness in generating hypotheses. The paucity of research on the impact of public involvement may reflect the lack, until recently, of conceptual frameworks to guide systematic evaluations of different aspects of public involvement.

Evaluating the impact of public involvement in health research

In 2000, the Director of Research and Development at the Department of Health, Sir John Patterson, stated: “No systematic evaluation has been undertaken to assess the impact of the involvement of consumers in the research process” (Hanley, 2000b). Few researchers have addressed this challenge (Staley, 2009; Brett et al, 2010). I therefore began to study this area, and three of the included publications reflect this research.

It is easy to ask questions about the impact, but difficult to provide answers. Research is limited, reflecting the complexity and challenges of exploring a multidimensional process that may be subject to internal and external influences at various stages, and can have different impacts over time. Important considerations include the choice of impact outcomes from different perspectives.

Research on this topic is characterised by retrospective observational studies with few details of the methods used, precluding replication. Systematic studies are rare (Staley, 2009; Brett et al, 2010). This is also a contested area, with some authors arguing that it is not appropriate to evaluate the impact of public involvement, given the many uncertainties and lack of agreed theoretical base (Purtell et al, 2012).

Recent reviews have identified perceived benefits of public involvement at all stages of the research process, whilst also revealing some negative consequences. Poor reporting of public involvement, inconsistencies in the use of language and theoretical approaches, have made the assessment and synthesis of the evidence more difficult to accomplish (Staley, 2009: Boote et al, 2009; Brett et al, 2010).

Mixed methods

The research paradigm chosen for my studies was mixed methods, combining both quantitative and qualitative procedures. This was because the research addressed complex issues that could not be answered by one approach alone, and the combined methods provided greater insight and understanding (Cresswell, 2009). The synthesis of different forms of knowledge was able to take account of multiple perspectives and experiences.

For instance, I used quantitative methods to answer questions about how many researchers were involving the public, combined with qualitative approaches to find out how the public was involved and why. Qualitative methods are particularly suited to research on public involvement, providing opportunities to hear individual voices, personal experiences, meanings and views on specific topics within self-defined frameworks.

Traditionally, quantitative research has been associated with a positivist view of an external reality, while qualitative research is more engaged with subjective realities. For this reason, research on public involvement has been conducted more frequently with qualitative methods, however mixed methods are now becoming more common.

Contribution of my research to the field of public involvement

The six publications presented in this thesis have contributed to developing understanding about the meaning and impact of public involvement in health research, and have introduced rigour and clarity to an area that was beset by confusion and uncertainty.

Within the first theme, I explore the meaning of public involvement in different ways, through three included publications:

- Publication 1: A consensus study to explore the meaning of successful public involvement in research (Telford et al, 2004)
- Publication 2: A national survey of researchers to find out how they were involving the public (Barber et al 2007a) and
- Publication 3: A reflection on the meaning of public involvement in mental health research (Telford and Faulkner, 2004).

The second theme focuses on the impact of public involvement. I show how my work has helped to develop the evidence base in an area that had been neglected, through three included publications:

- Publication 4: A prospective evaluation case study (Barber et al, 2011a)
- Publication 5: A mixed methods study to explore the feasibility of evaluating the impact of public involvement in research (Barber et al, 2011b), and
- Publication 6: A critical review of the impact of public involvement in research (Barber et al, 2012).

The six included publications have been drawn from a larger number of papers arising from my research on public involvement (see Table 1). I chose publications that best illustrate the research carried out within the themes of the meaning and impact of public involvement in research. Summaries are set out in the next section.

2. SUMMARIES OF THE INCLUDED PUBLICATIONS

All six of my included publications are summarised in this section, with pre-publication copies in Appendix 1. The first three summaries relate to the meaning of public involvement in health research, whilst the summaries of publications 4, 5 and 6 relate to the impact of public involvement.

Summary of publication 1

Relating to the meaning of public involvement in research

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.

In exploring the meaning of public involvement in research, I asked what it meant to involve the public successfully in research, and if public involvement is to be conducted successfully, what processes need to be in place? I conducted a study to see if it was possible to develop consensus-generated principles and indicators of successful public involvement in NHS research. I anticipated this would contribute to deepening understanding about public involvement, provide guidance and assist in the development of evaluations of the impact of public involvement.

There were two stages: an expert workshop where the nominal group technique was employed (Van de Ven & Delbecq, 1971), and a two-round postal Delphi process (Dalkey & Helmer, 1963). Researchers and members of the public who had knowledge and/or experience of public involvement were invited to take part.

Of the 131 people who agreed to take part, 96 people returned both rounds. Of those who completed both questionnaires and who agreed to provide a perspective, 33 described themselves as researchers, 29 as members of the public and 26 as both researchers and members of the public.

There was consensus that eight principles were clear and valid, each of which had at least one measurable indicator that was also agreed to be clear and valid (see Table 2). Sub-group analysis showed common ground between the way in which the three groups of participants rated the principles and indicators (Boote et al, 2006). The principles addressed both ethical and practical issues, and focussed predominantly on research processes.

Having established consensus-derived principles and indicators of successful public involvement, it was important to find out how UK researchers were interpreting health policies on public involvement. Were they involving the public? If so, how? The survey to explore this and also the researchers' views on public involvement are described in the summary of publication 2.

Table 2. Principles and indicators of successful public involvement in health research

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

Summary of publication 2

Relating to the meaning of public involvement in research

Barber R, Boote J D, Cooper C L. Involving consumers successfully in NHS research: a national survey. *Health Expectations,* 2007a; 10: 380-391.

Little was known about how researchers were involving the public when this survey was carried out. I conducted a national postal questionnaire survey of 900 health researchers and 15 members of the public, embedding the indicators within the questionnaire to investigate whether or not the research met the developed principles.

There were 518 researchers who responded to the survey, a response rate of 58%. Nine of the 15 members of the public identified by researchers also returned their questionnaire. Less than a quarter of the researchers who responded (17%) were found to involve the public. Of the 88 research projects with public involvement, members of the public were mostly involved as members of a steering group, designing research instruments, planning or designing research methods, identifying or prioritizing research topics or questions and disseminating the research findings. The main reasons given for not involving the public were that it was considered inappropriate or was never considered.

This survey showed that most studies that included the public met between one and four of the indicators. Those most likely to be met concerned the acknowledgement of public involvement in research publications and reports and details of the roles of members of the public. The indicators met less often related to applications for funds for members of the public, access for training, and reimbursement of indirect costs. Comments on the questionnaires revealed that a few researchers appeared to misunderstand the concept of public involvement, confusing the term with participation in the study.

Researchers were invited to offer suggestions for improving public involvement. Some expressed concerns about how to access members of the public and ensure that they were representative. Researchers called for more funding, training, guidance and information on involving the public. Public involvement at the early stage of research was endorsed, as was the value, with suggestions that it could increase the validity of research by addressing issues raised by the public. A few reservations were expressed, particularly in relation to basic scientific research:

> *"I see little or no role for consumers in my kind of laboratory-based fundamental research." Researcher*

Uncertainties about public involvement were common a decade ago, even in my own field of mental health, which has a long history of public involvement. I very much wanted to explore how far public involvement in mental health research had developed, and the results of my investigations are presented in the summary of publication 3 below.

Summary of publication 3

Relating to the meaning of public involvement in research

Telford R, Faulkner A. Learning about service user involvement in mental health research. *Journal of Mental Health,* 2004; 13: 549-559.

How is public involvement in mental health research conceptualised and understood? What are the reasons for public involvement? What are the barriers? These questions were explored in a critical review.

It was noted that the focus of early writing was on emancipatory research, which has the aim of empowerment at its heart and has been described as "changing and equalising relationships between the research and research subjects, and developing survivors' own knowledge collectively" (Beresford & Wallcraft, 1997). The importance of language in mental health was addressed. Whilst 'survivor' (of mental health services) is a term often encountered, the descriptor 'consumer' is considered inappropriate. 'Consumerism' implies choice, which has not been a prominent feature of mental health services, and is limited for those detained against their will (Godfrey & Wistow, 1997). The term ‘service user’ is more common.

It was pointed out that user-led research is valued as a method of promoting the ideas and aspirations of the survivor movement and gaining control and power over research and research relationships (Trivedi & Wykes; 2002). Trust and mutual respect are necessary for collaborative research, where the motives and incentives of researchers and the public may differ. For the public, seeking service improvements, asking different research questions, challenging models of understanding and developing skills, confidence and empowerment may be paramount (Trivedi & Wykes, 2002). Researchers may prize curiosity driven research, with the direction of research often determined by funding opportunities and research career aims.

Possible barriers to public involvement, including the conceptual framework within which the research is carried out, were described. Assumptions about who the research is for, how the research questions will be determined, and who will analyse and interpret the data may not be shared. Ideologies can differ, for example, holistic approaches that include quality of life research may be favoured by the public, but may not be as highly valued by some researchers working within a predominantly medical model, or by pharmaceutical organisations funding research.

It was noted that some potential barriers are specific to mental health research. Having a mental health diagnosis can imply impaired reasoning, in contrast to being a researcher, a role that is associated with rationality (Beresford, 2002b; Rose, 2003). This can raise concerns about the capability of those with a diagnosis of mental illness to undertake research. Developing shared research goals and clarifying motives are needed for collaborative mental health research to prosper.

While exploring different aspects of the meaning of public involvement in research, questions about the impact were never far away. I instigated an early evaluation study, summarised below, as the first of the included publications to address the theme of the impact of public involvement.

Summary of publication 4

Relating to the impact of public involvement in research

Barber R, Beresford P, Boote J, Cooper C, Faulkner A. Evaluating the impact of service user involvement on research. A prospective case study. ***International Journal of Consumer Studies,*** **2011a; 35: 609-615.**

When designing the consensus study that resulted in publication 1 (Telford et al, 2004), I was aware of the limitations of my knowledge and experience of public involvement in research. I therefore designed a prospective evaluation of public involvement to take place within the consensus study. I anticipated that this reflective qualitative study would provide a valuable opportunity to learn about the impact of public involvement, given the dearth of information in the literature.

The research was designed to explore the impact of two advisors providing a public perspective. Both brought substantial knowledge and experience of public involvement, as national leaders in this field. They also brought the theoretical approach of emancipatory research (Beresford, 2002a) which informed many aspects of the wider consensus study, as well as the evaluation. Planned reflective discussions between the two advisors and the three researchers were held immediately following three advisory group meetings and after the completion of the study. Discussions were recorded and transcribed, with the transcripts sent to all participants to check for accuracy.

I used an interpretive analysis approach (Seale, 2004) to analyse the data, based on open coding and categorisation (Strauss & Corbin, 2004). Agreement was reached among the researchers and the advisors about the main themes that emerged: trust and commitment, impact on the wider study, mutual learning, and the timing of service user involvement.

There was strong accord about the importance of the trust and commitment that developed between the researchers and the advisors.Having trust appeared to lead to franker exchanges of views. Discussions were wide ranging on many issues pertinent to developing principles of successful public involvement, including the meaning of public involvement, terminology, ethical issues, and power relationships. The advisors also commented on specific styles of interacting within some of the research meetings which could be interpreted as excluding.

The planned space for reflection seemed to facilitate openness to new ideas, leading to joint learning. I learned about possible reasons for tensions between researchers and service user advisors:

> *"This is work-life for some people. It's life-life for other people … some people come into this [public involvement] because they want to change the services, they want to change things for others, not for themselves, and it's personally important. It's not just a job … and that's where some of the conflicts come from." Service user researcher advisor ii.*

The reflective sessions highlighted the ways in which the public perspectives influenced the processes and outcomes of the consensus study, as well as affirming the value of productive working relationships. There was clear agreement that public involvement should begin as early as possible.

This paper was submitted for publication sometime after the study had taken place. Few impact studies had been reported in the literature, and it was thought that this publication might therefore be of wider interest. The lack of many formal impact studies led me to question the feasibility of evaluating the impact. I therefore designed a study to investigate this possibility, which is summarised below.

Summary of publication 5

Relating to the impact of public involvement in research

Barber R, Boote J, Parry G, Cooper C, Yeeles P, Cook S. Can the impact of public involvement on research be evaluated? A mixed methods study. *Health Expectations,* 2011b; 15: 229-241.

Given UK policy imperatives to involve the public in research, the lack of formal evaluation studies is striking. I considered the possibility that public involvement might be too difficult to evaluate because of the complexities referred to earlier. It might also be regarded as of intrinsic value, not requiring evaluation. I conducted a mixed methods study to explore these issues, investigating whether or not there was consensus that it is feasible to evaluate the impact of public involvement in research, and also explored researchers' views on the value of public involvement.

The design was a sequential mixed methods approach with three stages:

- An expert workshop
- A Delphi process, and
- Follow-up interviews.

The Expert Workshop

I held an expert workshop, bringing together eleven nationally and internationally eminent researchers and members of the public (Barber et al, 2007b). The participants, purposively selected, brought perspectives as researchers, research methodologists, commissioners and members of the public. During the structured workshop, the participants were asked to consider the value of public involvement, the key benefits and disbenefits, and whether or not it is feasible to evaluate the impact.

Delphi process

Drawing on the ideas deliberated at the expert workshop, I designed a two-round Delphi process to investigate whether or not consensus could be reached on the feasibility of evaluating the impact of public involvement on research processes, outcomes and key stakeholders in the research process.

A wide range of UK and international Delphi panellists were recruited from different settings, with 124 people completing both rounds. They comprised researchers, research managers, commissioners, as well as members of the public. Panellists were asked to rate the feasibility of evaluating the impact of public involvement on sixteen impact issues, spanning research processes, outcomes and key stakeholders. Panellists were also invited to provide comments on text boxes associated with each impact issue.

Agreement was established through the Delphi process that it is feasible to evaluate the impact of public involvement on five of sixteen impact issues:

- Identifying topics to research
- Prioritising topics
- Disseminating the findings
- Members of the public involved in the research, and
- The researchers.

Public involvement is closely linked with ethical issues, public accountability and transparency. We asked Delphi panellists if they agreed with the following statement: *I believe that public involvement in health and social research is of ethical and moral value in itself, regardless of its impact on research*. Three quarters of the Delphi panellists agreed, but at the same time, panellists also endorsed the importance of evaluating the impact, with one panellist observing:

> *"There may be a moral imperative for public involvement in research in terms of citizenship, accountability, rights etc., but if it is not having an impact it is a pretty pointless waste of time." Person with multiple perspectives, 89q.*

Follow-up telephone interviews

A purposive sample of 14 Delphi panellists were interviewed to explore their Delphi questionnaire responses, and to hear their opinions on the implications of the Delphi findings. Many talked of the challenge of evaluating the impact of public involvement on different types of research projects, employing various models of involvement, within differing contexts. They drew attention to the problems of tracking decisions resulting from involvement within a deliberative process, and discussed the complexities of evaluating a process that is subjective and socially constructed. They offered suggestions and examples of evaluation methods, and demonstrated their support for evaluating the impact.

This consensus study demonstrated agreement that it is feasible to evaluate the impact of public involvement on five impact issues. Different stakeholders will have different priorities, and it is for others to decide to which evaluations to give precedence.

Having developed knowledge and experience of the impact of public involvement, I wrote a critical review, which is summarised below.

Summary of publication 6

Relating to the impact of public involvement in research

Barber R, Boote J, Parry G, Cooper C, Yeeles P. ***Evaluating the impact of public involvement on research.*** **In: Barnes M, Cotterell P (eds)** ***Critical Perspectives on User Involvement*****. Bristol: Policy Press, 2012: 217-223.**

The last included publication is a critical review of the impact of public involvement in research, in which I reflect on what was known about the topic, summarising what I judged to be the main issues and challenges.

One of the first questions to discuss was whether or not to evaluate the impact. Not all authors believe that it is appropriate (Purtell & Wyatt, 2012), citing the lack of consensus about what ‘involvement’ means and the difficulties of learning from evaluations of different models of public involvement in diverse studies. I suggested that it was important to evaluate the impact: to discover how best to involve the public in different research activities, to identify possible deleterious effects, and to endeavour to achieve value for money. I also highlighted the need to explore possible mediating factors, such as different models of involvement and contexts, and how issues such as support and funding can influence the success of involvement.

I drew on original sources and recent reviews of the literature (Staley, 2009; Boote et al, 2009; Brett et al, 2010). Systematic studies were infrequently encountered (Brett et al, 2010), and there was a continuing absence of theoretical frameworks to increase understanding and generate hypotheses (Oliver et al, 2008).

I noted studies reporting the beneficial effects of public involvement in research process and outcomes, such as widening the range of research topics to include more issues of interest to the public (Rhodes et al, 2002, Caron-Flinterman et al, 2005; Staniszewska et al, 2007). Trial consent procedures were said to be improved (Ali et al, 2006), ethical issues were addressed and research designs amended to ensure that studies were more acceptable to participants (Koops & Lindley, 2002). Including the public in analysing and interpreting the data drew researchers' attention to new themes (Gillard et al, 2010).

Studies show that the public can benefit from being involved, with reports of increased knowledge, skills and confidence. Researchers have reported developing greater insight about issues important to members of the public as a result of involving them (Hewlett et al, 2006; Lindenmeyer et al, 2007), although some researchers have expressed reservations about having their professional research skills challenged (Thompson et al, 2009). A few deleterious effects have been identified, including members of the public hearing distressing information about their own condition when involved in studies, and occasional difficulties with the quality of the input from members of the public, due to their inexperience of research (Bryant & Beckett, 2006).

I reviewed the challenges to evaluating the impact of public involvement when there is a lack of agreement on conceptual frameworks and theoretical underpinnings, difficulties in isolating impact factors that are subject to mediating influences, with the possibility of longer term impacts that may evolve over time. I suggested that additional methods to evaluate complex interventions (Craig et al, 2008; Pawson & Tilley, 1997) should be explored.

All my research has been conducted with a team of researchers. My roles and responsibilities for the research relating to the included publications are clarified in the next section.

3. MY ROLE IN CONDUCTING THE STUDIES AND WRITING THE PUBLICATIONS

In this section, I describe my role in the studies which resulted in the six included publications, and give details of my role in writing the publications.

My role in publication 1

Relating to the meaning of public involvement in research

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.

and

My role in publication 2

Relating to the meaning of public involvement in research

Barber R, Boote J D, Cooper C L. Involving consumers successfully in NHS research: a national survey. *Health Expectations,* 2007a; 10: 380-391.

and

My role in publication 4

Relating to the impact of public involvement in research

Barber R, Beresford P, Boote J, Cooper C, Faulkner A. Evaluating the impact of service user involvement on research. A prospective case study. *International Journal of Consumer Studies,* 2011a; 35: 609-615.

These publications arose from a study that developed consensus-derived principles of successful public involvement in research. As the principal investigator, I designed the study, wrote the research bid, applied for ethical approval, conducted the research and wrote the three publications, all with assistance from my co-authors. I was responsible for taking all the important decisions in the study.

An early decision concerned the selection of a purposive sample of participants for an expert workshop in the first stage of the study, to ensure that a wide range of knowledge and experience was brought to the task. I also selected the Delphi panellists. Whom to invite and why, are important questions when recruiting to a Delphi panel (Jones & Hunter, 1995; Hasson et al, 2000).

I took the lead in sorting, analysing, interpreting and making decisions about the information that resulted from the expert workshop. These data were used to guide the composition of the Delphi questionnaires. Whilst the final decisions about the wording of the principles and indicators within the Dephi questionnaires were mine, they were based on discussions with my co-authors and the Advisory Group. I pre-selected a consensus level of 85% for both the expert workshop and the Delphi process.

My co-author Jonathan Boote conducted the Delphi statistical calculations. I led discussions on the interpretation of the findings, and the direction of further statistical analyses.

I designed the large-scale postal survey of researchers that incorporated the consensus-derived indicators of successful public involvement in research. The quantitative analyses were carried out by my co-author Jonathan Boote, with further analyses conducted after my interpretations of the findings, and suggestions for additional calculations. This followed consultations with research team members and the Advisory Group.

The analysis of the qualitative data in the questionnaire was conducted by me and my co-author Jonathan Boote using the Framework approach (Ritchie & Spencer, 1994). This method was chosen as one advocated when undertaking policy research, with discrete timescales, where recommendations and practical outcomes are envisaged, and where there is more than one researcher.

Publication 4 resulted from a ‘study within a study’; a prospective evaluation of the impact of public involvement in the first consensus study (publication 1). My role was to co-ordinate a collaborative investigation, where the topic guide was jointly agreed. I planned the meetings, recorded the reflective discussions, arranged for the recordings to be transcribed and ensured that they were sent to all the participants to be corrected where necessary.

I analysed all the transcripts, using an interpretive analysis approach (Seale, 2004), based on open coding and categorization (Strauss & Corbin, 2004) of the data. Categories between and within the transcripts were compared, using the constant comparative method to look for similarities and differences. The themes that emerged were shared with and agreed by my co-authors.

My role in publication 3

Relating to the meaning of public involvement in research

Telford R, Faulkner A. Learning about service user involvement in mental health research. *Journal of Mental Health,* 2004; 13: 549-559.

As I built up knowledge of public involvement, I was aware that this information was not widely known, particularly among my mental health colleagues. Academic publications on this topic were limited. I therefore suggested writing a joint paper for an academic journal with Alison Faulkner, one of the advisers to the consensus study, and someone nationally known in the mental health field.

As the lead author, I suggested the scope of the paper, and made a substantial contribution to the writing. The paper reflects discussions and exchanges of ideas between the two authors, with important contributions and significant writing from my co-author.

My role in publication 5

Relating to the impact of public involvement in research

Barber R, Boote J, Parry G, Cooper C, Yeeles P, Cook S. Can the impact of public involvement on research be evaluated? A mixed methods study. *Health Expectations,* 2011b; 15: 229-241.

and

My role in publication 6

Relating to the impact of public involvement in research

Barber R, Boote J, Parry G, Cooper C, Yeeles P. *Evaluating the impact of public involvement on research.* In: Barnes M, Cotterell P. (eds) *Critical Perspectives on User Involvement.* Bristol: Policy Press, 2012: 217-223.

As the principal investigator, I designed the study, wrote the research bid, applied for ethical approval, conducted the research and wrote the two publications, all with assistance from my co-authors. I was responsible for taking all the important decisions in the study.

My roles and responsibilities were similar to those mentioned earlier in relation to the first consensus study (publication 1), with the same challenges in selecting appropriate participants. One difference was my decision to include international participants in all three stages, to benefit from wider learning. I chose a pre-specified level of consensus of 80%. The Delphi quantitative analysis was carried out by my co-author, Jonathan Boote.

Another difference from the first consensus study was the inclusion of follow-up interviews with a purposive sample of Delphi panellists. I selected the interviewees, interviewed them, arranged for the transcription of their interviews, and sent them the transcripts for any necessary corrections.

Qualitative analysis of responses in the text boxes of the Delphi questionnaires and of the interviews, was conducted using an interpretative analysis approach (Seale, 2004), as described above in relation to publication 4. The data were analysed separately by my co-author Jonathan Boote and me. I presented our analysis to the research team and Advisory Group for further discussion and interpretation at different stages, re-analysed the data and wrote up the findings. The impact of this publication and the rest of my included publications are outlined in the next section.

4. THE IMPACT OF THE INCLUDED PUBLICATIONS

This section describes the impact of my six included publications. A selection of the citations can be found in Appendix 2.

Impact of publication 1

Relating to the meaning of public involvement in research

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.

The development of the principles of successful public involvement in research introduced rigour into a research area that was characterised by unsystematic descriptive studies that while valuable, had limited generalisability. The principles and their associated indicators have been regarded as "an important development in an under-researched area" (Lowes et al, 2011), as a good practice guide (Evans et al, 2006; Royal College of Nursing, 2007; Entwistle et al, 2008; Morrow et al, 2012), and a method for the World Health Organisation to ensure that the public is adequately represented in guideline development projects (Schunemann et al, 2006). The principles were also recommended in a Cochrane review when making decisions about how best to involve the public (Nilsen et al, 2013).

INVOLVE has included this publication in its recommended useful reading in the current 'Briefing Notes for Researchers' (INVOLVE, 2013), and the principles are currently displayed on the NIHR Health Technology Assessment Programme (HTA) website as 'principles to guide project planning' (NIHR HTA, 2013).

In a systematic review of public involvement in health and social care research, Brett and colleagues (2010) observed: "Telford et al (2004) attempted to ascertain the principles and indicators of successful involvement through a more formal Delphi process. Such work is very helpful in starting to develop a deeper understanding of PPI and start to unravel the components of PPI and the ways in which these different components could be captured or measured."

The principles "begin with establishing a culture that values what service users and carers offer" (Braye & Preston-Shoot, 2005), and have been used in a number of ways by national and international researchers. Bryant & Beckett (2006) conducted a study into the practicality and acceptability of an advocacy service in a hospital emergency department, and utilised the principles to evaluate public involvement. Similarly, the principles served as a framework to evaluate a cancer research network consumer research panel (Collins et al, 2005) and user involvement in diabetes care (Lindenmeyer et al, 2007).

The principles have guided consultation processes when developing health and social care briefing documents (Carroll et al, 2006), and in a study of primary care research, Howe et al (2006) adapted the principles to produce a statement of agreement that members of a research panel could expect researchers to observe.

Hanley et al (2009) demonstrated how it was possible to use the principles to evaluate the process of public involvement at a strategic level, when assessing the process of public involvement in the UK Clinical Research Collaboration advisory groups.

In Australia, the principles were included in a national workshop to steer thinking about generating principles applicable for Australian health research (Griffiths et al, 2004), were employed to evaluate a collaboration with the public in an alcohol and pregnancy project (Payne et al, 2011), and were also used as a quality marker for public involvement in surgical research and audit (Ahern et al, 2011).

This publication, which has over a hundred citations, has helped to clarify what it means to involve the public successfully in research. However, the principles are not comprehensive and have limitations. They do not address interpersonal issues such as power relationships, possible tensions between researchers and the public and learning from each other (Lindenmeyer et al, 2007). They do not take account of the wider context in which the research takes place. The Delphi process assumes a moderately high level of literacy, and is therefore not accessible for people with learning difficulties. Bryant and Beckett (2006) have suggested that the principles should be used as “minimum criteria to judge successful public involvement”.

Impact of publication 2

Relating to the meaning of public involvement in research

Barber R, Boote J D, Cooper C L. Involving consumers successfully in NHS research: a national survey. *Health Expectations,* 2007a; 10: 380-391.

The survey described in publication 2 was the most comprehensive survey of public involvement in health research carried out in the UK at that time. It showed how health policies on public involvement were being interpreted, demonstrated how health researchers were involving the public, and revealed what researchers understood public involvement to mean.

Both the survey and the development of the principles were regarded as “important developments in an under-researched area” (Lowes et al, 2011). The authors suggested that the principles and the survey raise questions about “how ‘successful’ involvement can or should be measured”. This publication has 26 national and international citations.

Impact of publication 3

Relating to the meaning of public involvement in research

Telford R, Faulkner A. Learning about service user involvement in mental health research. *Journal of Mental Health,* 2004; 13: 549-559.

The third and last of the included publications within the theme of the meaning of public involvement is a critical review. It clarified the main issues pertinent to public involvement in mental health research at that time. The paper suggests that members of the public and researchers may not share the same beliefs, values and conceptual frameworks associated with public involvement. It reveals potentially different motives and barriers to becoming involved, and discusses the importance of researchers and the public having enough common ground in order to undertake collaborative research.

It continues to be cited, in the international as well as the national literature, with 49 citations to date. Recent citations note motivating factors to becoming involved (Braye & Preston-Shoot, 2005; Holland & Blood, 2009; Marshall et al, 2010; Lowes et al, 2011), issues to consider when undertaking collaborative studies (Ahern et al, 2011; van der Ham et al, 2013), the value of experiential knowledge (Happell & Roper, 2007; Holland, 2007; Brown & Hemsley, 2008), also barriers (Goodwin & Happell, 2006; Brown & Hemsley, 2008; Richter et al, 2009). A recent editorial addressing mental health strategy in Europe also quoted this paper for a fuller discussion on barriers to public involvement (Callard & Rose, 2012).

This publication was written to inform mental health colleagues, researchers and the public when few academic papers in this field could be found (Simpson & House, 2002). The paper was informed by the literature, information about current initiatives, and joint discussions with my co-author. This publication was not based on empirical research, and reflects subjective viewpoints, but appeared to resonate with emerging thinking about public involvement in mental health research. It provides a model of good practice through its joint authorship.

Impact of publication 4

Relating to the impact of public involvement in research

Barber R, Beresford P, Boote J, Cooper C, Faulkner A. Evaluating the impact of service user involvement on research. A prospective case study. ***International Journal of Consumer Studies,*** **2011a; 35: 609-615.**

This was the first collaborative systematic prospective longitudinal case study on the impact of public involvement in research, and has eight citations. It was decided to publish the findings sometime after the evaluation had taken place, given the lack of systematic impact evaluations available in the literature.

Staley et al (2012) noted that our findings resonate with those from a subsequent retrospective reflection of public involvement in a number of projects (Hewlett et al, 2006). Both studies describe the impact of public involvement on the research, the researchers and on those providing a public perspective, sharing "general lessons of good practice", reporting on:

- The value of good working relationships based on mutual trust and respect
- The importance of involving the public at the early stages of the research
- Practical and support needs of those providing a public perspective, and
- Training or briefing in specific research methods.

As an exploratory reflective case study, it has limitations. The discussions during the evaluation reflected the developing views of five researchers (two of whom also provided public perspectives), throughout the research project. Staley et al (2012) asserted that while observational evaluations such as this study have made "a vital contribution to improving the quality of all involvement processes", it is not possible to conclude what works best in the absence of exploratory links between the context, mechanism and outcome.

Impact of publication 5

Relating to the impact of public involvement in research

Barber R, Boote J, Parry G, Cooper C, Yeeles P, Cook S. Can the impact of public involvement on research be evaluated? A mixed methods study. *Health Expectations*, 2011b; 15: 229-241.

This study is one of the few systematic investigations addressing the impact of public involvement in research, and has fifteen citations. It questioned the feasibility of evaluating the impact, and contributes to the evidence base by revealing consensus on the feasibility of evaluating the influence of public involvement on five of sixteen possible impact issues:

- Identifying topics to research
- Prioritising topics
- Disseminating the findings
- Members of the public involved in the research, and
- The researchers.

There are accounts in the literature of the beneficial impact of public involvement on these impact issues (Ramon et al, 2000; Oliver et al, 2004; Ross et al, 2005; Minogue et al, 2005; Hewlett et al, 2006; McLaughlin, 2006; Lindenmeyer et al, 2007; Cotterell et al, 2008). Recent research suggests scope to develop ways of evaluating the impact of public involvement on additional impact issues (Gillard et al, 2012).

Impact of publication 6

Relating to the impact of public involvement in research

Barber R, Boote J, Parry G, Cooper C, Yeeles P. *Evaluating the impact of public involvement on research*. In: Barnes M, Cotterell P. (eds) *Critical Perspectives on User Involvement.* Bristol: Policy Press, 2012: 217-223.

This chapter is a concise critical review of the impact of public involvement in research, in which I discuss the reasons for evaluating public involvement, as well as the benefits and challenges. The publication has generated some interest already (Gould, 2012), and is likely to be of value to those wishing to read a succinct summary of this expanding field.

The publication is a review and therefore reflects the views and judgements of the authors. Nevertheless, it presents the views of researchers experienced in this field, with deep knowledge of the area, who were able to guide readers to the main findings in the literature at that time.

Wider impact of the studies that go beyond the academic world

My research has had a wider impact beyond the academic world, both locally and nationally. I have given many presentations and workshops to colleagues in my own NHS trust and in other health organisations, providing information about current issues in public involvement. This work has influenced local NHS strategies and training, assisted in the implementation of NICE guidelines (NICE, 2013), and led to local and regional initiatives to develop public priorities for health research (Telford & Repper, 2002; Lucock et al, 2007). I also drew on my studies to provide regular joint training on public involvement to trainee clinical psychologists with a mental health service user.

At a national level, my studies informed my work as a mental health services reviewer for the Healthcare Commission, alerting me to question public involvement practices in Trusts, particularly in relation to their research and audit services. I have been invited by a number of organisations to provide advice on public involvement, chair conferences and workshops, give plenary and other presentations. These have included the Scottish School of Primary Care (Scottish School of Primary Care, 2013), NICE (NICE, 2013), and the James Lind Alliance (James Lind Alliance, 2013). I was also an invited speaker at the Toronto Seminar Series (Hanley, 2005), and have taken part in debates and conversations about public involvement initiated by Demos (Health Conversations, 2007: The Talking Cure, 2008), and the Royal Society (Royal Society, 2013).

My studies led me to become a member of an advisory group on public involvement at the Medical Research Council (MRC, 2013), using the findings from my research to contribute to many working groups and committees, included a Council subgroup on strategy. Outputs included a qualitative survey of public involvement in MRC Research Units (Barber, 2006)

Until September 2013, I was an advisory group member of INVOLVE (INVOLVE, 2013), where my research findings have been utilised in different ways. I have given presentations at various INVOLVE events, critically reviewed reports, served on advisory groups for specific projects, (including a project on user-led research and another to investigate ways in which public involvement can have positive effects of the quality of research). INVOLVE is currently exploring the possibility of standards on public involvement across the National Institute for Health Research (NIHR), and three of my publications included in this thesis are cited in a briefing paper to inform this initiative. I am a member of my local NIHR Research Design Service PPI Forum (NIHR Research Design Service, 2013), where my contributions are informed by my studies.

Whilst my research appear to have led to an increased understanding about public involvement, I have also encountered bewilderment, resistance and even hostility, usually from researchers unfamiliar with public involvement, and at times from people who fear that their research will be impaired if they involve the public. Relevant information about the possible ways in which public involvement can have a positive impact can sometimes moderate these concerns. However other issues, such as power relationships also feature, suggesting that this is a complex area that belies easy answers.

5. INTEGRATING THE MEANING AND IMPACT OF PUBLIC INVOLVEMENT IN RESEARCH

In this section I describe the conceptual and theoretical approaches that guided my studies. I also put forward a conceptual framework (Figure 1) that represents a synthesis of my current thinking about how to capture the meaning of public involvement, and consider ways of evaluating its impact.

Theoretical approaches and conceptual frameworks can increase understanding by presenting a wider context. This can be especially helpful for researchers, who involve the public because it is a political imperative, to become aware of how their research fits into this broader context.

Theoretical approaches

I drew on the framework described by Hanley et al (2000a) for all my studies from which my included publications are derived. The continuum of: *'consultation, collaboration and user-led'* helped me to define the type of public involvement to employ, which was *'consultation'*. Using this approach alerting me to the possibilities of straying into a more collaborative mode, potentially asking too much of the study advisors. My later research was collaborative, and I was able to reflect on the differences between the two modes.

Beresford and Evans (1999) suggested that there is an association between the degree of public involvement in research and its capacity to serve an empowering function. Whilst I was not conducting user-led research, I intended the research to be of a high ethical standard, authentic, and acceptable to those who would benefit from the research findings. I wished the research processes to be inclusive and transparent, to facilitate the voices of members of the public to be heard, and for the research to be used in an empowering manner.

Being attentive to the general aims of emancipatory research and associated underlying theoretical approaches ensured that I was aware of research practices that might be disempowering, such as using jargon and opaque language. However, Pease (2002) cautions that "it is … possible to regard empowerment as a more subtle refinement of domination, masked by the respectability of a liberatory discourse."

Conceptual framework of public involvement in research

The framework offered by Hanley (2000a) proved helpful in guiding my work, but does not claim to be comprehensive. The following framework (See Figure 1 and Table 3) was developed in the absence of such a model, integrating my ideas about the meaning and impact of public involvement in research. It built on a conceptual framework developed by Brett et al, (2010), in which the impact is considered within the context and process of public involvement (see section 1).

The conceptual framework (Figure 1) can be used in two ways. Firstly, it can help to conceptualise the meaning of public involvement in its widest sense, through the process of providing details of different aspects of public involvement. Populating the framework (see Table 3) will draw researchers' attention to the complexity of public involvement, and will help to clarify the purposes of involving the public in specific research activities. The framework is not rigid or prescriptive. Additional domains can be added and others deleted.

Secondly, it can be used to evaluate the impact of public involvement, by being employed as a tool to consider specific examples of public involvement, taking into account particular dimensions of the framework, and populating the different boxes and then exploring specified inter-relationships.

The framework highlights the plurality of ways in which public involvement in research can be conceptualised, and the many different possibilities for evaluating the impact. Its utility can only be judged after it has been employed in different research contexts, using various methods.

Figure 1. Conceptual framework of public involvement in research

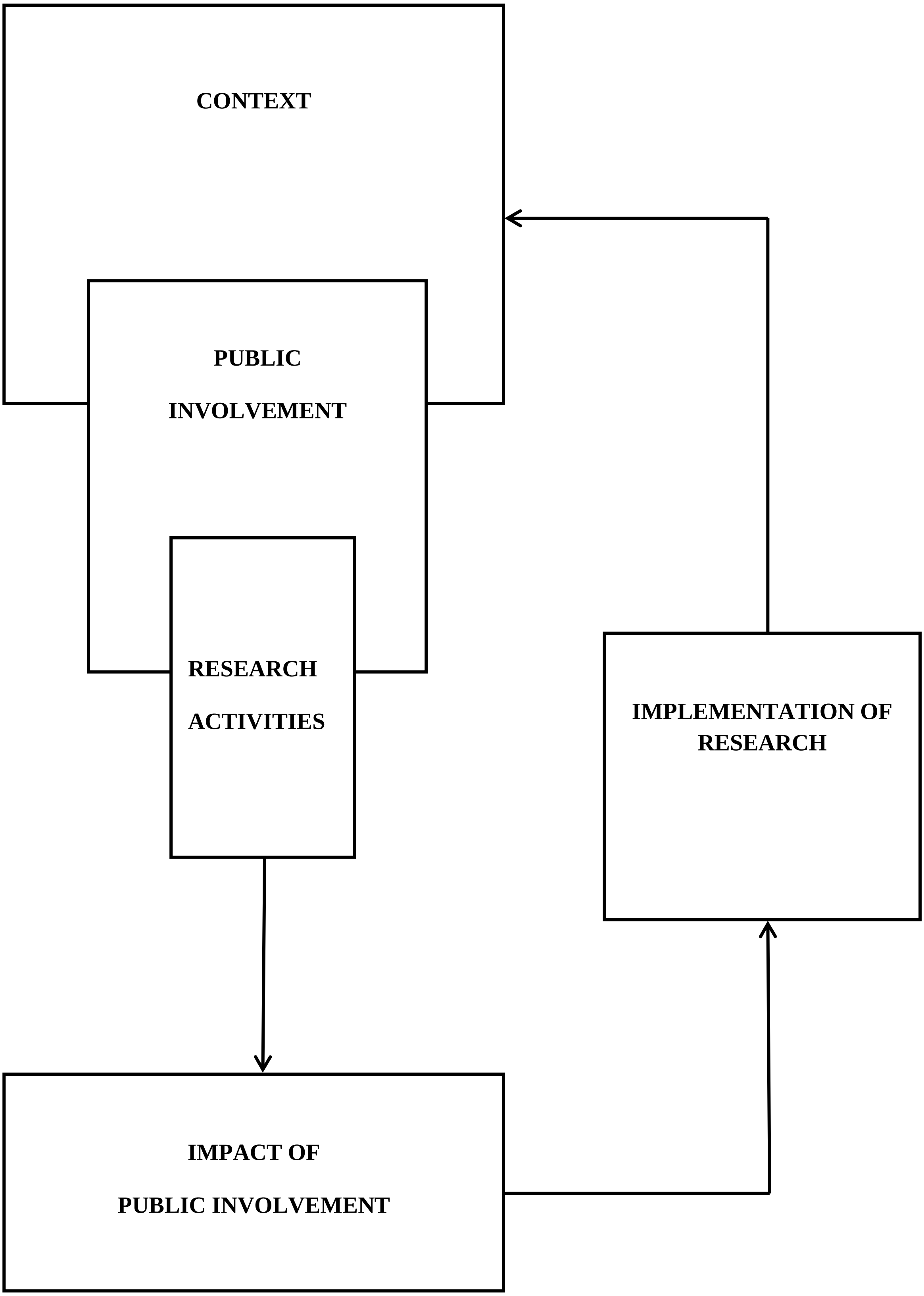

Table 3. Brief details of the conceptual framework of public involvement in research

The conceptual framework can be populated in the following way:

The context

Details should be provided in this space that take account of the wider and proximal context for public involvement, embracing practical, conceptual and interpersonal issues, such as the political context, type of organisation, resources available for public involvement, conceptual view of public involvement e.g consultation, and quality of working relationships,

Type(s) of public involved

Information should be given relating to the characteristics of the public, for instance whether a panel or individual members of the public are involved, and whether the members of the public bring specific attributes, such as experiential and/or research knowledge.

Research activities

Details should be available of the type of public involvement in research activities. These could include advising on research programmes or projects, interviewing research participants and analysing the data.

Impact issues

Details can be given of the various ways in which public involvement has made a difference to the specific aspects of research, for instance to research processes, outcomes and/or to researchers.

Implementation of research findings

Details should be given of ways in which members of the public contribute to implementing research findings. The results of the implementation will be fed back into the wider context.

Fuller details of the content of the conceptual framework can be found in Appendix 3.

In the next section I reflect on my personal development as a researcher, before discussing my included publications in relation to the wider literature, and making recommendations for future research.

6. REFLECTIONS ON MY PERSONAL DEVELOPMENT AS A RESEARCHER

My research career began in a clinical psychopharmacology research unit where I conducted studies of the effects of drugs, such as nicotine and cannabis on the human brain and behaviour, using quantitative methods. Following my training as a clinical psychologist, research opportunities were infrequent until I was commissioned to investigate minor brain injury in adults, again employing quantitative methods. The study was awarded the Albert Martin prize. While carrying out this research, I became aware of the limitations of quantitative methods, particularly when attempting to portray individual stories, and I later sought training in qualitative methods.

Throughout my research career, I have been extremely fortunate in working with inspirational researchers who have taught me so much. In turn, I hope I have passed on my research knowledge and experience, particularly in relation to public involvement, to others. Two researchers who have worked with me have gone on to develop research careers in public involvement. All three PhD theses that I have supervised have included public involvement.

My work as a clinical psychologist was undertaken at the same time as my studies on public involvement, enriching my research. I was aware of the considerable contribution that mental health service users make to developing services and advising organisations such as the Care Quality Commission. I learned how experiential knowledge provides valuable insights not accessible to professionals without such experiences.

All my studies have benefitted from public involvement, some of which has already been described (Barber et al, 2011a). One of the first things I learned from people bringing a public perspective was the importance of funding, not only to pay for time, expertise and to reimburse costs, but to affirm the value of the contribution and to reduce power differentials. A suggestion to include a reference group of people from minority ethnic groups in an early pilot study, revealed a wealth of cultural issues that were important to take account of, which I could have easily missed. Another important lesson was to think beyond the research to what might change as a result of the findings, a priority for the public, but not always for researchers.

I was aware of the strong ethical values brought by members of the public. This permeated all aspects of my research, ensuring that I considered decisions carefully, and in line with what I believed would be acceptable to the public. These ethical issues addressed notions of inclusion and valuing different perspectives. I also learned the importance of being flexible and accommodating other views, examining my prejudices and preconceptions. One example is being made aware that many of my views were mediated by an NHS ‘lens’.

7. DISCUSSION

I have presented six publications in this thesis that represent my contribution to the field of public involvement in health research.

Having previously discussed the impact and limitations of my publications, I now highlight where learning has developed since I conducted my studies, and suggest directions for future research. For reasons of clarity I have presented the two themes of the meaning and impact of public involvement separately. However there are many overlaps, with the meaning of public involvement informing how the impact could be evaluated.

Theoretical approaches to public involvement

Whilst much research in public involvement is pragmatic with little reference to theory, researchers are increasingly using theoretical approaches to guide their work and inform the interpretation of their findings (Rose, 2008; Thompson, 2009; Morrow et al, 2010; Gibson et al, 2012). This development will increase understanding of public involvement and is likely to lead to evaluations that are more rigorous and strategic. Not surprisingly, sociological theories, especially relating to power dynamics predominate.

Faulkner (2012) suggests that the issue of power is central for members of the public, and that when researchers explicitly share power, this engenders trust, resulting in more positive collaborative research. Public involvement is a dynamic and complex activity (Morrow et al, 2010), and productive public involvement can result from disagreements and lively debates enriching the research. It is dependent on mutual trust and learning (Lindenmeyer et al, 2007), and McLaughlin (2006) suggests that researchers who work collaboratively with the public need different research skills.

The theories chosen to underpin research will guide the study methods selected. In public involvement, these methods need to take account of the complexities. Not only are researchers and the public likely to have different values, perspectives, and aspirations for the research, but their conceptual frameworks may differ too. While public involvement is “work-life for some people. It’s life-life for other people” (Barber et al, 2011a). Thompson et al (2013) also suggest that public involvement can offer “spaces for the reconfiguration of self and identity”.

Views on the research outcomes, outputs and quality issues will almost certainly vary, and negotiations will be necessary to incorporate disparate perspectives. It is necessary for researchers involving the public to be skillful and receptive to considering and embracing new ways of working and sharing power. Qualitative methods have been employed most frequently to explore the complexities of public involvement, but increasingly, mixed methods are being used to take account of different dimensions of public involvement, and to synthesise different types of knowledge.

There is strong support for public involvement as a moral or ethical imperative (Barber et al, 2011b; Rose, 2013), but no concurrence on the theoretical underpinnings. In the absence of an agreed overarching framework, Rose (2013) has recently aasserted that "changing the knowledge producers will change the knowledge itself", and argues for a political conceptualisation of public involvement in research. As Rose (2013) observed, further research in this area will help to clarify "the content and boundaries" of public involvement. These boundaries could include basic scientific research, a discipline where public involvement is exceptional. Using an example of psychiatric genomics research, Baart and Abma (2010) show how public involvement can be achieved in fundmental research, suggesting that further progress in this area can be achieved.

Quality issues

There is no doubt that the quality of working relationships between researchers and the public is important, and likely to be closely associated with the success of public involvement (Ramon, 2001; Elberse, 2010).

Surprisingly, quality issues have been neglected until recently. It is self-evident that if public involvement is poorly understood and carried out in sub-optimal conditions, benefits will be largely absent. Research in this area is scarce. A notable exception is the work of Morrow and colleagues (2010) who developed a model and measure for quality public involvement in health research, to allow both researchers and the public to reflect on their experiences in a structured and consistent way.

Recently, the PiiAF Study Group (PiiAF, 2013) developed a public involvement impact assessment framework to support researchers in developing an impact assessment plan, which also has an emphasis on quality issues. The need to take account of contextual issues is embedded in the approaches of both studies, and this is also an important consideration for future studies.

A contested area

Public involvement is now more widespread in UK health research, supported by leading research funders (Lowes et al, 2011). There is also greater understanding of its meaning among the research community. There are a number of possible reasons for this: it has been promoted and clarified by UK policies and research governance (Department of Health, 2005), by initiatives from health research funding organisations (NIHR HTA, 2013), and through the work of INVOLVE (INVOLVE, 2013). There is also a growing literature to inform and guide researchers and the public, and I believe that my research has contributed to this.

There is still much to learn about the meaning of public involvement, and it remains a contested area. Recent papers by Ives et al (2013) and Staley (2013) illustrate one of the current debates. Ives et al (2013) put forward a ‘professionalisation paradox’, asserting that members of the public have to be trained in order to contribute to the conduct of research, but being trained will compromise their ‘lay’ status. The authors recommend that the public are therefore not trained or involved in carrying out research, but can be involved in other ways, such as in making decisions about the prioritisation of research agendas.

Staley (2013) commented that public involvement is a complex activity, with the nature of the involvement depending on the context. While some types of involvement do not require training, others, for example interviewing research participants, need adequate research training to ensure that interviews are carried out to the necessary standard so as not to compromise the research findings. Staley (2013) states that members of the public do not lose their unique public perspective just because they have research training. The writings of authors such as Beresford (2005), Faulkner (2012) and Rose (2013) are consistent with this view.

These are not sterile debates. As Staniszewska et al (2011) observed: “we need to reflect on and build an understanding of what good PPI looks like”. Having precision about the meaning, processes and outcomes, and reporting this in the literature, are also necessary steps to developing methods to evaluate the impact of public involvement.

The impact literature is growing, partly reflecting the willingness of commissioners to resource such research, and recognising that researchers are more likely to regard public involvement as more than a political imperative if they have evidence of its beneficial effects (Robinson et al, 2010).

The challenges in evaluating public involvement in research should not be underestimated. Disagreements about the language and conceptual approaches to public involvement remain, while poor reporting of public involvement in the literature precludes learning from previous studies (Boote et al, 2009; Staniszewska et al, 2011). Theoretical underpinnings are often absent, and there are differing opinions on the most appropriate methods to employ. Exploration of public involvement in the implementation of research is at a very early stage.

Future challenges for public involvement in research

We now have more knowledge about the complexities of public involvement, and increasing opportunities to find out how, when and why it works best (Staley, 2009; Brett et al, 2010). Future productive research on the meaning and impact of public involvement will benefit from clearly specifying theoretical approaches to guide the models, methods and interpretation of findings from such studies.

My experience of carrying out research in this field suggests that focusing on the context of public involvement, working relationships and also the implementation of the findings of research could be fruitful. For future learning to take place, accurate and detailed information about key aspects of public involvement should be recorded in publications.

8. CONCLUSIONS

Six publications presented in this thesis outline my contribution to developing knowledge and understanding about the meaning and impact of public involvement in health research.

I show that there is consensus on what it means to involve the public successfully in research, and agreement that it is feasible to evaluate the impact of public involvement on five impact issues.

I have helped to clarify how researchers were interpreting UK health policies on public involvement and involving the public in their research, and show the different ways in which public involvement has had impact, through a qualitative prospective case study. Two critical reviews evaluate current research on the meaning and impact of public involvement.

While I have shown agreement on important aspects of public involvement, many differences remain. This continues to be a contested area, with debates generating new ideas and furthering knowledge and understanding. I suggest areas for future productive research.

The aspiration of enhancing knowledge and evidence of public involvement is to improve the quality of research, and ensure that it will be of more value and relevance to the recipients of that research.

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10. APPENDICES

APPENDIX 1: PRE-PUBLICATION COPIES OF THE INCLUDED PUBLICATIONS

Pre-publication copy of Publication 1

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.

Authors:

Rosemary Telford, BA MSc MAppSci, Consultant Clinical Psychologist, Sheffield Care Trust; Honorary Research Fellow, School of Health and Related Research, University of Sheffield.

Jonathan D Boote, MA (Cantab) MSc, PhD, Senior Research Officer, Clinical Effectiveness Directorate, Sheffield Care Trust; Honorary Research Fellow, School of Health and Related Research, University of Sheffield.

Cindy L Cooper, BSc (Hons) PhD, Senior Research Fellow, School of Health and Related Research, University of Sheffield.

Abstract

Objective: To obtain consensus on the principles and indicators of successful consumer involvement in NHS research

Design: Consensus methods were used. An expert workshop, employing the nominal group technique was used to generate potential principles and indicators. A two-round postal Delphi process was used to obtain consensus on the principles and indicators.

Setting and participants: Participants were drawn from health, social care, universities and consumer organisations. A purposive sampling strategy was used to identify people who had experience and/or knowledge of consumer involvement in NHS research. Six researchers and seven consumers participated in an expert workshop. Ninety-six people completed both rounds of the Delphi process.

Main outcome measures: Consensus on principles and indicators of successful consumer involvement in NHS research.

Results: Eight principles were developed through an expert workshop and Delphi process, and rated as both clear and valid. Consensus was reached on at least one clear and valid indicator by which to measure each principle.

Conclusions: Consensus has been obtained on eight principles of successful consumer involvement in NHS research. They may help commissioners, researchers and consumers to deepen their understanding of this issue, and can be used to guide good practice.

Introduction

The involvement of consumers is central to NHS Research and Development policy.[1,2] Current NHS guidance on research governance states that consumer involvement should exist at every stage of research where appropriate.[3] Consumers are said to bring unique perspectives to research, making it more relevant to their needs, and therefore to the NHS.[4,5] The value of consumer involvement in health research has been acknowledged both nationally and internationally, with many influential bodies, such as the Health

Technology Assessment Programme,[6] the Medical Research Council,[7] the National Cancer Research Institute,[8] the Cochrane Collaboration,[9] and the Consumers' Health Forum of Australia,[10] including consumers as partners in research.

Consumer involvement in health research is a relatively new concept for health professionals, with little empirical research to draw on. Most accounts to date have been descriptive or anecdotal with uncertain generalisability, and it is not clear how consumers can influence and benefit the research process.[11] In 2000, Sir John Patterson, the Director of Research and Development at the Department of Health stated that: "No systematic evaluation has been undertaken to assess the impact of the involvement of consumers in the research process." [12] Few studies have risen to this challenge, and there continues to be a lack of evidence of the effectiveness of consumer involvement in research.[13]

Despite clear directives from the Department of Health and guidance from the Consumers in NHS Research (re-named INVOLVE) Support Unit [4,14] implementation of the policy has been sporadic, with limited understanding among health professionals about the meaning and implications of active partnership with consumers in research.[15] One survey of health researchers revealed that many were unsure if they had involved consumers or not in their research. [16]

The present study set out to develop through consensus methodology, principles of successful consumer involvement in NHS research, and indicators by which the principles could be measured. It was anticipated that these would be of interest to commissioners, researchers and consumers; would assist in developing further understanding about the meaning of consumer involvement in NHS research; would provide guidance for good practice; and might also be a first step in developing robust ways of assessing the impact on research of consumer involvement.

Methods

Consensus methods were employed in two stages: (1) an expert workshop which utilized the nominal group technique (NGT), and (2) a two-round postal Delphi process.

An expert workshop

An expert workshop was held in January 2002 with the aim of developing principles or standards of successful consumer involvement in NHS research. In order to evaluate whether the principles could be implemented, the intention was also to develop indicators by which to measure the principles. The criteria for inviting consumers and researchers to the expert workshop were: (1) some ‘standing’ in the field of consumer involvement in research. This was interpreted as at least one published article or report on the topic of consumer involvement in research, or membership of a relevant committee; (2) a willingness to share ideas with others.

The NGT was used to facilitate discussion at the expert workshop around the question “what is meant by the successful involvement of consumers in research?” The NGT is a highly controlled small-group process for generating ideas.[17] Typical applications of the technique are for the development of consensus guidelines or standards in areas where research-based evidence is absent or inconclusive.[18] The key components of the method are: formulation and presentation of the nominal question; silent generation of ideas in writing; feedback from group members to record each idea in a succinct phrase; group discussion of each idea in turn for clarification and evaluation; individual voting on priority ideas; feedback of results; and further discussion and re-voting. There was no prior collation of principles from the literature in advance of the expert workshop. Participants were given four examples of potential principles and indicators beforehand.

By using an NGT, a number of principles were proposed by the workshop participants. The retained principles were those considered important by 85% or more of the participants for assessing if consumers are successfully involved in NHS research. Participants were also facilitated to identify indicators by which the principles could be measured. Following discussions with the Advisory Group, a cut-off of 85% was chosen in this study to set a high level of consensus. There does not appear to be agreement on what constitutes consensus when using consensus methods, and different criteria may be used for describing when consensus is reached. However the importance of clearly determining consensus before the method is used has been highlighted[19].

A two-round postal Delphi process

Consensus was sought from a wider group of researchers and consumers with knowledge or experience of consumer involvement in research on the retained principles developed at the expert workshop, and their associated indicators. A two round postal Delphi process was used for this purpose. The Delphi process is defined as a method used to obtain the most reliable consensus by a group of experts, through a series of intensive questionnaires, interspersed with controlled feedback[20]. Key characteristics of the Delphi process include a panel of experts who do not meet face-to-face, two or more rounds of questionnaires or interviews to develop ideas, and the systematic emergence of a consensus.[21]

The number of people in the UK who have knowledge or experience of consumer involvement in NHS research is limited and we therefore used a variety of means to recruit as many Delphi participants as possible:

- Each expert workshop participant was asked to pass on invitations to take part to up to five consumers known to them

- UK authors of at least one journal article or report on consumer involvement in NHS research, and speakers at relevant national and regional conferences were invited to take part

- An invitation to participate was published in the Consumers in NHS Research Support Unit Newsletter

- Consumers who contributed to the Consumers in NHS Research Support Unit publication “Getting involved in research: a guide for consumers”[14] were contacted care of the Support Unit.

Through these means, 131 people agreed to take part in the Delphi study.

In April 2002, the round one Delphi questionnaire was sent out. This questionnaire incorporated the retained principles developed at the workshop, and between one and five indicators for each principle. In this round, participants were invited to reword existing principles and indicators and to contribute further principles and indicators if they wished.

Delphi questionnaires in both rounds asked respondents to rate the principles on two 9-point scales: *clarity* (the extent to which the principle is expressed in clear, precise and unambiguous language); and *validity* (the extent to which the principle is important for assessing if consumers are successfully involved in NHS research). Participants were asked to rate each indicator on three 9-point scales: *clarity* (the extent to which the indicator is expressed in clear, precise and unambiguous language); *validity* (the extent to which the indicator is a good measure of the associated principle) and *feasibility* (the extent to which the data for this indicator is, or could be made, available and consistently recorded). The above definitions of clarity, validity and feasibility were included in the questionnaire. Panellists were also invited to contact the researchers for further clarification if necessary.

Completed round one questionnaires were then analysed by the research team in order to generate data to be fed back to participants at round two. Information fed back related to: (1) the median rating of each principle and indicator on the clarity, validity and feasibility scales; (2) distribution data relating to each scale point on each scale; and (3) if consensus was achieved at round one.

The level of consensus was set at 85% before the mailing of round one. A principle was to be retained if 85% or more of the panel rated it between 7-9 on the 9-point scale on *both* clarity and validity. An indicator was to be retained if 85% or more of the panel rated it between 7-9 on clarity *and* validity *and* feasibility.

The round two questionnaire was sent out in July 2002. At round two, participants were requested to rate the original principles and indicators again, in the light of the provided median and distribution data relating to round one. Participants were also invited to rate any new principles and indicators proposed in the first round. If consensus was achieved at round one, participants were not invited to re-rate at round two.

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, influencing the methodology and the interpretation of the results.

Results

Expert Workshop

Six researchers and seven consumers attended the expert workshop. Thirteen principles were generated, with 85% consensus on 12 of them (see Table 1). The principle that was not retained because of poor agreement stated that the process of involving consumers in research should be enjoyable. (One of the 12 principles (C) was later split into two principles, C and D, as a result of responses during the Delphi process, thus giving thirteen principles in total). There was not enough time to develop indicators of the principles on the day and they were subsequently produced by consulting the literature, using material from the expert workshop (post-its, flip charts and notes of the discussions), postal consultation of members of the expert workshop, and by consulting Advisory Group members.

Delphi

Description of the sample

Of the 131 people who agreed to take part in the study, first round questionnaires were received from 110, giving an attrition rate of 16%. Second round questionnaires were sent to these 110 participants, of which 96 were returned, yielding a round two attrition rate of 13%. Demographic data presented relate to those returning both rounds of the questionnaire (n=96).

Most Delphi panellists were aged between 36-55 years, and more women (n=59) than men (n=37) participated. The ethnic origin of most of the sample was White UK (n=85). Panellists described themselves as providing one of the following perspectives: consumer, researcher, consumer and researcher, other or consumer and other. The perspective rated most frequently was that of researcher (n=33), followed by consumer (n=29) then consumer and researcher (n=26). Consumer perspectives were broken down further into five groupings taken from a list of options based on the definition of 'consumer' employed by Consumers in NHS Research[14]: an advocate/activist/consumer representative (n=21), a patient or long-term user of services (n=15), an employee of an organisation that is for consumers e.g. a charity (n=12), a member of an organisation of consumers where the organisation is managed by more than 50% of people with that experience or health condition (n=9), and a carer (n=8). Although only one was asked for, some panellists provided more than one consumer perspective.

Those identifying themselves as researchers were asked to provide information on the type(s) of health research with which they had been most actively involved. The most common was health services research (n=53). Other kinds of research included clinical trials (n=16), secondary research (n=13), behavioural research (n=10) and population-based research (n=10).

We asked all panellists to provide up to three health areas in which they had most active experience of consumer involvement in research. The five dominant health areas were mental health, physical and learning disabilities, cancer, pregnancy, childbirth and childcare, and the health of older adults.

Rating of the principles and indicators

Table 1 displays clarity and validity ratings of the thirteen principles of successful consumer involvement in NHS research. Eight of these satisfied the initial retention criterion, and data relating to their associated indicators were then examined.

[Insert Table 1 about here]

Table 2 displays the clarity and validity ratings of the indicators of the eight retained principles. Both Tables 1 and 2 display the results of round 2 only. At the suggestion of Delphi participants, a small number changes were made between rounds 1 and 2. These changes concerned: (1) splitting one principle into two separate principles; (2) suggesting indicators to existing principles (e.g. H3 and I4); and (3) refining the wording of existing principles and indicators. Space does not allow a detailed discussion of such changes; however, the following two examples are offered. At round 1 principle C read, “The roles of consumers are negotiated, and their expectations clarified”. Panellists considered that the principle covered two separate issues, so this principle was split into principles C and D at round 2 (see Table 1). At round 1, principle I read, “Consumers have access to training, mentoring and personal support, to enable them to be involved in research”. Some panellists expressed their dislike of the term ‘mentoring’ in the principle, while others argued that consumers may not actually want to have access to such things. Therefore, at round 2 the principle read, “Consumers are offered training and personal support, to enable them to be involved in research.”

[Insert Table 2 about here]

During the Delphi process a number of people voiced their concern about the issue of feasibility (the extent to which data for the indicator is, or could be, made available and consistently recorded by research teams). Some found feasibility difficult to rate in the abstract: “feasibility was hard to assess without context”, others questioned why it should be measured, and several found the concept confusing. These observations raised doubts about the validity of the ratings on feasibility, and it was therefore decided to remove the issue of feasibility from the data analysis. The retention criterion for the indicators was therefore adjusted. An indicator was now retained if 85% or more of the panel rated it between 7-9 on the 9-point scales of clarity and validity only. Table 2 shows that eight of the retained principles have at least one clear and valid measurable indicator as rated by 85% or more of the panel. These were Principles D, F, H, I, J, K, L and M.

In summary, through an expert workshop and a two-round Delphi process, eight clear and valid principles of successful consumer involvement in NHS research have been developed, each of which has at least one clear and valid indicator (see Table 3).

[Insert Table 3 about here]

Discussion

Using a systematic approach, consensus has been achieved among researchers and consumers on eight clear and valid principles of successful consumer involvement in NHS research. Previous authors have identified mismatches between the views and priorities of researchers and consumers,[22,23,24] but findings in this paper suggest there is concordance about fundamental aspects of successful consumer involvement in research. The principles address research process issues, and all have associated clear and valid indicators. We did not adopt a weighting system for the principles on the advice of the expert workshop members.

The principles address ethical, moral and practical issues, and are congruent with guidance offered by INVOLVE on methods of involving consumers in research[4,14] and key principles said to underlie the philosophy held by many service-user researchers about involving them in research[25]. The principles reflect similar work that addressed the importance of being clear about why researchers wish to involve consumers or service-users in research, funding and training issues, and the need for research findings to be available in accessible formats.

The Toronto Group[26] has presented a range of degrees of service user involvement in research along a number of dimensions ranging from high to low involvement, to initiate a theoretical debate about the changing role and relations of research for research practitioners. Eight research issues, including research funding, research design and process, and dissemination were given as examples for readers to informally assess their own research activities against a continuum. Using ‘dissemination’ as an example, four possible levels of service user involvement are listed, ranging from “research participants/service users and their organisations make the decisions about research dissemination and publication formats”, through “research participants/service users and their organisations are involved in the decision making process for this” to “research participants are not involved in the process of dissemination and findings are not produced in accessible formats.” It is possible to map some of the principles developed in this study within the schema offered by the Toronto Group[26], and where the principles can be located suggests that they reflect an intermediate level of service user involvement.

The value and utility of the principles and indicators have yet to be established. They will almost certainly need to be further developed and refined. Future work is needed to establish how transferable they are to different research methodologies and models of consumer involvement.

Health services research was by far the most frequently cited area from which our researcher participants were drawn, with consumer involvement more commonly reported in certain health topics (mental health, physical disability and learning difficulties, cancer, pregnancy, childbirth and childcare, and the health of older adults). These findings suggest that the policy on consumer involvement may be more developed in these research categories, and/or that these health areas attract more research activity.

The principles and indicators that emerged during this study may be more appropriate to models of research in which the researcher leads and invites the involvement of consumers in research. Whether or not the principles can be adapted for user-led research has yet to be tested. Over a quarter of our Delphi respondents described themselves as 'consumer-researchers', suggesting that researchers and consumers can have overlapping roles.[27] We did not explore the complexities of the terms 'consumer' and 'consumer-researcher' or how these categories may have been interpreted by respondents in this study.

Combining the expert workshop and the Delphi process enabled the identification and refinement of principles and indicators by a large number of people, who were knowledgeable or experienced in the area of consumer involvement in research. These methods have been successfully used together in a previous study that developed key priorities for a consensus statement on user involvement in cancer services.[28] While the Delphi process is more frequently associated with the development of consensus on treatment decisions, it has also been employed to develop quality indicators for primary care mental health care,[29] and in this study, it proved to be an effective way of generating consensus on the descriptors or standards of what are considered to be successful ways of involving consumers in NHS research.

As the aim was to target 'expert' participants, we used a systematic process to recruit as many people as possible from the small number of potential participants. The diversity of our participants was limited, and probably reflects that of the 'experts' in this field. Although we consulted a reference group of people from minority ethnic groups during the preparatory stages of this research, and one of the members continued to act as an advisor during the course of this study, we acknowledge the lack of ethnic diversity influencing this work. We did not specifically seek the opinions of people with disabilities during in this research, and recognise that this too is a limitation of the study.

In many cases, feasibility (the extent to which data for the indicator is, or could be, made available and consistently recorded) was consistently rated lower than that of clarity and validity. An example of an indicator that did not meet the 85% consensus level on feasibility is: "Consumers gave advice to researchers on how to recruit participants to the research". Participants may have felt that it was too soon for the data on the indicators to be recorded in a consistent way. If so, it is not known if this concerns current or future feasibility. Is this an issue of low expectations that will change as people become aware of more examples of consumer involvement, or do people hold the view that it will never be feasible? This can be tested, and the authors are undertaking a national survey of NHS lead researchers to explore this issue. Another explanation is that other more appropriate measurable indicators of the principles should be identified. The Delphi questionnaire was a long and complex instrument, and several people told the research team that they found the concept of feasibility unclear, despite being given an explanation.

This study marks an early attempt to employ rigorous methods in an area where little empirical research has so far been undertaken. The main benefits of the principles are in guiding good practice, providing recommendations for commissioning research, and in deepening understanding about involving consumers in research. Having developed the principles, additional work is required to develop feasible indicators, in order to monitor and evaluate the principles. Findings from this study suggest that this task will be challenging.

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Acknowledgements

We would like to thank members of our Advisory Group: Peter Beresford, Sarah Buckland, Adebola Fatogun, Alison Faulkner, Allen Hutchinson, Paula Nicolson and Glenys Parry for their expert assistance with many aspects of this study. We are indebted to Stephen Campbell and Tracey Shield for their advice on the Delphi process. This research was funded by NHS Executive Trent, and we thank them for their interest and support of this research, we also wish to thank Marion Stobbs for expert secretarial skills.

We gratefully acknowledge the participation of all members of the expert workshop and those who took part in the Delphi process.

Participants at the Expert Workshop:

Marian Barnes

Peter Beresford

Adebola Fatogun

Alison Faulkner

Heather Goodare

Marcia Kelson

Tina Leonard

Shirley Nurock

Maire O’Donnell

Sandy Oliver

Barbara Read

Jane Royle

Charlotte Williamson

Participants of the Delphi process who completed both rounds and agreed to be named:

Ade	Adebajo
John	Appleby
Sheena M	Bevan
Catherine	Beverley
Mildred	Blaxter
Lucy	Blenkiron
Andrew	Booth
Ric	Bowl
David P	Britt
Charlie	Brooker
Peter	Cardy
Iain	Chalmers
Jiri	Chard
Norma	Clarke
Cynthia	Clarkson
David	Clayton-Evans
Sarah	Clement
Elizabeth	Clough
Jo	Cooke
Ann	Davis
Ann	Decent
Paul	Dieppe
Clare	Dimmer
Soo	Downe
Pam	Enderby
Clare	Evans
Gerard	Finnegan
Ray	Fitzpatrick
Margaret C	Flynn
Bob	Gann
Franca	Garrick
Kathie	Godfrey

Gordon	Grant
Gill	Gyte
Bec	Hanley
Alisa	Harrison
Richard	Harvey
Andrew	Herxheimer
David	Hoe-Richardson
Christine	Hogg
Helen	Hooper
U Hla	Htay
Rosemary	Humphreys
Lynda	Jessopp
Alistair	Kent
Ruth	Ker
Lynn	Kerridge
Sarah	King
Vinod	Kumar
Sharon	Marazzi
Hazel	Marshall-Cork
Sheila	McFarlane
Angela	McKean
Helen	Millar
Virginia	Minogue
Annie	Mitchell
Jane	Morrell
Lesley	Munro
Catherine	Nelson
Eileen	O'Keefe
John	O'Sullivan
Carey	Ostrer
Kathryn	Page
David	Pilgrim
Derek J	Podesta
David	Potter
Maggie	Rastall
Jennie	Rennie
Julie	Repper
Ann	Richardson
Mervyn Lewis	Richardson
Tony	Ryan
Laurel	Salthouse
Marie Claire	Shankland
Tony	Stevens
Jackie	Sturt
Debbie	Tallon
Jane	Taylor
Hazel	Thornton
Ann	Truesdale
J A	Tweed
Anthony	Webber
Jane	Wheeler

David John	Wilde
Walter	Wills
Adrienne	Wright
Sam	Young

Table 1: Clarity and validity ratings of the principles of successful consumer involvement in research. Retained principles in bold

	Principle	Clarity		Validity	
		Median	**Consensus[1]**	**Median**	**Consensus[1]**
A	The research will lead to benefits for consumers, in terms identified by the consumers themselves	7	No	8	Yes
B	Consumers are involved in every stage of the research, from identifying the research area through to sharing the research findings	8	Yes	8	No
C	Consumers' expectations of being involved in the research are made clear to the researcher	7	No	8	No
D	**The roles of consumers are agreed between the researchers and consumers involved in the research**	**8**	**Yes**	**8**	**Yes**
E	Consumers have the opportunity to engage in research in the manner and at the level they wish, opting out of being involved in research at any time	8	Yes	7	No
F	**Researchers budget appropriately for the costs of consumer involvement in research**	**8**	**Yes**	**8**	**Yes**
G	Consumers are from sections of society and walks of life that are appropriate to the research	7	No	7	No
H	**Researchers respect the differing skills, knowledge and experience of consumers**	**8**	**Yes**	**8.5**	**Yes**
I	**Consumers are offered training and personal support, to enable them to be involved in research**	**8**	**Yes**	**8**	**Yes**
J	**Researchers ensure that they have the necessary skills to involve consumers in the research process**	**8**	**Yes**	**8**	**Yes**
K	**Consumers are involved in decisions about how participants are both recruited and kept informed about the progress of the research**	**8**	**Yes**	**8**	**Yes**
L	**Consumer involvement is described in research reports**	**9**	**Yes**	**9**	**Yes**
M	**Research findings are available to consumers, in formats and in language they can easily understand**	**9**	**Yes**	**9**	**Yes**

[1] Consensus defined as 85% of panellists rating the scale item between the tertiles of 1-3 OR 4-6 OR 7-9. Yes = consensus reached; no = consensus not reached

Table 2: Clarity and validity ratings of indicators of the eight retained principles of successful consumer involvement in NHS research Retained principles and indicators in bold

Principle and associated indicators	Clarity		Validity	
	Median	Consensus[1]	Median	Consensus[1]
D: The roles of consumers are agreed between the researchers and consumers involved in the research				
• D1: Researchers' expectations of what they wanted from consumers were recorded at the beginning of the research	8	Yes	7	No
• D2: The roles of consumers in the research were agreed on an individual basis	8	Yes	7	No
• **D3: The roles of consumers in the research were documented**	**8**	**Yes**	**8**	**Yes**
• D4: Consumers' roles in the research were reviewed during the research process	8	No	7	No
• D5: Consumers were asked about how they wished to be involved in the research	8	Yes	8	No

F: Researchers budget appropriately for the costs of consumer involvement in research				
• **F1: Researchers applied for funding to involve consumers in the research**	**8**	**Yes**	**9**	**Yes**
• **F2: Consumers were reimbursed for their travel costs**	**8**	**Yes**	**9**	**Yes**
• **F3: Consumers were reimbursed for their indirect costs (e.g. carer costs)**	**9**	**Yes**	**9**	**Yes**
• F4: Consumers were offered reimbursement for their time	9	Yes	8	No
• F5: Consumers negotiated the rate of reimbursement for their expertise	8	No	7	No

[1] Consensus defined as 85% of panellists rating a scale item between the tertiles of 1-3 OR 4-6 OR 7-9. Yes = consensus reached; no = consensus not reached

Table 2 continued

Principle and associated indicators	Clarity		Validity	
	Median	Consensus[1]	Median	Consensus[1]
H: Researchers respect the differing skills, knowledge and experience of consumers				
• H1: Consumers' skills, knowledge and experience were recorded at the beginning of the research	8	Yes	7	No
• **H2: The contribution of consumers' skills, knowledge and experience was included in research reports and papers**	**8**	**Yes**	**8**	**Yes**
• H3: Consumers' skills, knowledge and experience were used to the full where relevant	7	No	8	No
I: Consumers are offered training and personal support, to enable them to be involved in research				
• **I1: Consumers' training needs related to their involvement in the research were agreed between consumers and researchers**	**8**	**Yes**	**8**	**Yes**
• **I2: Consumers had access to training to facilitate their involvement in the research**	**8**	**Yes**	**8**	**Yes**
• **I3: Mentors were available to provide personal and technical support to consumers**	**8**	**Yes**	**8**	**Yes**
• I4: In order to provide peer support, at least 2 consumers were involved in the research at the same time	8	No	8	No
• I5: Consumers' experiences of their involvement were reviewed and responded to in the course of the research	8	No	7	No

[1] Consensus defined as 85% of panellists rating a scale item between the tertiles of 1-3 OR 4-6 OR 7-9. Yes = consensus reached; no = consensus not reached.

Table 2 continued

Principle and associated indicators	Clarity		Validity	
	Median	**Consensus[1]**	**Median**	**Consensus[1]**
J: Researchers ensure that they have the necessary skills to involve consumers in the research process				
• J1: Researchers assessed their own training needs in relation to involving consumers in the research	8	No	7	No
• **J2: Researchers ensured that their own training needs were met in relation to involving consumers in the research**	**8**	**Yes**	**8**	**Yes**
K: Consumers are involved in decisions about how participants are both recruited and kept informed about the progress of the research				
• **K1: Consumers gave advice to researchers on how to recruit participants to the research**	**8**	**Yes**	**8**	**Yes**
• **K2: Consumers gave advice to researchers on how to keep participants informed about the progress of the research**	**8**	**Yes**	**8**	**Yes**

[1] Consensus defined as 85% of panellists rating a scale item between the tertiles of 1-3 OR 4-6 OR 7-9. Yes = consensus reached; no = consensus not reached.

Table 2 continued

Principle and associated indicators	Clarity		Validity	
	Median	**Consensus**[1]	**Median**	**Consensus**[1]
L: Consumer involvement is described in research reports				
• **L1: The involvement of consumers in the research reports and publications was acknowledged**	**9**	**Yes**	**9**	**Yes**
• **L2: Details were given in the research reports and publications of how consumers were involved in the research process**	**8**	**Yes**	**8**	**Yes**
• L3: Consumers' views of the research findings were explicitly documented in the research reports and publications	8	Yes	8	No
• L4: The impact of the consumers' involvement in the research was described in the research reports and publications	7	No	7	No

[1] Consensus defined as 85% of panellists rating a scale item between the tertiles of 1-3 OR 4-6 OR 7-9. Yes = consensus reached; no = consensus not reached.

Table 2 continued

Principle and associated indicators	*Clarity*		Validity	
	Median	**Consensus**[1]	**Median**	**Consensus**[1]
M: Research findings are available to consumers, in formats and in language they can easily understand				
• M1: The research findings were publicly available	8	Yes	8	No
• **M2: Research findings were disseminated to consumers involved in the research in appropriate formats (e.g. large print, translations, audio, Braille)**	**8**	**Yes**	**8**	**Yes**
• **M3: The distribution of the research findings to relevant consumer groups was in appropriate formats and easily understandable language**	**8**	**Yes**	**8**	**Yes**
• **M4: Consumers involved in the research gave their advice on the choice of methods used to distribute the research findings**	**8**	**Yes**	**8**	**Yes**
• M5: Consumers involved in the research were given the opportunity to distribute research findings to their own networks and/or contacts unless prevented by the research funding body	8	Yes	8	No

[1] Consensus defined as 85% of panellists rating a scale item between the tertiles of 1-3 OR 4-6 OR 7-9. Yes = consensus reached; no = consensus not reached.

Table 3: The 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 were 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

Pre-publication copy of Publication 2

Barber R, Boote J D, Cooper C L. Involving consumers successfully in NHS research: a national survey. *Health Expectations,* 2007a; 10: 380-391.

Authors:

Rosemary Telford, BA MSc MAppSci, Consultant Clinical Psychologist, Sheffield Care Trust; Honorary Senior Research Fellow, School of Health and Related Research, University of Sheffield.

Jonathan D Boote, MA (Cantab) MSc, PhD, Research Manager (Governance), Sheffield Health and Social Research Directorate; Honorary Research Fellow, School of Health and Related Research, University of Sheffield.

Cindy L Cooper, BSc (Hons) PhD, Director of Clinical Trials Support Unit, School of Health and Related Research, University of Sheffield.

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 organisations 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 randomised 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 has been described in a systematic study of the processes and outcomes of identification and prioritisation 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 prioritising 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: (a) how far and in what way consumers are currently involved in UK health research and (b) 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, organisations 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 (1) an expert workshop of consumers and researchers that employed the nominal group technique and (2) a two-round postal Delphi process. Full details are available [27, 29].

[Table 1 here]

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, 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: (1) the types of health research, as classified by the Department of Health, that were most associated with consumer involvement (see Table 2.), (2) the nature of consumer involvement, (3) how many recently completed NHS research projects met the indicators of principles of successful consumer involvement in NHS research, (4) the reasons for not involving consumers and (5) respondents' suggestions for improving consumer involvement in health research.

[Table 2 here]

The questionnaire included ten of the sixteen consensus-derived indicators (see Table 3). Those selected for inclusion in the questionnaire were the ones which achieved higher ratings on '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 three weeks after the first posting.

[Table 3 here]

Sampling frames

Two sampling frames were used for the survey: (1) 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. (2) 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 1,016 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 organisation 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/prioritising 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.

[Table 3 here]

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: (a) access to consumers, (b) representativeness of consumers, (c) motivation and expertise of consumers and (d) 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 recognising 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: (a) funding and support, (b) time, (c) education and training, and (d) 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 consumers involvement entails in reality (time and costs) and more funding to initiate changes based on what consumers say.” Responders 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: (a) the early stages of research, (b) dissemination and feedback to consumers and (c) research methods. There was clear support for consumer involvement at the early stages of research, with suggestions addressing the prioritising 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: (a) the value and/or appropriateness of consumer involvement in research and (b) 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 prioritising 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 are 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 organisations, such as the Alzheimer’s Society’s Quality in Research Dementia (QRD) initiative [36] 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 (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 e.g. “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 recognise that the generalisability 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.

Acknowledgements

We would like to thank members of our Advisory Group: Peter Beresford, Sarah Buckland, Adebola Fatogun, Alison Faulkner, Allen Hutchinson, Paula Nicolson and Glenys Parry for their expert assistance with many aspects of this study. We are grateful to all who participated in the postal survey. Thanks to Marion Stobbs for her expert secretarial skills. The research project was funded by NHS Executive Trent, and we thank them for their interest and support of this research.

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Table 1. Principles and indicators of successful consumer involvement in NHS research. Indicators in bold were embedded in the postal questionnaire.

Principles	**Indicator(s)**
The roles of consumers are agreed between the researchers and consumers involved in the research	• **The roles of consumers in the research were documented**
Researchers budget appropriately for the costs of consumer involvement in research	• **Researchers applied for funding to involve the consumers in the research** • **Consumers were reimbursed for their travel costs** • **Consumers were reimbursed for their indirect costs (e.g. carer costs)**
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**
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
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
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**
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**
Research findings are available to consumers, in formats and in language they can easily understand	• **Research findings were disseminated to consumers 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

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

Pre-publication copy of Publication 3

Telford R, Faulkner A. Learning about service user involvement in mental health research. *Journal of Mental Health,* 2004; 13: 549-559.

Authors:

Rosemary Telford, Sheffield Care Trust; School of Health and Related Research, University of Sheffield.

Alison Faulkner, Independent Survivor Researcher

Abstract

Service user involvement in mental health research is a relatively new concept for health professionals. The aims of this paper were to investigate: how far service user involvement in mental health research appears to have been understood, how far it is happening, reasons why service users get involved in research, and barriers to closer involvement from both service user and researcher perspectives. The literature was examined to explore the extent of service user involvement in mental health research, and ways in which service users are carrying out research. It was concluded that while there is little empirical research in this area, increasingly service user involvement in mental health research can be found in the peer-reviewed domain, and at all levels of the research process. The alternative literature (including what is commonly called the grey literature) offers a rich source to learn from. Consideration of the barriers to closer service user involvement highlights likely challenges to traditional researcher-led ideologies and processes.

Introduction

The notion of service user involvement in planning and developing mental health services is well established, and has been supported in the UK by policy directives from the Department of Health (1999a,b). Despite a long tradition of espoused support for service user involvement, there is little evidence that it is widespread in the NHS (NIMHE, 2003; Peck, Gulliver, & Towel, 2002). The reasons for this are complex, and include scarce resources, confusion about the meaning and purpose of service user involvement, resistance from professional staff, and an over-reliance on a small number of service users, sometimes to the detriment of their own health (Bowl, 1996; Pilgrim &Waldron, 1998; Crawford et al., 2002; Peck et al., 2002).

Mental health professionals are less familiar with the concept of service users as active participants in the research process, but in other disciplines this is not a new idea. In the disability field and in feminist research ideology, emancipatory research (research with the aim of empowerment at its core) has been around for some time (Barnes & Mercer, 1997). Here it is commonplace for research on women to be undertaken by women, research on particular disabilities to be undertaken by people experiencing those disabilities, and for research to be undertaken by people from black and minority ethnic communities where the research involves their community. This has introduced new challenges to the research process, to researchers and to those being researched, which we address in this paper.

Until recently, very little service user research on mental health issues had been reported in the academic literature (Simpson & House, 2002), and we examine possible reasons for this. Currently increasing numbers of academic papers by service user researchers can be found in peer-reviewed journals (Beresford, 2002; Faulkner & Thomas, 2002; Trivedi & Wykes, 2002; Rose, 2003; Rose, Fleischmann, Wykes, Leese, & Bindman, 2003). This paper considers what is meant by service user involvement in research, why service users might want to undertake research, and gives examples to demonstrate how far it is happening. It discusses possible barriers to involving service users in mental health research, including methodological constraints. The paucity of any empirical research in this area may be considered a barrier, but we suggest that there is much to learn from the alternative or grey literature in addition to academic research.

Policy initiatives

For those who work in the NHS, there is clear guidance from the Department of Health about involving service users in health research. *Patient and Public Involvement in the NHS* (DoH, 1999a) acknowledged the importance of service user involvement in many aspects of health service developments, including research, while *Research and Development for a First Class Service* (DoH, 1999b) requires Trusts holding NHS R&D Support Funding to demonstrate evidence of involving service users in research activity. More recently *Research Governance Framework for Health and Social Care* (DoH, 2001) addressed two areas of relevance to service users: (i) a call for the active involvement of service users and carers at every stage of research where appropriate and; (ii) a move towards greater openness about research undertaken by organisations, in particular, wider and more accessible dissemination of their findings.

In 1996, the Department of Health established the Standing Advisory Group on Consumer Involvement in the NHS R&D Programme, later known as ‘Consumers in NHS Research’, with the aim of ensuring that consumer involvement in R&D within the NHS improves the way that research is prioritised, commissioned, undertaken and disseminated. Recently, the remit of ‘Consumers in NHS Research’ widened to include involvement in public health and social care research, and the name was changed to ‘INVOLVE’ (2003).

The impact of these policy developments has been to introduce into a range of public funding streams, requirements or encouragements for researchers to demonstrate in funding applications how service users will be involved in their research projects (National Coordinating Centre for Health Technology Assessment, 2003; NHS Service Delivery and Organisation, 2003). It has also resulted in service user involvement being on the agenda of NHS R&D frameworks such as the R&D Strategic Review of Mental Health Research (DoH, 2002), and the NHS National Programme on Forensic Mental Health Research and Development (2004).

Language and meaning

Terminological issues are important, as they reflect not only the way we see the world, but also the way in which others see us. There does not appear to be accepted or acceptable terminology to describe people who use health services, and the term ‘consumer’ has been adopted by a number of UK and international health organizations concerned with service user involvement (Cochrane Consumer Group, 2003; National Cancer Research Institute Consumer Liaison Group, 2003). INVOLVE (2003) defined ‘consumers as’ ‘patients, carers, long-term users of services, organisations representing consumers’ interests, and members of the public who are the targets of health promotion plans.’ (Royle, Steel, Hanley, & Bradburn, 2001). Many people are uncomfortable with the term ‘consumer’, particularly in relation to receiving mental health services. Consumerist notions of choice in the context of a marketplace sit uneasily within services that typically offer limited choice, and no choice at all when people are detained against their will (Barnes, 1997; Godfrey & Wistow, 1997; Peck & Barker, 1997). INVOLVE (2003) has responded to this sometimes controversial label by replacing ‘consumer involvement’ with ‘public involvement’, as has the Medical Research Council (2004). In the mental health field, the majority of people using services have chosen to use the term ‘service user’.

Pilgrim and Waldron (1998) captured the spirit of service user involvement in research in the context of the planning of mental health services: ‘‘The aim is to take service users beyond the role of passive suppliers of opinion, to a role of active negotiators for change’’. Hanley et al. (2004) highlighted the active nature of public involvement in research: ‘‘Doing research *with* or *by* the public rather than to, about, or for the public’’. Mental health service users may be involved in any or all of the stages of research, from defining the priorities for research through commissioning, designing and carrying out research, to the dissemination of the findings. We draw on lessons learned from service user involvement in other areas of health and social research, and note that the terms ‘researcher’ and ‘service user’ are not necessarily discrete categories. People commonly have overlapping roles (Herxheimer & Goodare, 1999), each of which has the potential to inform the others.

Motives and incentives for collaborative research

There is a distinction to be made between user-led or user-controlled research, and user involvement in research (often referred to as collaborative research). Many service users and user organizations would argue for the value of user-controlled research as a means of taking forward the user or survivor movement and of retaining power in research relationships. They may also be less interested in getting involved in other people’s research, than in having some control over the research that is carried out (Trivedi & Wykes, 2002).

There are likely to be conflicts in the collaborative or involvement model, which stem from fundamental differences in stakeholder viewpoints. Thus, in considering the reasons for involving service users in research, it is important to consider the motives of academic and clinical researchers and the motives of service users separately. For any collaboration to be successful, there will need to be sufficient common ground on which to work.

The motives of service users include the following (Trivedi & Wykes, 2002; Faulkner & Morris, 2003:

- Frustration with clinical academic research
- Promoting the value of expertise by experience
- Seeking change and improvements
- Asking different questions. . . and getting different answers
- Questioning the independence of services and professionals
- Challenging models of understanding
- Developing skills, confidence and empowerment.

Frustration with clinical academic research is often based on the subject area deemed suitable for investigation; for example, the causes of particular mental health problems, and the relative efficacy of different drugs and other treatments or interventions. This approach, in the view of many service users, tends to fragment the experience of living with the diagnosis and is not holistic. The topics that service users are more often interested in tend to concern practical issues and aspects of daily living, information about and access to services, and the exploration of strategies or ways of managing from a ‘whole person’ perspective (DoH, 2002; Thornicroft, Rose, Huxley, Dale, & Wykes, 2002). Service users may also wish to ask research questions about the nature of the mental health services provided.

Recognising the value of ‘expertise by experience’’ is a potentially validating and affirming notion for service users and is increasingly being recognized in policy initiatives. For example, the National Institute for Mental Health (England) (NIMHE, 2003) has established a users and carers group entitled ‘Experts by Experience’. This phrase has been adopted by certain mental health service user organisations, and the political moves to involve them in partnerships with professionals in designing and delivering services implies a value to the experiential perspective. In research, the argument is that research undertaken from the experiential perspective should be at least as valuable and as influential as research from the professional perspective. In this context we acknowledge that all research has its own perspective or bias. Indeed, without this perspective, research is in danger of becoming distant from and irrelevant to the lived experience, having less potential impact on practice (Beresford & Evans, 1999; Beresford, 2003). In bringing together the two perspectives, there may be added value in ensuring that a research investigation is meaningful and influences practice.

One of the strongest motives for service users to become involved in research is the desire to bring about change and improvements to services and practice; a wish to improve their own lives or the lives of others. This can be in conflict with academic researchers who may not only be more cautious about the potential for research to bring about change, but have different motives that commonly reflect their roles and practices within academic institutions, such as pursuing knowledge for knowledge sake, publishing and attaining research funding. Furthermore, the capacity to bring about change may not be in the hands of the researchers or collaborators; other external agencies, resources and political motives may militate against it.

Another powerful motivation for service users is the potential to gain skills and training, as well as financial reward, for the endeavour. In our view, it is a fundamental principle of involving service users in research to offer such rewards (Ramon, 2000). This implies that people are being valued for what they have to contribute to the process, and furthermore increases the likelihood that people will stay the course. Another possible outcome is that people may, through the acquisition of skills and experience, improve their chances of future employment. Furthermore, service users can become the objects of study so often in both mental health practice and research that it can be liberating and empowering to become the active researchers, thinkers and initiators of research.

Indeed, for many survivor researchers empowerment itself should be a goal of involvement in research; emancipatory research explicitly addresses this issue (see below).

Turning now to the motives of researchers, there is no doubt that many are influenced by pragmatic considerations to involve service users in research. It is becoming increasingly common for funding applications to require service users to be part of the research project. Academic careers may depend upon the willingness of service users to become research partners or collaborators. Research governance has set out clear policies and procedures to comply with, and research funds may be withheld until the commissioners are assured of the ways in which service users will be actively participating in the research. However, many researchers share the view articulated by Entwistle, Renfrew, Yearley, Forrester, & Lamont (1998), that as citizens and taxpayers, service users are entitled to influence the ways in which NHS services can improve, including publicly funded research.

Evidence is emerging of ways in which service users have influenced the course and process of research in a productive manner (Carrick, Mitchell, & Lloyd, 2001; Oliver et al., 2001; Trivedi & Wykes, 2002). In particular, service user interviewers are said to have strengthened the validity of responses from other service users (Clark, Scott, Boydell, Goering, 1999; Polowczyk, Brutus, Orvieto, Vidal, & Cipriani, 1993). However, empirical research is scant in this area (Hanley, Truesdale, King, Elbourne, & Chalmers, 2001; Boote, Telford, & Cooper, 2002), and Simpson and House (2003) speculate that ‘‘user or carer involvement may not lend itself to conventional study by randomized controlled trials’’. Herron-Marx, Stacey, Williams, & Repper (2003) suggest that ‘‘lack of evidence may mean lack of foresight, interest, commitment and/or resource allocation to do the evaluation, documentation, research, publication and dissemination work that would produce the evidence. Differences in levels of evidence may depend on who has access to what funding sources, as well as the agenda of particular funding sources.’’

The barriers to involvement

In this section we discuss a number of issues that may present as possible barriers to closer involvement of service users in research: conceptual frameworks and research approaches, understandings, practical issues, funding, research bias, and issues specific to mental health research. Being aware of these as potential pitfalls may in itself lead to a successful negotiation of research processes between researchers and service users.

The conceptual framework within which the research is undertaken may have profound implications for service user involvement, raising fundamental questions about whom the research is for, who determines the research questions and who analyses and interprets the data. A significant barrier to the involvement of service users in research is the potential incompatibility of ideologies. Service users, with a greater interest in an holistic approach to mental health and to challenging existing approaches, may remain marginalised by clinical academics whose research perpetuates the dominance of the medical model. User-led research initiated, developed and implemented by service users is likely to address questions that challenge the existing system whether explicitly or implicitly through the choice of research topics (Department of Health, 2002; Thornicroft, et al., 2002).

Conceptual frameworks also determine the nature of the relationship between the researcher and the researched. Undertaking emancipatory research, for instance, involves, ‘‘changing and equalising relationships between the research and research subjects, and developing survivors’ own knowledge collectively’’ (Beresford & Wallcraft, 1997). This is an approach more common within sociology, in disability research and increasingly in survivor (or service user) research. In contrast, research led and funded by institutions may well invite service users to become involved in that research but may propose their research in terms of professionally-defined qualities and outcomes. Research approaches differ in the way in which they allow greater or lesser distance, and/or power sharing between researchers and service users (Carrick et al., 2001; Trivedi & Wykes, 2002).

Many researchers continue to misunderstand the concept of involving service users in research (Telford, Beverley, Cooper, & Boote, 2002). In our experience, it is quite common for researchers to say that they have involved service users, when they have given them questionnaires or talked to them about their research, or because service users are the ‘subjects’ of their research. This may reflect prevailing notions of ‘active doctor—passive patient’, which can be held by either service user or practitioner, or simply an unfamiliarity with the overall concept.

Practical issues also present a barrier. Who should you ask to provide a service user perspective? Researchers may express concerns about the ‘representativeness’ of service users (Hanley et al., 2004), but remain silent about the ‘representativeness’ of researchers. Trying to find the ‘right type’ of service user can inhibit the success of collaborative research (Faulkner, 2003). Many researchers have addressed the need for both training and support as requirements for the successful involvement of service users in research (Ramon, 2000; Trivedi & Wykes, 2002; Nicholls, Wright, Waters, & Wells, 2003; Faulkner, 2004). Researchers may be unaware of the need to support service users or how to provide it. They may also be unaware of their own training needs, particularly in relation to communication skills. It can cost more to involve service users, and take longer to complete the work (Trivedi & Wykes, 2002; Nicholls et al., 2003). However, it should be pointed out that assistance is available in the form of guidance and principles of good practice on service user involvement in research (Beresford & Evans, 1999; Faulkner & Morris, 2003; INVOLVE, 2003; Telford, Boote, & Cooper, 2004).

The growing dominance of the pharmaceutical and biotechnology industries in setting the research agenda presents another potential barrier. In 1992 – 3, just over half of all health R&D was funded by the pharmaceutical industry (Hogg, 1999), and accusations have been made about biased research and the selected reporting of findings by the drug industry (Angell, 2000; Montaner, O’Shaughnessy, & Schechter, 2001). Herxheimer (2004) acknowledges that ‘‘Grants from and joint projects with pharmaceutical companies can help them [patients’ organizations] grow and be more influential, but can also distort and misrepresent their agendas’’. The implications for research that is user-led or collaborative are not known. However it is likely that research funded by drug companies, focusing on drug treatments, will take place at the expense of research that is of more interest to service users, such as research into more holistic aspects of mental health.

Some barriers are specific to mental health research. Of central importance is the notion that because of their ‘impaired state’, service users are thought to be unable to make reliable judgements about their therapy (Macran, Ross, Hardy, & Shapiro, 1999). Both Rose (2003) and Beresford (2002) refer to the apparent contradiction between being a researcher, which implies being able to think and act rationally, and being diagnosed as mentally ill, which implies irrationality. This can be a barrier in the minds of researchers or professionals who may believe it is not possible to be both. As Rose (2003) states: ‘‘I have been in research meetings that suddenly felt like a ward round.’’ Other barriers include the influence of the ‘drug metaphor’ (Stiles & Shapiro, 1989) where the research goal is to identify ‘active ingredients’ within a ‘passive service user – active therapist’ model.

The debate about objectivity may present another barrier to the involvement of service users in research. The stereotype is that clinical academic researchers believe themselves to be objective and ‘scientific’, and service users to be subjective, and unscientific with unrepresentative views. Service users on the other hand observe researchers pursuing a narrow research agenda reflecting their own academic interests, in the mistaken belief that it is scientifically objective. Challenges to these attitudes can be found in the writing of authors such as Ong (1996), who consider the synergistic effects of integrating service user perspectives with those of professionals. One of the central precepts of emancipatory and qualitative research is that the researchers are open and transparent about their own assumptions and perspectives (Mason, 2002).

There is scope for funding organisations to be powerful champions of service user involvement in research, whether this is user-led or collaborative research. Unless there is acknowledgment of the need for resources to support training, mentoring and practical support where necessary for service users, as well as payment, the opportunity for research to be influenced by service users will be limited. Currently little funding is made available for service user-led or service user-controlled research. However, it should be noted that advancements are being made, for example the Health Technology Assessment (National Coordinating Centre for Health Technology Assessment, 2004) and the National Programme for Forensic Mental Health R&D (2004) have made significant progress towards involving service users in their research policies and procedures.

Service user involvement in mental health research in practice

Despite the barriers we have highlighted, service users are now involved at all stages of the research process and in different ways: at policy levels (DoH, 2002), initiating emancipatory and user-led research (Faulkner & Layzell, 2000; Shaping Our Lives, 2003), and as research collaborators and advisors (Faulkner & Morris, 2003; Rose, 2003; Wykes, 2003). The following examples are by no means comprehensive:

- The Mental Health Foundation's Strategies for Living programme began in 1997, with the aim of 'documenting and disseminating people's strategies for living with mental distress' through research as well as through networks, newsletters and publications. The first phase supported six user-led research projects through funding, training and support (Nicholls, 2001). The second phase, which reported in 2003, supported 16 projects around the UK, all of which were initiated by local user groups or individuals (Nicholls et al, 2003). The programme was innovative in that it sought from the start to be entirely led by service users.

- The Service User Research Enterprise (SURE) is well established at the Institute of Psychiatry in London. Research undertaken to date includes a user-led ECT Review which has been used to inform the NICE Health Technology Appraisal (Rose, Fleischmann, Wykes, Lees, & Birdman, 2003), a project on continuity of care, user involvement in change management, and a study of young people in primary care.

- User focused monitoring (UFM), based at the Sainsbury Centre for Mental Health (2003), was developed as a model and a method for evaluating and researching the experiences of mental health service users in community and hospital settings (Rose, 2001). It makes three claims: to empower service users by giving service users work as interviewers, to enable the voices of the most disabled users to be heard and influence care delivery, and to provide more accurate and sensitive information about service users' experiences of mental health services than traditional, professional approaches. UFM projects are now taking place in many areas, including Bristol, Nottingham and Swansea.

- Of more recent interest, NIMHE (2003) has established a mental health research network co-ordinated by a collaboration between the Institute of Psychiatry and the University of Manchester. Within this network a small service user research group (or hub) is being established to co-ordinate service user-led research in mental health and collaborative initiatives. The tender for this has recently been awarded to The Mental Health Foundation (2003) Strategies for Living project in collaboration with Shaping Our Lives (2003) and members of the NIMHE (2003) Experts by Experience group.

Whilst there are a number of nationally known examples of service user involvement in mental health research, routine involvement is not extensive. A scoping study of mental health research in the North East, Yorkshire and Humberside (Northern Centre for Mental Health, 2002), revealed that service users rarely took part in setting the research agenda, ‘‘the control of research programmes is very much in the hands of the professionals’’, and there was an absence of networks to disseminate research findings.

Reviewing the literature

As recently as 2002, Faulkner and Thomas were unable to identify any papers published in psychiatric journals addressing user-led research. However, interest in this area is increasing in the academic press. Health Expectations publishes papers about aspects of public participation in health care and health policy, including public involvement in research. The British Medical Journal recently devoted an edition to patient and public issues in medicine (British Medical Journal, 14 June 2003), and an editorial in the Journal of Mental Health (Wykes, 2003) welcomed submissions of academic papers by service users to the journal. There is now a growing number of papers by service user and survivor researchers, often from academic institutions, in the peer-reviewed literature (Beresford, 2002; Trivedi & Wykes, 2002; Rose et al, 2003), nevertheless it remains the case that publication of service user-led mental health research in academic journals is rare.

By contrast, there is much to be found in the alternative or grey literature. Books, reports, articles, papers and web based information are available, and address theoretical and practical aspects of different types of service user involvement in research, including mental health research. For example, the Mental Health Foundation (2003) has published and/or enabled the publication of reports from the small projects they have been supporting (Somerset Spirituality Project Research Team 2002; Bodman et al., 2003; Essien, 2003). Local user groups and projects carrying out service evaluations or studies of user views are unlikely to publish their results in the academic literature unless they have links with a local university. The authors, in researching this paper, became aware of many research projects and reports by word-of-mouth and through recently-established networks, e.g. the email discussion forum based at the Mental Health Foundation (2003) and the UFM network at the Sainsbury Centre for Mental Health (2003). INVOLVE (2003) has made available a series of reports, papers, briefing notes, newsletters, advice on funding issues, and a database of research projects involving service users are available to guide service users and researchers.

The authors believe it is essential for researchers carrying out literature reviews in this field, or wishing to undertake collaborative research, to take into account the extensive alternative literature. Some of these reports do not reach or indeed attempt to reach the standards necessary for a peer-reviewed journal, but others are methodologically rigorous, and most offer a wealth of expertise and knowledge. Given that they are aimed at an audience of service users, service providers and others unfamiliar with academic language, they frequently constitute more accessible forms of communication.

Conclusion

There are many barriers to the successful involvement of service users in mental health research. In particular, there are likely to be fundamental ideological differences in approach between service users and researchers. However, as this paper has shown, there are increasing examples of organisations and projects overcoming these barriers and demonstrating the value of service user involvement in research at every level of the research process. Much of the impetus for developments has come from service users, questioning the relevance of research ‘about them without them’ and leading by example. Service user involvement in mental health research is underpinned by moral and ethical beliefs concerning the rights of citizens to shape their future, and by consumerist aspirations for choice. It is also strengthened by Department of Health policies and initiatives to empower collaborative and user-led research.

For service user involvement in mental health research to become more widespread, it will be necessary for researchers to learn from the alternative (or grey) literature as well as from peer-reviewed literature, and be open to challenges to traditional research ideologies and processes. Common ground will need to be established among researchers and service users to develop shared research goals and to clarify motives for collaboration. Further information is required about the effectiveness of service user involvement in research, and the impact on service users and researchers, as well as on research outcomes and processes.

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Pre-publication copy of Publication 4

Barber R, Beresford P, Boote J, Cooper C, Faulkner A. Evaluating the impact of service user involvement on research. A prospective case study. *International Journal of Consumer Studies,* 2011a; 35: 609-615.

Authors:

Rosemary Barber, School of Health and Related Research, University of Sheffield

Peter Beresford, Centre for Citizen Participation and School of Health Sciences and Social Care, Brunel University

Jonathan Boote, NIHR Research Design Service for Yorkshire and the Humber, University of Sheffield

Cindy Cooper, Clinical Trials Research Unit, University of Sheffield

Alison Faulkner, Research, Training and Consultancy in Mental Health

Abstract

As service user involvement in health and social care research has become more firmly embedded in health policies, both in the UK and internationally, there is increasing interest in evaluating its potential benefits and outcomes. Impact studies have highlighted a range of different types of service user involvement, using diverse research methods, within various research topics and involving different stakeholders. Potential benefits to research, researchers and the service users actively involved in research have been identified, along with the possibility of some negative consequences. Many impact studies have been criticised for being based on informal retrospective accounts of researchers and service users working together. Few have been underpinned by conceptual models, and there is a paucity of detailed accounts of the process of involvement that would enable replication.

This paper reports an account of a prospective, qualitative exploration of service user involvement within a study, where the aims of the evaluation were agreed beforehand. Reflective discussions about the process and progress of service user involvement at different stages of the study were recorded, transcribed and analysed. The qualitative analysis identified perceived benefits to research, researchers and service user researchers that endorsed previous findings. The analysis also highlighted subjective and interpersonal aspects of service user involvement that have seldom been reported. This evaluation demonstrates the benefits of allowing time for structured reflection and adds to the understanding of the process and meaning of service user involvement in research.

Introduction

The importance of service user involvement in health and social care research is recognised in the UK and also internationally (National Health and Medical Research Council, 2002; Department of Health, 2006; National Institutes of Health, 2011). Guidance on service user involvement in research is also available (Hanley *et al.*, 2004; Faulkner, 2004a: Telford, *et al.,* 2004; McKenzie and Hanley, 2007; Morrow *et al.,* 2010).

Why involve service users in research? Pragmatic, moral and political cases have been put forward (Enwistle *et al.*, 1998; Beresford, 2002; McCormick *et al.*, 2004). The Council of Europe (2000) recommended that the right of the public to be involved in the decision-making processes affecting health care is a basic and essential part of any democratic society, while a report from the National Health and Medical Research Council (2002) stated that public scrutiny and debate helped to enhance the integrity and accountability of research. According to the National Institute for Health Research (2011, 1 screen), ‘involving patients and members of the public in research can lead to better research, clearer outcomes, and faster uptake of new evidence’.   Reviews of service user involvement in health and social care research have highlighted a wide range of theoretical approaches and conceptual models, indicating how widespread it has now become (Staley, 2009; Boote *et al.*, 2010; Brett *et al.*, 2010). There are many examples of service user involvement in identifying and prioritising research topics, identifying outcome measures, carrying out research, analysing and interpreting data, and disseminating the findings. Collaborative and consultative levels of research predominate (Faulkner, 2010), although the number of user-controlled research studies is increasing (Rose 2004; Turner and Beresford, 2005).

Has service user involvement in research made a difference?

There is a growing literature on the impact of service user involvement on research, providing details of the potentially beneficial (and regressive) effects on research processes and outcomes, and on key stakeholders. Systematic reviews on the topic reveal that much of the evidence consists of descriptive, often retrospective, accounts of involvement (Oliver *et al.,* 2004; Smith *et al.,* 2005; Brett *et al.,* 2010). Reports on service user involvement in identifying and prioritising research suggest that involving service users increases the range of research topics, highlighting issues of importance to service users (Rhodes *et al.,* 2002; Caron-Flinterman *et al.,* 2005; Hewlett *et al.,* 2006; McLaughlin, 2006; Staniszewska *et al.,* 2007). McCormick *et al.,* (2004, p.636) observed that involving people with breast cancer led to more complex research questions and changes to research methods to investigate them. It was concluded that service user involvement ‘pushed the science forward more quickly.’ Service user involvement at the research design stage has contributed to improving trial consent procedures (Ali *et al.,* 2006), with involvement said to lead to a more ethically acceptable research design (Koops and Lindley, 2002) and enhanced recruitment and accrual rates (Staley, 2009).

It has also been reported that where studies have employed service users as co-researchers and interviewers, responses during interviews appear to be particularly candid, influencing the quality of the data in a positive way (Clark *et al.,* 1999; Faulkner, 2006; Williamson *et al.,* 2010). Some studies suggest that the benefits of service user involvement in analysing data include: modifying researchers’ misinterpretations (Savage *et al.,* 2006); identifying new themes (Fisher, 2002); highlighting findings of most relevance to service users (Ross *et al.,* 2005); questioning the interpretations of researchers, and making adjustments to how findings have been reported (Rose, 2004; Faulkner, 2006). Service user involvement in disseminating research findings was said to enhance the power and credibility of the findings (Smith *et al.,* 2008), leading to wider and more accessible dissemination (Barnard *et al.,* 2005; McLaughlin 2006). Some negative effects of service user involvement on research processes and outcomes have been identified. One study reported that the inexperience of a service user peer interviewer had a negative impact on data collection, but it was suggested that this could be remedied by support and training (Bryant and Beckett, 2006). Some tensions and barriers between different stakeholders were identified at the research design stage concerning variable levels of understanding of service users about health research methods, time and costs, and difficulties raised when researchers used jargon and complex language (Boote *et al.,* 2010).

Service user involvement is associated with empowerment and strengthening of the service user voice (Macaulay *et al.,* 1999; Beresford, 2002). Other positive effects described by service users include increased knowledge, skills, and confidence (Rhodes *et al.*, 2002) and support and camaraderie from others in user groups (Cotterell *et al.*, 2010). Some negative consequences, such as feeling overburdened (Clark, 2004), reliving distressing memories, hearing stark medical details or being referred to as ‘professional users’ have also been reported (Cotterell *et al.,* 2008; Cotterell *et al.,* 2010). We know little about the effects of service user involvement in research on researchers (Staley, 2009; Brett *et al.,* 2010), but there are suggestions that such involvement has led to researchers developing a deeper understanding of service user issues (Hewlett *et al.,* 2006; Lindenmeyer *et al.,* 2007), and prompted them to challenge their own beliefs and assumptions (Hewlett *et al.,* 2006). Some authors have noted concerns about additional time and costs required (Rhodes *et al.,* 2002; Wright *et al.,* 2006). Others have voiced perceived threats to professional skills and knowledge (Thompson *et al.,* 2009), and the relinquishing of some power (Lindenmeyer *et al.,* 2007). Hubbard *et al.* (2007, p.241) suggested that ‘many researchers find it difficult giving up control in order to share knowledge and power and have learnt to espouse scientific methodologies that typically exclude ‘lay people’.

Importance of organisational issues and interpersonal issues

There is growing recognition of the tensions and barriers that can prevent productive alliances between researchers and service users. Hubbard *et al.* (2007, p.242) state that: ‘tensions between traditional research practices and cultures and implementing an agenda of involvement must be acknowledged and strategies developed to overcome them if the agenda of involvement is to become more than a fringe activity.’ Some studies show how this can be done (McCormick *et al.,* 2004; Baart and Abma, 2010; Elberse *et al.,* 2010). Descriptions of the process of service user involvement in research can provide valuable information about why, when and how involvement is carried out. Narrative accounts are now becoming more structured and rigorous, addressing the impacts on research and on key stakeholders (Rhodes *et al.,* 2002; Faulkner, 2004b; Minogue *et al.,* 2005; Fudge *et al.,* 2008; Caldon *et al.,* 2010; Williamson *et al.,* 2010; Elberse *et al.,* 2010; Lindenmeyer *et al.,* 2007). Detailed accounts of the process of service user involvement however remain limited and there is more to learn. This paper reports a prospective, reflective, exploratory case study that was carried out to evaluate service user researcher involvement in a wider study to develop principles of successful service user involvement in research.

Method

The objective of this evaluation was to explore and reflect on the process and outcome of service user involvement on a wider study. This was undertaken by identifying the views of two service user researchers who were members of the advisory group, and those of three researchers at regular intervals during the progress of the wider study. The wider study was undertaken to develop principles and indicators of successful service user involvement in research (Telford *et al.,* 2004; Boote *et al.,* 2006), which were then tested out in a national survey (Barber *et al.,* 2007). Consensus methods (Jones and Hunter; 1995) were used in the wider study; an Expert Workshop followed by a Delphi process. The Expert Workshop was conducted using the nominal group technique, a controlled small group process for generating ideas. The Delphi process is a structured interactive method for exploring agreement among a group of experts using a series of questionnaires, interspersed by controlled feedback. The aim of consensus methods is to explore the level of agreement where there is a limited evidence base. The service user researchers participated in the Expert Workshop and agreed to advise the research team on the subsequent Delphi process. They also agreed to participate in a qualitative evaluation of service user involvement in the wider study. Reflective discussions were held after three advisory group meetings, with a fourth meeting held at the end of the project. The discussions were facilitated by a member of the research team. A protocol and topic guide were jointly developed and refined (available on request from the first author). The meetings were recorded and transcribed, with transcripts sent to all participants to check for accuracy. All transcripts were analysed by the principal investigator using an interpretative analysis approach (Seale, 2004), based on open coding and categorisation (Strauss and Corbin; 2004) of the data. Categories within and between transcripts were compared, looking for similarities and differences, using the constant comparative method**.** Agreement was reached among the researchers and service user researchers about the main themes that emerged. The decision for the analysis to be conducted by the principal investigator was based on pragmatic reasons concerning the time commitments of the other researchers and service user researchers.

There are many definitions of ‘public’ and ‘public involvement’ (Hanley *et al.,* 2004; Beresford, 2010), with terms used interchangeably, and often interpreted in different ways. We are using the term ‘service user’ in this paper to reflect the type of involvement that has its roots in survivor research and emancipatory research. We acknowledge that there are many types of involvement, including, for instance, voluntary organisations acting on behalf of service users. The theoretical model that was brought to this study by the service user researchers was that of emancipatory research (Beresford, 1990; 2005; Beresford and Evans, 1999). This approach was initiated by the disabled people’s movement and can be characterised by a number of themes: more equal social relations in research production between researchers and participants; commitment to the empowerment of disabled people; adoption of a social model of disability; and a wider aspiration for broader social and political change (Turner and Beresford; 2005). We received a favourable ethical opinion from the North Trent Research Ethics Committee.

Results

Four main themes emerged from the analysis of the transcribed discussions of the reflective meetings: trust and commitment, impact on the wider study, mutual learning, and timing of service user involvement. All of the following quotes are from the final meeting, reflecting issues raised in earlier discussions. It is likely that the longer length of this meeting allowed more time for deeper reflection.

Trust and commitment

At the start of the first reflective meeting, one of the service user researchers suggested ground rules: be courteous, try to say what you feel at the time, build trust, try not to be defensive and respect confidentiality. There was unanimous agreement to adopt the ground rules and it was likely that this, combined with planned regular reflective meetings, contributed to a high level of trust:

> *Trust and commitment. I meant by commitment the sense that there was a commitment to this way of doing things on a genuine basis. And my feeling is to be truthful that if you can begin to have a sense of trust and if you can have some feel that there is a commitment it will be OK. Service user researcher i*

During the evaluation, the research team tried to accommodate the requests of the service user researchers; for instance, by meeting in their preferred locations and arranging a group meeting rather than a telephone conference. The importance of being listened to was also noted:

> *I have felt a genuine sense of being listened to and a sense of trust and respect which I think has been very good. Service user researcher ii*

The issue of trust was a recurring theme, mentioned here in relation to a discussion about tokenism:

> *There's always been a lot of trust at the beginning and that was important for me…. I think that this is a big issue because if service user involvement seems imposed on people, on service users as well as researchers, you're not going to have that trust. So even though we can come up with principles and we can come up with recommendations, they are only really relevant where there is trust. Researcher iii*

Impact on the wider study

It is likely that the good working relationships that emerged made it easier for the service user researchers to offer advice to the research team, and for the recommendations to be accepted:

> *I felt we were able to offer useful input which was obviously being received. Service user researcher i*

The service user researchers influenced the decision about the level of consensus adopted in the Delphi process, interpreted the findings at different stages of the study, and highlighted connections with previous and current research. They commented on particular styles of interaction during some of the meetings, describing how certain types of behaviour could be excluding. They also placed the work within current health and social care policy contexts, epistemologies and conceptual models. The researchers believed that service user involvement led to the wider study being more grounded:

> *If [service user researchers] were not involved I don't think the study would have been as grounded and as readily usable to other service users.… When we've been developing these principles, you made us think, "well, what's it all about? What's the meaning? What's the implications of these principles?" which I think is very, very crucial because they are not just glib guidelines. They have implications and you've actually made us think through very carefully what the results actually mean to stakeholders in the whole [field of] user involvement. Researcher ii*

Throughout the wider study, the service user researchers offered suggestions to improve the clarity of the research documents to increase the accessibility to a wider range of potential participants. During the development of the Delphi questionnaires, they made suggestions about how participants bringing the perspective of 'service users' could be categorised. They recommended some changes to the wording of the questionnaires and to the indicators of the principles.

> *It's made us think through very carefully, to make our work improve in terms of clarity because ... we've got to be able to think through what we actually mean all the time, and it's made the research very genuine.... for example, explain what the Delphi means, and explain very clearly all the way through, so the research is very transparent and very open in terms of we're not trying to hide behind methodology. We're not hiding behind statistics. It's all very very open and very honest, which is really positive. Researcher ii*

In addition, members of the research team learned more about disseminating the findings in an accessible manner, by observing the service user researchers give clear presentations to a wide audience that included people with physical and learning difficulties.

Mutual learning

The service user researchers were invited to be part of the advisory group because of their substantial knowledge and experience of survivor/service user involvement in research. As leaders in their field, the research team were aware of their work through their papers, publications and conference presentations, and anticipated that their contribution would enhance the wider study. At the time, the researchers had limited experience of service user involvement in research, but had acquired knowledge through familiarisation with the literature and by attending conferences. Discussions at the reflective meetings were wide ranging, reflecting the broad scope of the wider study to develop principles of successful service user involvement in research. The topics discussed included the meaning of service user involvement, ethical matters, terminology, and issues about power and tokenism, and the service user researchers provided illustrative examples from previous studies. This was particularly illuminating when discussing possible underlying issues concerning tensions and barriers between researchers and service users:

> *Roles and responsibilities are terribly important …. If you come into it [service user involvement] as a service user primarily and not a researcher at all, then you've got to feel secure about your position in the project …. It's peoples' lives you know. This is work-life for some people. It's life-life for other people you know. It's like some people come into this [service user involvement] because they want to change the services, they want to change things for others, not for themselves, and it's personally terribly important. It's not just a job. You know, and that's where some of the conflicts come from. Service user Researcher ii*

The service user researchers also suggested conferences and other opportunities for the research team to increase and deepen their knowledge of service user involvement:

> *You linked us into wider networks, informed us of the wider world. We would otherwise I think have been focusing in quite a narrow way. Researcher i*

The reflective sessions provided an opportunity for the researchers to become aware of the extent of the influence of the service user researchers, and one researcher noted the value of contributions from the service user researchers in relation to quantitative aspects of the Delphi process:

> *So I think one thing that it's taught me is that even quite a quantitative methodology can be influenced by service users. Researcher iii*

Although the service user researchers had extensive research knowledge and experience, they were not familiar with the Delphi methodology, which had also been a new research method for the research team. They welcomed the opportunity to learn more about it:

> *I felt I'd learnt something, quite a lot, I learnt about the method that was being used which was something I hadn't come across before…. It's given me an extra sort of area of knowledge, you know, that I could possibly use in the future. Service user researcher ii*

Timing of service user involvement

There were suggestions that the study might have benefited from early joint learning and including service user researchers as research team members:

> *But what I would have liked to have done, I think, is started working together much earlier on in the process, but also have some joint training in the Delphi methodology ... because you two [service user researchers] joined us a bit later down the line it seemed we knew what we were talking about when we'd only learnt about it 2 weeks before…. If you had come in earlier …. we could have done the design slightly differently so that we could actually use your potential more, you know, you could influence the design even more … I think that even with something as rigid as the Delphi methodology I think service users' and different perspectives are very important. And even though you were able to influence that, I think that if we would had been able to work as a team all the time at every single stage, you would have been able to influence it even more. Researcher iii*

The importance of involving the service user researchers at an early stage of the wider study was also linked to the potential for the research to be more accessible:

> *And the other thing we could have done better is involve you right at the beginning.... Perhaps we could have done a multi-methods study, a Delphi with other things, because the Delphi is quite a complex document and people might have been excluded from this study. Researcher ii*

Discussion

This prospective evaluation of service user involvement within a wider study suggests that there is much to be gained from planned reflective discussions of the processes and outcomes of service user involvement in research. The four main themes that emerged (of trust and commitment, impact on the wider study, mutual learning and the timing of service user involvement) highlighted the importance of subjective relationships and clarified the impact that the service user researchers had on research processes and outcomes. It is likely that the theme of trust and commitment that emerged was itself strengthened by having the opportunity for honest reflection. The reflective sessions therefore not only provided a structure for themes to emerge, but also appeared to offer opportunities for specific outcomes, such as the development of trust. A topic guide, jointly agreed and refined by both the researchers and service user researchers, was used to prompt discussions that captured details of the impact of service user researcher involvement that might otherwise have been lost. A more formal approach to reflection has recently been described by Morrow *et al.* (2010), who suggested the potential learning from using a structure for deliberation about experiences of researchers and service users working together. The authors developed a Quality Involvement Framework and also a questionnaire to enable researchers and service users to reflect and understand more about the processes that can influence the quality of involvement. The questionnaire addresses issues about research relationships, ways of doing research and research structures, and the authors suggest that the questions can be used flexibly to prompt discussion or individual reflection.

The issue of trust that emerged between researchers and service user researchers in this evaluation was highly valued. Trust appeared to underpin the positive working relationships that developed, which in turn enhanced the beneficial impact of service user researcher involvement on research processes and outputs. Other authors have commented on the importance of trust in the context of involvement. Caldon *et al.*, (2010, p. 548) observed how early negotiations in a study provided a means of engendering ‘mutual respect, trust and confidence in each others’ skills’, and also ensured better communication. Sometimes trust followed initial scepticism. McCormick *et al.* (2004) described how women affected by cancer developed trust with the scientists they worked with on research boards through their collaborative work. They had previously expressed fear and anxiety in relation to the scientists, who in turn were said to have held some preconceptions about ‘hysterical women’ with breast cancer.

The impact of the service user researchers on the wider study was considerable, and included the research design, interpretation of the findings and the dissemination strategy. This reflected the substantial knowledge and experience of the service user researchers, not only of research, but also of service user involvement in research. This level of expertise is not typical; however other studies have reported similar positive service user impacts on these research outputs and processes (Staley, 2009). Morrow *et al.* (2010) highlighted the need to understand more about the processes and outcomes of service user involvement in research. The reflective discussions, as set out in this paper, provided an opportunity for the service user researchers to raise many issues about subjective and interpersonal aspects of service user involvement that can influence the quality of service user involvement and might otherwise have been overlooked. In particular, they recommended how the wider study could be made more accessible to others, and commented on interpersonal dynamics that could be excluding.

One of the themes that emerged from this evaluation of service user involvement in a wider study concerned mutual learning, with the researchers developing a deeper knowledge and experience of service user researcher involvement in research and the service user researchers discovering more about the Delphi process and associated quantitative analyses. Learning has been reported as a positive outcome of service user involvement in previous studies (Minogue *et al.*, 2005; Wyatt *et al.*, 2008). Andejeski *et al.* (2002a,b) described a peer reviewing process with lay reviewers who had survived cancer, and observed that this allowed the scientists to learn about the concerns of breast cancer survivors first hand. In the evaluation reported in the present study, it was particularly helpful for the researchers to understand how tensions between researchers and service users could arise, particularly in relation to issues about exclusion of service users, and to learn how these could cause distress and impede productive ways of working. The service user researchers commented on working practices in the wider study and also drew on their experiences to give examples of good practice and suggested ways in which unhelpful ways of working could be improved. Although there is little in the literature to guide us, recent case studies have provided insights into the interplay of organisational and personal issues which can influence or modify the impact of service user involvement (Rhodes *et al.*, 2002; Barnard *et al.*, 2005; Minogue *et al.*, 2005; Bryant and Beckett, 2006; Staniszewska *et al.*, 2007; Fudge *et al.*, 2008; Baart and Abma, 2010; Williamson *et al.*, 2010). Williamson *et al.* (2010) noted that team building exercises resolved some unhelpful group dynamics that had arisen within a research team. Elberse et al. (2010) concluded that involving service users in research is not in itself an automatic guarantee that their knowledge and perspectives will be included in decision-making processes. Using a case study, the authors described how exclusion mechanisms (such as leaving certain people out or allowing less time for particular people to speak) and inclusion strategies (for example, the lack of titles on name badges and the use of clear and informal language) can influence the process and outcomes of a dialogue meeting between researchers and service users. These findings resonate with examples of inclusion and exclusion of service users given by the service user researchers who were involved in the wider study.

Not surprisingly, the impact of service user involvement is said to be greater if service users are involved at all stages of research projects, and preferably at the beginning (Minogue *et al.*, 2005; Staley, 2009). Faulkner (2006) suggested that early involvement can lead to greater commitment and ownership of the research. It was clear from the evaluation of service user researcher involvement in a wider study that the service user researchers had a considerable impact. Had they been involved at the earliest stage, they would have had more opportunity to influence the design and methods, and this may have improved the accessibility of the wider study, thus enhancing the quality of the research.

Conclusion

This prospective evaluation of service user involvement in a wider study highlighted the benefits of repeated joint reflective sessions. The sessions facilitated the development of trust and commitment as well as providing an opportunity to capture details of the impact of service user researcher involvement that might otherwise have been lost. The structure also offered a forum for mutual learning and the sharing of knowledge. Deliberations at the reflective meetings focussed on the processes and outcomes of research, as well as on interpersonal and subjective processes; issues which can have profound effects on productive working relationships between researchers and service users, but are rarely addressed. We suggest that exploration of the process, as well as the outcome, of service user involvement is essential to understanding how, when and why service user involvement works, and that reflective sessions can offer a valuable means of achieving this.

Acknowledgements

We should like to thank the NHS Executive Trent for funding this study. We are indebted to all members of the Advisory Group and to the participants of the study.

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Pre-publication copy of Publication 5

Barber R, Boote J, Parry G, Cooper C, Yeeles P, Cook S. Can the impact of public involvement on research be evaluated? A mixed methods study. *Health Expectations,* 2011b; 15: 229-241.

Authors:

Rosemary Telford, BA MSc MAppSci, Consultant Clinical Psychologist, Sheffield Care Trust; Honorary Senior Research Fellow, School of Health and Related Research, University of Sheffield.

Jonathan D Boote, MA (Cantab) MSc, PhD, Research Fellow, NIHR Research Design Service for Yorkshire and the Humber.

Glenys D Parry, BA DipClinPsych PhD, Professor of Applied Psychological Therapies, Centre for Psychological Services Research, University of Sheffield.

Cindy L Cooper, BSc PhD, Director of Clinical Trials Research Unit/Senior Research Fellow, School of Health and Related Research, University of Sheffield.

Philippa Yeeles, BA DipSW MSc, Deputy Director INVOLVE, Eastleigh, Hampshire.

Sarah Cook, Dip COT M Ed PhD, Reader in Occupational Therapy, Centre for Health and Social Care Research, Sheffield Hallam University.

ABSTRACT

Background Public involvement is central to health and social research policies, yet few systematic evaluations of its impact have been carried out, raising questions about the feasibility of evaluating the impact of public involvement.

Objective To investigate whether it is feasible to evaluate the impact of public involvement on health and social research.

Design Mixed methods including a two-round Delphi study with pre-specified 80% consensus criterion, with follow up interviews. UK and international panellists came from different settings, including universities, health and social care institutions and charitable organisations. They comprised researchers, members of the public, research managers, commissioners and policy makers, self-selected as having knowledge and/or experience of public involvement in health and/or social research; 124 completed both rounds of the Delphi process. A purposive sample of 14 panellists was interviewed.

Results Consensus was reached that it is feasible to evaluate the impact of public involvement on 5 of 16 impact issues: identifying and prioritising research topics, disseminating research findings and on key stakeholders. Qualitative analysis revealed the complexities of evaluating a process that is subjective and socially constructed. While many panellists believed that it is morally right to involve the public in research, they also considered that it is appropriate to evaluate the impact of public involvement.

Conclusions This study found consensus among panellists that it is feasible to evaluate the impact of public involvement on some research processes, outcomes and on key stakeholders. The value of public involvement and the importance of evaluating its impact were endorsed.

INTRODUCTION

Public involvement is firmly established in health and social research policies in the UK and internationally [National Institutes of Health Director's Council of Public Representatives (http://copr.nih.gov/); Consumers' Health Forum of Australia (http://www.chf.org.au/)] [1]. It is said to be of intrinsic value, reflecting democratic aspirations of accountability and transparency [2]. Public perspectives can complement those of researchers [3], raising awareness of health, social and ethical issues that reflect wider community values [4-6]. Has public involvement made a difference to research processes, outcomes, and key stakeholders? Few impact studies have been carried out, but there is an increasing number of reports showing the potential for public involvement to enhance the quality of research, to make it more relevant to those who use services [7-15], and to improve the evidence-practice gap [16].

Given the growing importance of public involvement policies [17] and associated requirements for researchers to comply [18], the dearth of supporting evidence is striking. Possible reasons for this include: public involvement is perceived to be relatively recent, as a concept and practice in research [19]; evaluating the impact is seen as too difficult and public involvement is considered to be of intrinsic value and therefore does not require evaluation [20]. This study explored the last two of these potential explanations, acknowledging that public involvement can have different types of impact and that some impacts are likely to be more amenable to evaluation than others. We sought to establish whether consensus could be reached that it is feasible to evaluate the impact of public involvement on research processes, outcomes and on key stakeholders in the research process, anticipating that this would help to clarify theoretical and practical issues that could guide future impact studies.

METHODS

We used the INVOLVE definition of public involvement [INVOLVE (http://www.invo.org.uk)]: “Many people define public involvement in research as doing research ‘with’ or ‘by’ the public, rather than ‘to’, ‘about’ or ‘for’ the public.” We used the term ‘public’ to include patients, users of health and social services, informal carers and organisations representing people who use services. Public involvement in this study was provided by one author offering a public perspective and another providing a perspective from working in the field of public involvement in research. We received a favourable ethical opinion from the North Trent Research Ethics Committee.

A sequential mixed methods design was chosen [21]with three stages: (1) an Expert Workshop of researchers and the public [22] that generated issues concerning the feasibility of evaluating the impact of public involvement; (2) a two-round Delphi process [23] to investigate whether or not there was consensus on these issues and (3) telephone follow-up interviews of a purposive sample of Delphi panellists to explore their responses to the Delphi process in more depth and to seek their views on the implications of the findings. This paper focuses on the Delphi process and interviews. The Delphi rounds took place between November 2007 and April 2008, and the interviews were undertaken between June and October 2008.

Delphi process and follow up interviews

The Delphi process is a structured interactive method for exploring consensus among a group of experts through a series of questionnaires, interspersed by controlled feedback. This method has been used in health and social care research when there is a limited evidence base [23-27]. Typically, a panel of experts from a geographically dispersed population completes two or more rounds of email or postal questionnaires, with the aim of clarifying issues of uncertainty. No particular size of panel is recommended, and sample sizes of four ranging up to 3,000 have been reported [26]. The composition of the panel and how ‘experts’ are defined is important and will depend on the aims of the Delphi process being undertaken [23,28].

In this study, the intention was to recruit a diverse Delphi panel of: (1) members of the public, (2) researchers and (3) ‘others’ (research managers, commissioners, policy makers and analysts). We aimed to attain a range of perspectives from international as well as UK panellists. Our criterion for being an expert was to have knowledge and/or experience of public involvement in health and/or social research (self-defined).

Recruitment to the Delphi panel and follow up interviews

A purposive sampling strategy was used to recruit the Delphi panel, by sending invitations to:

- People who had published in the area of public involvement in research.
- Directors, Chief Executives and Heads of major health and social organisations with policies on public involvement in research.
- Directors, Chief Executives and Heads of major health and social charities advocating public involvement in research.

- Public involvement advocates.
- Public involvement health and social care leads.
- UK research managers and commissioners.

We also used ‘snowballing’ techniques, inviting individuals and people from different organisations to contact others who might meet our inclusion criteria. We do not know how many people forwarded our invitation, but estimate that approximately 395 invitations were sent. As this was a Delphi process, our aim was not to recruit a representative sample, but a diverse panel of experts. We stopped recruiting when we had achieved this. People decided themselves whether they had knowledge and/or experience of public involvement in health and/or social research, and were offered the INVOLVE definition for guidance.

Panellists were asked to select the perspectives that they would be providing in the Delphi process from six categories: (1) member of the public (with the INVOLVE definition provided); (2) researcher; (3) research manager; (4) research commissioner or funder; (5) policy maker or analyst; (6) another or multiple perspectives (e.g. a researcher who is also a member of the public through being a carer).

Those who provided the perspective of a member of the public were asked to indicate the group(s) that best described them from five categories: (1) patient or long-term user of services; (2) informal (i.e. unpaid) carer; (3) advocate/activist/representative of members of the public; (4) employee of an organisation for members of the public (e.g. a charity); (5) member of an organisation of members of the public (where the organisation is managed by more than 50% of people with that experience or health condition).

We invited a purposive sample of seventeen panellists to take part in follow-up interviews, to explore their responses to the Delphi questionnaires in more detail and to seek their views on the implications of the findings. The panellists were selected by their contributions to the Delphi questionnaires, where their responses appeared to add substantially to the debate. We also took into account the need to reflect the diversity of perspectives in the panel, the different research topics and methods that panellists reported themselves engaged in. Consent was sought to tape-record all interviews that were transcribed verbatim. The transcripts were returned to the interviewees to check for accuracy.

Impact issues

At Round 1, panellists were invited to rate the feasibility of evaluating impacts of public involvement on research processes, outcomes and on stakeholders, using nine-point scales anchored by “not feasible” and “very feasible” (see Table 1). We defined ‘feasible’ as ‘can it be done’? There is no agreed level of consensus to employ, and published Delphi studies have used 51%, 70%, 80% and 85% [28,29]. The level of consensus in this study was set in advance at 80% or over, consistent with that of the earlier Expert Workshop [22], and with the aim of achieving robust findings. Sixteen impact issues were developed by the research team from outcomes generated at the Expert Workshop and from their detailed knowledge of the literature. Impact issues were sub-divided into three groups: (1) research processes, n=8; (2) research outcomes, n=6; and (3) key stakeholders, n=2 (see Table 1). At Round 2, panellists were asked to re-rate those impact issues where consensus was not achieved at Round 1. One reminder was used for both Rounds. Text boxes were provided for panellists to comment on Round 1 and 2 questionnaires.

Value statement

Public involvement is strongly associated with moral and ethical issues, public accountability and transparency, encapsulated in the World Health Organisation’s Alma-Ata: “the people have the right and duty to participate individually and collectively in the planning and implementation of their health care” [30]. Therefore Delphi panellists were asked at Round 1 whether they agreed or not with the following statement: *I believe that public involvement in health and social research is of ethical and moral value in itself, regardless of its impact on research.* Consensus was not sought on this, and the question was not repeated in Round 2. It was included as we wished to explore whether or not the pattern of responses to this statement would be associated with patterns of responses to the impact issues included in the Delphi questionnaires.

Analysis

Quantitative analysis

Data from the Round 1 questionnaires were summarised and the following conveyed to panellists at Round 2: (1) the median rating of each impact issue; (2) distribution data relating to each scale point on each scale and (3) whether or not consensus was achieved. A sub-group analysis (Mann-Whitney U and Kruskall-Wallis tests) was undertaken to explore differences between the ratings of three groups of panellists: members of the public, researchers and ‘others’.

Qualitative analysis

Qualitative analysis of responses in the text boxes of both Delphi questionnaires and the follow-up interviews allowed exploration of the quantitative findings. The data were analysed separately by two researchers (RB and JB). Codes and categories were refined collaboratively using an interpretative analysis approach [31], based on open coding and categorisation [32,33] during the examination of the data. Categories within and between the data were compared, looking for similarities and differences, using the constant comparative method**.** Any contradictions between the main themes identified by the two analysts were considered informative and enlightening and were used in the interpretation of the findings. Other team members and the advisory panel participated in discussions about the qualitative analysis and interpretation of the findings at key stages.

RESULTS

Participants

Delphi panellists

> Using our sampling strategy, approximately 395 invitations were sent, and 175 people agreed to take part. Reasons for non-response/non-participation included: incorrect email or postal address; potential panellists on study/maternity/sick leave; changed job or role; pressure of work or family circumstances; not being funded to take part; and not meeting the inclusion criterion. The 175 people who agreed to take part included people who were

unsure if they met the criterion and chose to see the questionnaire before deciding to participate. Of these, 145 returned their Round 1 questionnaire, giving an attrition rate of 17%. We received 124 completed Round 2 questionnaires, yielding an attrition rate of 14%. Of the 124 panellists completing both Rounds, 50 were members of the public (including patients/service users, patient/service user researchers, advocates, carers, members of charities and those with 'multiple perspectives'), 37 were researchers and 36 were 'others' (research commissioners, managers, policy makers and analysts). One person was not classified. There were 108 participants from the UK and 16 from other countries. The types of research most frequently engaged in were: service delivery (n=83), public health/preventive health (n=45), clinical trials (n=43) and health technology assessment (n=31). The research topics that panel members had most experience of were: mental health (n=30), cancer (n=27), public involvement in research (n=12) and older people (n=10). Panellists were able to provide more than one category for 'types of research' and 'research topics'.

Telephone interviewees

Seventeen Delphi panellists were invited to be interviewed. Three declined; one because of health reasons and two were too busy. Of the 14 interviewees, 12 were from the UK, one was from Australia and another from the US. Nine of the interviewees were researchers (of whom one was a user of multiple services and the other brought multiple perspectives); two were policymakers or policy analysts (of whom one brought the perspective of a carer); two brought multiple perspectives and one described themself as a member of the public.

The types of research interviewees were most frequently engaged in were service delivery (n=4), clinical trials (n=3), social care research (n=3) and basic science (n=2). The research topics that interviewees had most experience of were: public involvement in research (n=6) and cancer (n=3). In the quotes below, 'q' refers to quotes from the Delphi questionnaires, while 'i' refers to quotes from the interviews.

Qualitative findings

The results are presented in an integrated manner that reflects the mixed methods approach. The qualitative findings helped to clarify and elaborate the quantitative results (see Tables 1 and 2), and also revealed additional information.

Perceived importance of evaluating the impact of public involvement

Many panellists highlighted the importance of evaluating the impact of public involvement, whilst acknowledging the complexity of the process:

> *'Well, I think at the moment it is actually very important because, you know, clearly there is this confusion as to whether the public do actually make an important contribution and we need, we need whatever evidence is available'. (35i Person with multiple perspectives)*

> *'We do need to develop knowledge on user involvement but we don't need to necessarily say whether it's a good or a bad thing. We need to explore what's good about it and what's bad about it in different contexts. It can't possibly be a wholly positive or negative thing, we need to be more critical than that and really look at different research contexts and different people in different research contexts as well.' (81i Researcher)*

The impetus for evaluation appeared to be linked to accountability: 'In short, I think you can't do, sort of, science that's funded by national government without some accountability to the public purse.' *(26i Researcher).*

Impact issues that were considered feasible to evaluate

As Table 1 shows, consensus was reached among panellists that it is feasible to evaluate the impact of public involvement on five of the sixteen impact issues. They are presented below with illustrative quotes:

- Identifying topics to be researched

> *'This question seems to be about asking new questions, which public engagement is very good at. My guess would be that researchers would be reasonably good at tracking where these new questions have come from.' (28q Policy maker)*

- Prioritising topics to be researched

> *'This is highly feasible and should be a regular part of the process for identifying research strategy.' (31q Member of the public)*

- Disseminating research

> *'One could evaluate levels of understanding and awareness based upon the involvement, or non-involvement, of the public in the dissemination of research.' (37q Research commissioner)*

- Members of the public involved in the research

> *'Satisfaction, understanding, capacity, confidence etc could all reasonably be evaluated.' (10q Multiple perspectives)*

- Members of the research team.

> *'I think it would be best done longitudinally in order to capture the changing nature of impact, rather than as interviews/questionnaires conducted at set times.' (63q Researcher)*

A subgroup analysis of ratings of the impact factors was carried out, with the panel divided into three groups: members of the public, researchers and others (see Table 2). Of the five impact issues where significant differences were found, two related to impact issues that were considered feasible to evaluate: identifying and prioritising topics to be researched. In each case, significant differences were found between the ratings of members of the public and others, with the public rating the impact as more feasible to evaluate than others.

Impact issues not considered feasible to evaluate and wider issues

Eleven out of sixteen impact issues were not considered feasible to evaluate (see Table 1), and it is interesting to consider the comments made on some of these, particularly when they also refer to wider aspects of public involvement. The quote below, about commissioning research, draws attention to the high costs of evaluation, which emerged as a recurring theme:

> *'I don't think an evaluation is impossible, it is just that it unlikely to be feasible within time and budgetary constraints. Such an evaluation will need comparisons, before and after, individual feedback from the commissioning body, close scrutiny of the commissioning process - I'm not convinced how feasible this may be, not matter how ideal it is.' (56i Researcher)*

Several panellists had reservations about public involvement in basic science, expressed here in relation to the feasibility of evaluating the impact of public involvement on research design:

> *'More difficult to be as confident this could be done overall as the scope for public involvement to have an impact on research design depends on the design itself and the area of investigation, e.g. harder for there to be scope to influence basic laboratory science than a patient survey for instance.' (49q Research Commissioner)*

However, the potential for the public to contribute to wider aspects of basic research, such as ethical issues, was acknowledged:

> *'Most people really do accept a division of labour. You know there are places where one's expertise just doesn't go… If you were looking at something like GM foods, you know, the actual kind of, the kind of biology of it, you know, its really, you don't want to ask the public about that because, you know, how would they know? But the politics of it, you would, right? You know, the values or the impact that, you know, GM foods have on food supply to the third world or, you know, those kind, those are the kind of things when I think the public involvement is crucial …' (26i Researcher)*

Ethical and moral issues

At Round 1, 109/145 (75.2%) panellists agreed (33/145, 22.8%) or strongly agreed (76/145, 52.4%) that public involvement is of intrinsic value. No associations were found between responses to the value statement and patterns of ratings on the impact issues. This data analysis (consisting of a series of non-parametric statistical tests) is available on request from the first author. Qualitative analysis revealed enthusiasm for public involvement in terms of it being of ethical and moral value, yet many participants asserted the need to evaluate the impact:

> *'There may be a moral imperative for public involvement in research in terms of citizenship, accountability, rights etc. but if it is not having an impact it is a pretty pointless waste of time. Involvement must be meaningful. There is no point in going through the motions because it is the right thing to do'. (89q Person with multiple perspectives)*

> *'Then why evaluate it? Why would one evaluate something that is just intrinsically, morally right and, I mean I think one should try and evaluate it because there are lots of people who don't think it's intrinsically right. And also, it's not quite just public involvement, it's what kind of public*

> *involvement when and how, I think one would want to evaluate the impact.' (4i Researcher)*

Quality issues

The question about the intrinsic value of public involvement prompted some to reflect on the quality that public involvement adds to research:

> *'I can equally well see arguments for and against that statement [value statement], depending on the nature of the research. However, I think its impact on research is the most important consideration and the fact that it is likely to improve the quality of the research is the strongest argument for advocating it.' (91q Researcher)*

Few panellists believed it was feasible to evaluate the impact of public involvement on the quality of research, and most drew attention to the problems in defining 'quality':

> *'Very very difficult – I expect a number of different definitions of quality would compete, for example value for money versus research relevant to service users' interests.' (65q Researcher)*

Some panellists proposed a discussion about what constitutes 'quality research' suggesting that it needed to be defined collectively. A small number offered suggestions:

> *'Unless public involvement is seen as an a priori indicator of research quality, the assessment of research quality usually depends on more generic factors (e.g. research methods and design; sufficient examples of data; evidence of validation/triangulation etc).' (103q Researcher)*

> *'Standard measures of the quality of research, e.g. impact rating of the journal in which published, citation indices, etc may play a role, but difficult to isolate the precise impact of PPI [patient and public involvement]'. (135q Member of the Public)*

Social constructions and subjective experiences

Some Delphi panellists cautioned against considering public involvement as a mechanistic, or procedural activity, rather than as a dynamic partnership and collaboration. This was clearly articulated by one panellist:

> *'We've begun to look at user involvement more about relationships and relationships in social contexts. To not necessarily think of user involvement as putting people into research situations but more to think about how professionals and members of the lay public interact with each other in different contexts. And I really think we really need to recognise that user*

> *involvement is both socially constructed but it's also subjectively experienced and I think that's the key to it really to think in those terms, that it is a social process that's linked to professional practice but it's also experienced subjectively. I don't think you can separate the two and that's probably why evaluation is quite difficult because to have a form of evaluation that encompasses those issues of social construction and subjective experience is very difficult.'* (81i Researcher)

DISCUSSION

There are compelling reasons for investigating the impact of public involvement: to identify best ways of involving the public meaningfully in different research activities; to explore the possibility of deleterious effects and to achieve value for money. While potential benefits have been acknowledged, costs have also been identified, such as additional time and funding, as well as potentially negative effects on the public [15]. This study endorsed the value of public involvement and the importance of evaluating the impact, yet few impact issues were considered feasible to evaluate. We consider some of the possible reasons for this in the following sections. A broad definition of 'feasible' was given to panellists: 'can it be done?' and different dimensions of feasibility were addressed in the panellists' responses, whether or not they believed that evaluation was feasible. These included: different methodological approaches; practical ways of how it could or could not be done; wider issues that might have some bearing on the complexity of the evaluation process (such as the research context, organisational issues and the attitudes of key stakeholders); and possible constraints such as costs.

The impact of public involvement on research processes, outcomes and on stakeholders

Consensus was reached by panellists on the feasibility of evaluating the impact of public involvement on identifying and prioritising research topics. This is consistent with reports that public involvement can lead to a wider range of identified and prioritised research topics that are more relevant to service users [Alzheimer's Society Quality Research in Dementia (http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1109) [3,9,12,34-37]. Some panellists referred to these studies in their responses to the questionnaires and in interviews. Consensus was also established on the feasibility of evaluating the impact of public involvement in disseminating research findings. There are accounts of a range of ways in which the public has been involved in dissemination activities; through newsletters, conferences and joint authorship [11,12,37-38].

The highest level of consensus related to the feasibility of evaluating the impact of public involvement on members of the public involved in research. This reflects accounts of positive benefits, such as increased self-confidence, knowledge of the topic area and learning new skills, including research skills [3,12-13,39-43], and also the possibility of negative impacts [4]. There is now more awareness of the need to anticipate and prepare for potentially negative effects, such as the emotional strain of hearing distressing accounts of illnesses and conditions similar to one's own, overwork and frustration at the limited opportunities to influence the direction of the research [13,39].

We know less about the effects of public involvement on researchers, an impact issue considered feasible to evaluate by panellists. Some evidence suggests that it can deepen understanding of patient issues [44-45], and prompt researchers to challenge their own beliefs and assumptions [3]. While this can be a positive experience [46], some researchers have expressed concerns about perceived threats to their professional skills and knowledge [47], and it is suggested that different research skills are needed by researchers who work collaboratively with members of the public [12].

Panellists did not consider that it was feasible to evaluate the impact of public involvement on many research processes and outcomes (see Table 1). Employing a mixed methods approach, that takes account of the qualitative findings, allows us to speculate on possible explanations for this. Many panellists referred to the sheer complexity of public involvement, with different conceptual frameworks, terminology and practice, making it difficult to generalise across research projects. Others highlighted the challenges of trying to track decisions made specifically as a result of public involvement within a deliberative process, while identifying what might have happened if public involvement had not been present. Difficulties in taking into account the wider research context, which may include political, organisational, structural and strategic constraints, were also mentioned. Some questioned the appropriateness of applying scientific enquiry to a social, collaborative partnership, where mutual learning takes place during personal interactions.

These reservations reflect the difficulties of assessing quality issues in research [48], and echo some of the findings from a recent comprehensive literature review of the impact of public involvement in research that also highlighted the gains from public involvement: “Some researchers have reflected on how to assess the impact of involvement and when and how best to involve the public in research. Their main conclusions have been that it is difficult to assess the impact of involvement or to predict where involvement would have the greatest impact”. [15]. Guidance on evaluating complex interventions [49] is a timely addition to methodological approaches to evaluating the impact of public involvement, but there are also recommendations that: “strengthening the evidence base may therefore not only be about finding the most robust and rigorous ways of assessing impact, but also about helping researchers and the public to find the most useful and consistent way of telling their stories” [15]. The finding that members of the public rated the feasibility of evaluating some impact issues higher than researchers and others, could reflect their experience of changes resulting from their influence, and/or being more confident that methods of capturing this could be identified. Another possibility is that researchers and others sought more rigorous evidence of impact: “The vast majority of the evidence of impact is based on the views of researchers and members of the public who have worked together on a research project. Most often these views have been obtained informally” [15].

Ethical and moral value of public involvement in research

The case for public involvement is often presented in terms of normative or substantive arguments [50], particularly in relation to basic science. ‘Normative’ arguments view public involvement as an end in itself, considering moral or political values such as fairness and justice, while substantive arguments consider the effects of the contribution of the public, for example in terms of quality and relevance. Many panellists viewed public involvement to be of intrinsic value, and this appears to reflect prevailing views about its value internationally [30]. Several panellists believed that this intrinsic value should not be considered independent of its impact, suggesting that support for public involvement is not unreserved, underlying the importance of evaluating its impact.

Limitations and strengths of this study

Apart from the lack of international panellists, we believe we achieved diversity of perspective in our panel. Eight out of the fourteen telephone interviewees were researchers, but half of these brought additional perspectives. The requirement for panellists to have expertise in public involvement could have pre-disposed the panel towards a favourable view of the feasibility of evaluating its impact. If this is the case, consensus about the limitations of evaluating the impact of public involvement can be viewed as a robust finding. Few panellists had experience of public involvement in basic research, but as this area is less well developed, it is unlikely that many types of pre-clinical research would be represented. Most research areas associated with public involvement were included. In a few instances, panellists articulated their beliefs about the impact of public involvement rather than their views about the feasibility of evaluating its impact.

The 16 impact issues were developed to help to clarify when and how it might be feasible to evaluate the impact of public involvement. We recognise the limitations of this simplistic approach, in view of the complex and dynamic nature of public involvement, which has been described as ‘relationships in social contexts’ [51]. In an assessment of the benefits of public involvement in diabetes research, it was suggested that ‘its impact on research stems from the continuing interaction between researchers and users, and the general ethos of learning from each other in an on-going process’ [44].

Implications of the study

Policies on public involvement in health and social research have been implemented widely, but we know little about the difference they have made. Most panellists agreed that there are ethical and moral reasons for public involvement, and there was consensus among the panellists that it is feasible to evaluate its impact on identifying and prioritising topics to be researched, disseminating research, and on members of the public and members of the research team. Although these have been suggested as feasible to evaluate, different stakeholders may have different priorities, and it is for others to decide whether or not these impact issues should be privileged as priorities for future evaluations.

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Acknowledgements

We are indebted to all who took part in the Delphi study, and list below Delphi panellists who completed both rounds of the Delphi process and agreed to be named: Ade Adebajo, Geoff Aitchison, Richard Baker, Angela Barnard, Di Barnes, Marian Barnes, Catherine Beverley, Arlene Blanchard, Ric Bowl, Louca-Mai Brady, Anke Bramesfeld, David Britt, Fiona Brooks, Louise Bryant, Brian Buckley, David Buglar, Amanda Burls, Ceri Butler, Sarah Carr, Edward Carter, Iain Chalmers, Helen Christensen, Graham Cockshutt, Nicola Coe, Karen Collins, Jo Cooke, Phil Cotterell, Angela Coulter, Donna Cox, Mike Crawford, David Crepaz-Keay, Sally Crossing, Sally Crowe, Jill Davies, Pam de Clive-Lowe, Simon Denegri, Mark Doel, Jim Elliott, Pam Enderby, Richard Errington, Christine Farrell, Pete Fleischmann, Lester Firkins, Julie Flynn, Leslie Forsyth, Olivia Freeman, Nina Fudge, Tony Gilbert, Afaf Girgis, Jon Glasby, Paul Godin, Joanna Goven, Tanya Graham, Gordon Grant, Laura Greene, Bec Hanley, Amanda Harris, Hilary Hearnshaw, Sandy Herron-Marx, Tony Hostick, David Howe, Gill Hubbard, Ron Jamieson, Zena Jones, Gavin Kendall, Alastair Kent, Sam Laubsch, Martin Lodemore, Elspeth Macdonald, Paul Mainwaring, Heather Maggs, Ron Marsh, Melanie Maxwell, Timothy Milewa, Helen Millar, Virginia Minogue, Annie Mitchell, Brigid Morris, Sara Morris, Gail Mountain, Janet Messer, Paola Mosconi, Shirley Nurock, Margaret O’Connor, Bie Nio Ong, Sue Palmer Hill, William Phillips, Susan Pickard, Vanessa Pinfold, Michael Preston-Shoot, Lynne Ramsay, Lesley Roberts, Diana Robinson, Iliana Rokkou, Panayiota Romios, Cath Roper, Diana Rose, Fiona Ross, Carla Saunders, John Sitzia, Elizabeth Smith, Sophie Staniszewska, Kristina Staley, Jane Stewart, Jack Stilgoe, Jackie Sturt, Graham Tanner, Diane Thompson, Graham Thornicroft, Hazel Thornton, Michael Turner, Christine Vial, Paul Ward, Tracey Williamson, Elaine Willis, James Wilsdon, Roger Wilson, Barbara Woodward-Carlton, David Wright, Til Wykes and Sally Young.

We are grateful to Sheffield Health and Social Research Consortium for funding this study.

Table 1 Panel ratings on the feasibility of evaluating the impact of public involvement on research processes, outcomes and stakeholders

Impact issue: ***How feasible do you think it would be to evaluate the impact of public involvement on…***[1]	**Percentage of Panel rating the impact issue between the 3 main tertiles**[2]			**Mean**	**Feasible to evaluate** **(defined as 80% or more of Panel providing a 7-9 rating)**
	1-3	**4-6**	**7-9**		
RESEARCH PROCESSES					
Identifying topics to be researched	1.6	24.5	**83.0**	7.39	**Yes**
Prioritising topics to be researched	1.6	12.0	**86.3**	7.54	**Yes**
Commissioning research	0.8	29.8	67.6	6.98	No
Research design	1.6	31.4	66.1	6.87	No
Managing research	4.0	52.4	42.7	6.19	No
Collecting data	2.4	26.6	69.3	6.95	No
Analysing research findings	5.6	50.0	42.7	6.16	No
Interpreting research findings	5.6	52.4	39.5	6.13	No
RESEARCH OUTCOMES					
Disseminating research	0.8	10.4	**87.9**	7.40	**Yes**
Determining the usefulness of research findings	4.0	33.1	60.5	6.55	No
Implementing research findings	8.9	47.7	42.7	6.02	No
The overall quality of public involvement in a research study or research-related activity	4.0	29.0	64.6	6.76	No
The overall quality of the research	8.9	49.9	37.9	5.85	No
The overall impact of the research	7.2	69.3	21.8	5.35	No
STAKEHOLDERS					
The member(s) of the public involved in the research	0.8	4.8	**91.9**	7.93	**Yes**
The member(s) of the research team	5.5	10.3	**81.4**	7.45	**Yes**

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[1] Impact issues where consensus was reached on feasibility are in bold

[2] Note that the percentages for each impact issue may not add up to 100% because some panel members may not have provided a rating. Tertile percentage figures where consensus was reached on feasibility (i.e. 80% or over) given in bold

Table 2: The feasibility of evaluating the impact of public involvement on research processes, outcomes and stakeholders: Kruskall-Wallis tests on panel subgroup mean ratings

Impact issue: ***How feasible do you think it would be to evaluate the impact of public involvement on…***[3]	**Subgroup mean ratings**			
	Public	**Researchers**	**Others**	***P***
Identifying topics to be researched	7.69	7.33	7.03	0.015[4]
Prioritising topics to be researched	7.77	7.51	7.25	0.007[5]
Commissioning research	7.21	7.05	6.57	0.065
Research design	7.13	6.73	6.63	0.181
Managing research	6.16	6.49	5.92	0.299
Collecting data	7.17	7.06	6.53	0.084
Analysing research findings	6.35	6.50	5.54	0.004[6]
Interpreting research findings	6.33	6.22	5.77	0.203
Disseminating research	7.49	7.35	7.31	0.242
Determining the usefulness of research findings	6.70	6.73	6.12	0.091
Implementing research findings	6.38	6.11	5.42	0.041[7]
The overall quality of public involvement in a research study or research-related activity	6.96	6.72	6.51	0.266
The overall quality of the research	6.47	5.76	5.17	0.000[8]
The overall impact of the research	5.61	5.41	4.97	0.370
The member(s) of the public involved in the research	8.02	7.92	7.83	0.613
The member(s) of the research team	7.35	7.51	7.36	0.679

---

[3] Impact issues where consensus was reached on feasibility are in bold

[4] significant difference between the ratings of members of the public and others (p=0.004; Mann-Whitney *U*-test)

[5] significant difference between the ratings of members of the public and others (p=0.002; Mann-Whitney *U*-test)

[6] significant difference between the ratings of: (1) researchers and others (p=0.004; Mann-Whitney *U*-test); (2) members of the public and others (p=0.003; Mann-Whitney *U*-test)

[7] significant difference between the ratings of members of the public and others (p=0.013; Mann-Whitney *U*-test)

[8] significant difference between the ratings of: (1) researchers and members of the public (p=0.015; Mann-Whitney *U*-test); (2) members of the public and others (p=0.000; Mann-Whitney *U*-test)

Pre-publication copy of Publication 6

Barber R, Boote J, Parry G, Cooper C, Yeeles P. Evaluating the impact of public involvement on research. In: Barnes M, Cotterell P (eds) *Critical Perspectives on User Involvement*. Bristol: Policy Press, 2012: 217-223.

Only 20% of this publication is reproduced here, in line with copyright regulations

Authors:

Rosemary Telford, BA MSc MAppSci, Consultant Clinical Psychologist, Sheffield Care Trust; Honorary Research Fellow, School of Health and Related Research, University of Sheffield.

Jonathan D Boote, MA (Cantab) MSc, PhD, Senior Research Officer, Clinical Effectiveness Directorate, Sheffield Care Trust; Honorary Research Fellow, School of Health and Related Research, University of Sheffield.

Glenys D Parry, BA, DipClinPsych, PhD, Centre for Psychological Services Research, University of Sheffield.

Cindy L Cooper, BSc (Hons) PhD, Senior Research Fellow, School of Health and Related Research, University of Sheffield.

Philippa Yeeles, BA, DipSW, MSc, INVOLVE, Eastleigh.

Introduction

There has been a substantial increase in public involvement in research both in the UK and internationally during the past decade (Caron-Flinterman et al, 2006; National Health and Medical Research Council, 2002; National Institutes of Health Director's Council of Public Representatives, 2010; UKCRC, 2011). The public is now involved in many different types of research activities in a variety of ways, including identifying and prioritising research topics, carrying out research, analysing data and interpreting and disseminating the findings (Hanley et al, 2003). Yet, surprisingly, there have been few attempts to assess the impact of public involvement in a systematic way (Staley, 2009), and there are limited theoretical models and frameworks to inform the development of impact measures (Boote et al, 2002; Oliver et al, 2004; Telford et al, 2004; Brett, 2010). This chapter suggests why it is important to investigate the impact of public involvement in health and social research, presents a brief overview of what we know already and highlights some of the challenges. We use the term ‘public’ to include patients, people who use health and social services, informal carers and organisations that represent people who use health and social services, and the INVOLVE (Hanley et al, 2003) definition of public involvement: ‘many people define public involvement in research as doing research “with” or “by” the public, rather than “to”, “about” or “for” the public’.

The value of public involvement in research is contested, with both substantive and normative arguments being made (see Purtell et al, Chapter Seventeen). Substantive arguments consider public involvement as a means to an end, for example in terms of its potential to improve the quality and relevance of the research. Normative arguments view public involvement as an end in itself; a democratic right, associated with public accountability and transparency, taking into account moral and political values such as fairness and justice (Caron-Flinterman et al, 2006)…

References

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Brett, J., Staniszewska, S., Monkford, C., Seers, K., Heron-Marx, S. and Bayliss, H. (2010) *The PIRICOM Study: A systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research*, London: UK Clinical Research Collaboration.

Caron-Flinterman, J. F., Broerse, J. E. W., Teerling, J., Van Alst, M. L. Y., Klaasen, S., Swart, L. E. and Bunders, J. F. G. (2006) ‘Stakeholder participation in health research agenda setting: the case of asthma and COPD research in the Netherlands', *Science and Public Policy*, vol 33, no 4, pp 291-304.

Hanley, B., Bradburn, J., Gorin, S., Barnes, M., Evans, C., Goodare, H., Kelson, M., Kent, A., Oliver, S. and Wallcraft, J. (2000) *Involving consumers in research and development in the NHS: Briefing notes for researchers*, Winchester: Consumers in NHS Research Support Unit, Help for Health Trust (second edition published 2003).

National Health and Medical Research Council (2002) *Statement on Consumer and Community Participation in Health and Medical Research.* Canberra, Australia: Commonwealth of Australia.

National Institutes of Health Director's Council of Public Representatives (2010) www.copr.nih.gov/About_COPR.SHTM

UK Clinical Research Collaboration (2011) *Patient and Public Involvement Strategic Plan 2008-2011,* London: UK Clinical Research Collaboration www.ukcrc.org/patientsandpublic/ppi/ppistratplan/

Oliver, S., Clarke-Jones, L., Rees, R., Milne, R., Buchanan, P., Gabbay, J., Gyte, G., Oakley, A. and Stein, K. (2004) 'Involving consumers in Research and Development agenda setting for the NHS: developing an evidence-based approach', *Health Technology Assessment Monographs*, vol 8, no 15, pp 1-148.

Purtell R., Rickard W. and Wyatt K. (2012) *Should we? Could we? Measuring involvement.* In: Barnes M, Cotterell P (Eds.) *Critical Perspectives on User Involvement.* (pp. 209-215). Bristol: Policy Press, 2012.

Staley, K. (2009) *Exploring impact: Public involvement in NHS, public health and social care research*, Eastleigh: INVOLVE.

Telford, R., Boote, J. and Cooper, C. (2004) 'What does it mean to involve consumers successfully in NHS research? A consensus study', *Health Expectations,* vol 7, no 3, pp 92-103.

APPENDIX 2: REQUESTS AND PERMISSIONS

Requests to publishers for permission to publish

The following request was made to the publishers of my included publications:

"I am a postgraduate research candidate at the University of Sheffield working towards my PhD by Publication thesis on: **Exploring the meaning and impact of public involvement in health research.**

I wish to include the following published material in my thesis, and am contacting you as the rights-holder:

[Full details of the included publication]

I wish to include this work as part of my submission for a PhD by Publication. I am also required to submit an electronic version of my thesis, which I am required to deposit in White Rose eTheses Online repository (http://etheses.whiterose.ac.uk/). The repository is non-commercial and openly available to all.

I would be grateful if you could advise if this will be acceptable.

With thanks and kind regards

Rosemary Barber (formerly Rosemary Telford)"

Responses to requests for permission to publish

All publishers gave their permission. The Policy press advised that only 20% of the included publication, a book chapter, could be published. The detailed responses are below:

Permission from the publishers to publish publication 1

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.

and publication 2

Barber R, Boote J D, Cooper C L. Involving consumers successfully in NHS research: a national survey. *Health Expectations,* 2007a; 10: 380-391.

and publication 5

Barber R, Boote J, Parry G, Cooper C, Yeeles P, Cook S. Can the impact of public involvement on research be evaluated? A mixed methods study. *Health Expectations,* 2011b; 15: 229-241.

On 7 March 2013 11:32, Permission Requests - UK <permissionsuk@wiley.com> wrote:

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Permission is granted for you to use the material requested for your thesis/dissertation subject to the usual acknowledgements and on the understanding that you will reapply for permission if you wish to distribute or publish your thesis/dissertation commercially.

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Permission from the publishers to publish publication 3

Telford R, Faulkner A. Learning about service user involvement in mental health research. *Journal of Mental Health,* 2004; 13: 549-559.

From: Copyright Clearance Center <rightslink@marketing.copyright.com>
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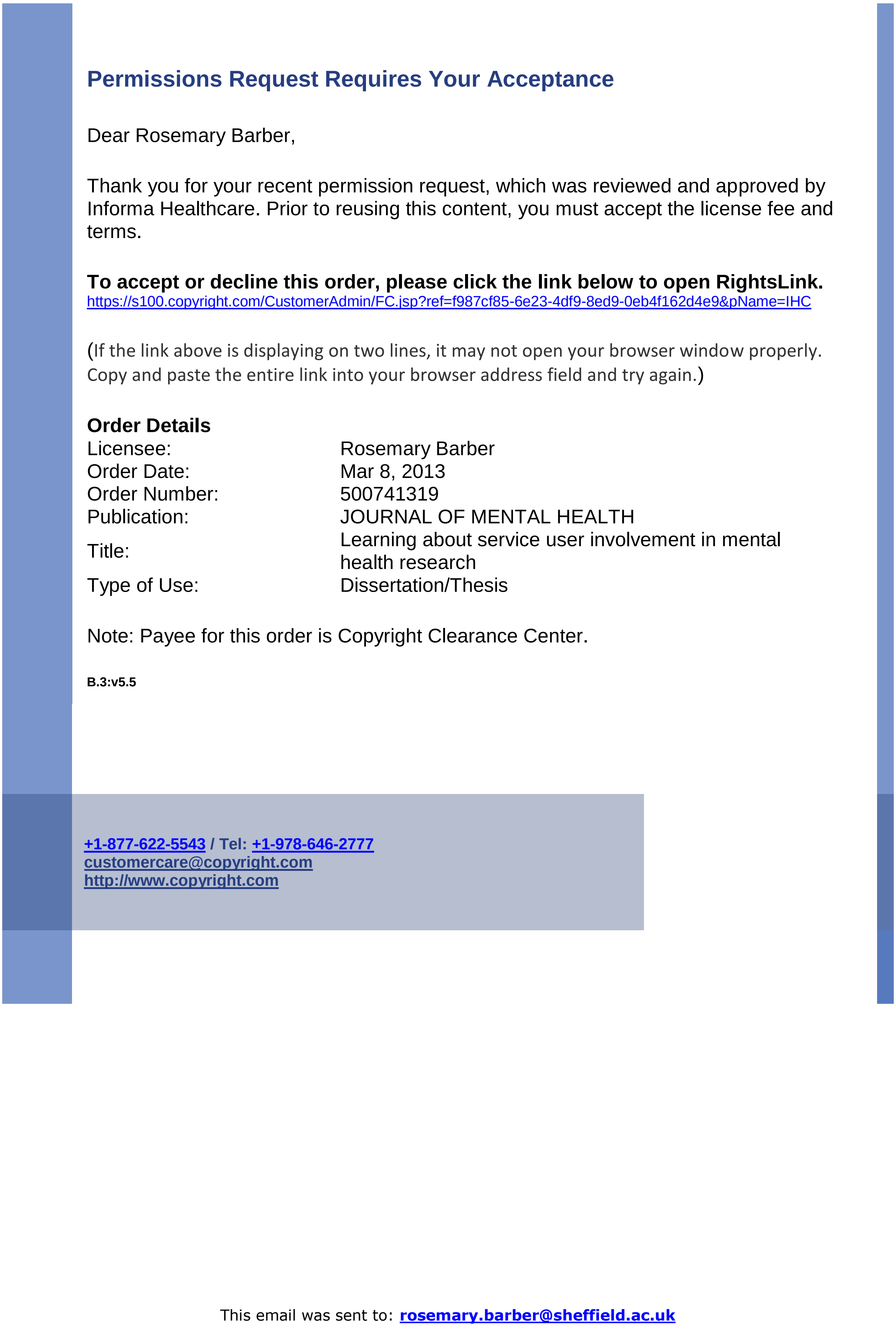

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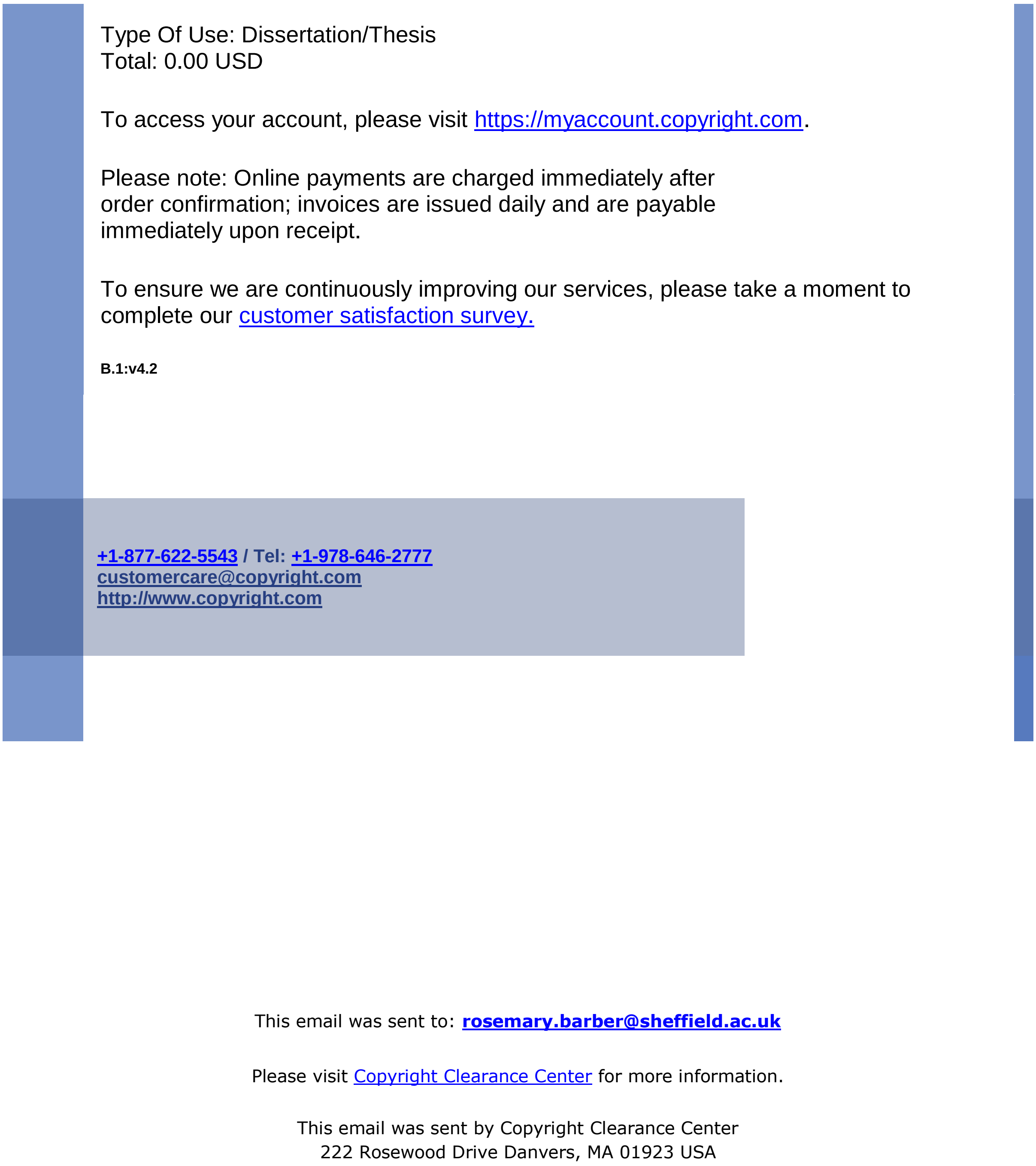

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Barber R, Boote J, Parry G, Cooper C, Yeeles P. *Evaluating the impact of public involvement on research*. In: Barnes M, Cotterell P (eds) *Critical Perspectives on User Involvement.* Bristol: Policy Press, 2012: 217-223.

From: Laura Vickers <laura.vickers@bristol.ac.uk>
Date: 4 March 2013 15:09
Subject: RE: Query re: Publishing a chapter from a book in a PhD by publication thesis
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary

Many thanks for your message below. Including this chapter in your PhD thesis is fine, we ask that you cite the full original source and seek permission from your co-authors. Regarding the depositing of the electronic thesis on an online repository please see our website for our policy on institutional repositories:
http://www.policypress.co.uk/info_archiving.asp?#monographs

If you have any further questions please do let me know.

All best wishes

Laura

Requests to co-authors for permission to publish, and agreement on the nature of my contribution to the included publications

The following requests were made to the co-authors of my included publications. Details of my requests for each publication and my co-authors' replies are below. All co-authors agreed to my requests.:

Publication 1

Permission from co-authors to publish, and agreement about the nature of my contribution to the publication

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.

Letter to co-authors:

"I am registered as a postgraduate research candidate at the University of Sheffield working towards my PhD by Publication thesis on: **Exploring the meaning and impact of public involvement in health research**. Regulations for the thesis require the inclusion of the following published material and, in addition to contacting the relevant journal, I am contacting you as co-author of:

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.

I wish to include this work as part of my submission for a PhD by Publication. I am also required to submit an electronic version of my thesis, which I am required to deposit in White Rose eTheses Online repository (http://etheses.whiterose.ac.uk/). The repository is non-commercial and openly available to all.

I would be grateful if you could advise if this will be acceptable to you, subject to the journal's agreement.

In addition I am required to provide an accurate summary of the nature of my contribution to this paper. I would be grateful if you would review the following for accuracy, making any alterations you feel necessary.

Contribution of the candidate:

As the principal investigator, I designed the study, wrote the research bid, applied for ethical approval, and conducted the research, all with assistance from my co-authors. I was responsible for taking all the important decisions in the study.

I took the lead in sorting, analysing, interpreting and making decisions about the information that resulted from the expert workshop. This data was used to guide the composition of the Delphi questionnaires. Whilst the final decisions about the wording of the principles and indicators within the Dephi questionnaires were mine, they were based on discussions with my co-authors and the Advisory Group. I pre-selected a consensus level of 85% for both the expert workshop and the Delphi process. I also selected the Delphi panellists.

My co-author Jonathan Boote conducted the Delphi statistical calculations. I led discussions on the interpretation of the findings, and the direction of further statistical analyses. I produced a first draft of the publication, to which my co-authors contributed revisions. All three authors approved the final draft.

Many thanks for your help

With best wishes

Rosemary"

Replies from co-authors

From: Jonathan D Boote <j.boote@sheffield.ac.uk>
Date: 9 April 2013 19:21
Subject: Re: PhD by publication - Permission from co-authors to publish
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary

I am happy as a co-author of this paper for you to include it in your PhD by publication. I am also happy with the description of your contribution to this work.

With best wishes
Jonathan

From: Cindy L Cooper <c.l.cooper@sheffield.ac.uk>
Date: 5 April 2013 16:49
Subject: Re: PhD by Publication - Permission from co-authors to publish
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Rosemary

Yes I'm happy for you to include the paper and can confirm that the summary of the nature of your contribution is accurate

Best wishes

Cindy

Publication 2

Permission from co-authors to publish, and agreement about the nature of my contribution to the publication

Barber R, Boote J D, Cooper C L. Involving consumers successfully in NHS research: a national survey. *Health Expectations,* 2007a; 10: 380-391.

Letter to co-authors:

"I am registered as a postgraduate research candidate at the University of Sheffield working towards my PhD by Publication thesis on: **Exploring the meaning and impact of public involvement in health research**. Regulations for the thesis require the inclusion of the following published material and, in addition to contacting the relevant journal, I am contacting you as co-author of:

Barber R, Boote J D, Cooper C L. Involving consumers successfully in NHS research: a national survey. *Health Expectations,* 2007; 10: 380-391.

I wish to include this work as part of my submission for a PhD by Publication. I am also required to submit an electronic version of my thesis, which I am required to deposit in White Rose eTheses Online repository (http://etheses.whiterose.ac.uk/). The repository is non-commercial and openly available to all.

I would be grateful if you could advise if this will be acceptable to you, subject to the journal's agreement.

In addition I am required to provide an accurate summary of the nature of my contribution to this paper. I would be grateful if you would review the following for accuracy, making any alterations you feel necessary.

Contribution of the candidate:

As the principal investigator, I designed the study, wrote the research bid, applied for ethical approval, and conducted the research, all with assistance from my co-authors. I was responsible for taking all the important decisions in the study.

I designed the large-scale postal survey of researchers that incorporated the consensus-derived indicators of successful public involvement in research. The quantitative analyses were carried out by my co-author Jonathan Boote, with further analyses conducted after my interpretations of the findings, and suggestions for additional calculations. This followed consultations with research team members and the Advisory Group.

The analysis of the qualitative data in the questionnaire was conducted by me and my co-author Jonathan Boote using the Framework approach (Ritchie & Spencer, 1994).

I produced a first draft of the publication, to which my co-authors contributed revisions. All three authors approved the final draft.

Many thanks for your help

With best wishes

Rosemary”

Replies from co-authors

From: Jonathan D Boote <j.boote@sheffield.ac.uk>
Date: 9 April 2013 19:21
Subject: Re: PhD by publication - permission from co-authors to publish publication 2
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary

I am happy as a co-author of this paper for you to include it in your PhD by publication. I am also happy with the description of your contribution to this work.

With best wishes
Jonathan

From: Cindy L Cooper <c.l.cooper@sheffield.ac.uk>
Date: 5 April 2013 17:03
Subject: Re: PhD by publication - permissions from co-authors to publish publication 2
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Rosemary

Yes I'm happy for you to include the paper and can confirm that the summary of the nature of your contribution is accurate

Best wishes

Cindy

Publication 3

Permission from co-authors to publish, and agreement about the nature of my contribution to the publication

Telford R, Faulkner A. Learning about service user involvement in mental health research. ***Journal of Mental Health,*** **2004; 13: 549-559.**

Letter to co-author:

“I am registered as a postgraduate research candidate at the University of Sheffield working towards my PhD by Publication thesis on: **Exploring the meaning and impact of public involvement in health research**. Regulations for the thesis require the inclusion of the following published material and, in addition to contacting the relevant journal, I am contacting you as co-author of:

Telford R, Faulkner A. Learning about service user involvement in mental health research. ***Journal of Mental Health,*** **2004; 13, 6: 549-559.**

I wish to include this work as part of my submission for a PhD by Publication. I am also required to submit an electronic version of my thesis, which I am required to deposit in White Rose eTheses Online repository (http://etheses.whiterose.ac.uk/). The repository is non-commercial and openly available to all.

I would be grateful if you could advise if this will be acceptable to you, subject to the journal’s agreement.

In addition I am required to provide an accurate summary of the nature of my contribution to this paper. I would be grateful if you would review the following for accuracy, making any alterations you feel necessary.

Contribution of the candidate:

As the lead author, I suggested the scope of the paper, and made a substantial contribution to the writing. The paper reflects discussions and exchanges of ideas between the two authors, with important contributions and significant writing from my co-author, Alison Faulkner. Both authors approved the final draft.

Many thanks for your help

With best wishes

Rosemary”

Reply from co-author

From: Alison Faulkner <alison.faulkner2@btinternet.com>
Date: 9 April 2013 17:13
Subject: Re: PhD by publication - permissions to publish from co-authors - Journal of Mental Health paper
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary
I am happy to confirm that this is fine,

Best wishes,

Alison

Publication 4

Permission from co-authors to publish, and agreement about the nature of my contribution to the publication

Barber R, Beresford P, Boote J, Cooper C, Faulkner A. Evaluating the impact of service user involvement on research. A prospective case study. *International Journal of Consumer Studies,* 2011a; 35: 609-615.

Letter to co-authors:

“I am registered as a postgraduate research candidate at the University of Sheffield working towards my PhD by Publication thesis on: **Exploring the meaning and impact of public involvement in health research**. Regulations for the thesis require the inclusion of the following published material and, in addition to contacting the relevant journal, I am contacting you as co-author of:

Barber R, Beresford P, Boote J, Cooper C, Faulkner A. Evaluating the impact of service user involvement on research. A prospective case study. *International Journal of Consumer Studies,* 2011; 35: 609-615.

I wish to include this work as part of my submission for a PhD by Publication. I am also required to submit an electronic version of my thesis, which I am required to deposit in White Rose eTheses Online repository (http://etheses.whiterose.ac.uk/). The repository is non-commercial and openly available to all.

I would be grateful if you could advise if this will be acceptable to you, subject to the journal’s agreement.

In addition I am required to provide an accurate summary of the nature of my contribution to this paper. I would be grateful if you would review the following for accuracy, making any alterations you feel necessary.

Contribution of the candidate:

As the principal investigator, I designed the study, wrote the research bid, applied for ethical approval, and conducted the research, all with assistance from my co-authors. I was responsible for taking all the important decisions in the study.

My role was to co-ordinate a collaborative investigation, where the topic guide was jointly agreed. I planned the meetings, recorded the reflective discussions, arranged for the recordings to be transcribed and ensured that they were sent to all the participants to be corrected where necessary.

I analysed all the transcripts, using an interpretive analysis approach (Seale, 2004), based on open coding and categorization (Strauss and Corbin, 2004) of the data. Categories between and within the transcripts were compared, using the constant comparative method to look for similarities and differences. The themes that emerged were shared with and agreed by my co-authors. I produced a first draft of the publication, to which my co-authors contributed revisions. All five authors approved the final draft.

Many thanks for your help

With best wishes

Rosemary"

Replies from co-authors

From: Peter Beresford <peter.beresford3@btopenworld.com>
Date: 8 April 2013 15:41
Subject: Re: PhD by publication - permissions from co-authors to publish - International Journal of Consumer Studies
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>
Cc: Peter Beresford <peter.beresford3@btopenworld.com>

hello Rosemary. I hope this goes well. As you say this is generally a depressing time. I am v happy for you to include this article and feel your statement is a proper and accurate one. hope that provides the information you need. all best for now. peter

From: Jonathan D Boote <j.boote@sheffield.ac.uk>
Date: 9 April 2013 19:21
Subject: Re: PhD by publication - permissions from co-authors to publish - Publication 4
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary

I am happy as a co-author of this paper for you to include it in your PhD by publication. I am also happy with the description of your contribution to this work.

With best wishes
Jonathan

From: Cindy L Cooper <c.l.cooper@sheffield.ac.uk>
Date: 8 April 2013 12:04
Subject: Re: PhD by publication - permissions from co-authors to publish - Publication 4
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Rosemary

Yes I'm happy for you to include the paper and can confirm that the summary of the nature of your contribution is accurate

Best wishes

Cindy

From: Alison Faulkner <alison.faulkner2@btinternet.com>
Date: 9 April 2013 17:13
Subject: Re: PhD by publication - permissions to publish from co-authors - International Journal of Consumer Studies
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary
I am happy to confirm that this is fine by me.

Best wishes,

Alison

Publication 5

Permission from co-authors to publish, and agreement about the nature of my contribution to the publication

Barber R, Boote J, Parry G, Cooper C, Yeeles P, Cook S. Can the impact of public involvement on research be evaluated? A mixed methods study. *Health Expectations,* 2011b; 15: 229-241.

Letter to co-authors:

"I am registered as a postgraduate research candidate at the University of Sheffield working towards my PhD by Publication thesis on: **Exploring the meaning and impact of public involvement in health research**. Regulations for the thesis require the inclusion of the following published material and, in addition to contacting the relevant journal, I am contacting you as co-author of:

Barber R, Boote J, Parry G, Cooper C, Yeeles P, Cook S. Can the impact of public involvement on research be evaluated? A mixed methods study. *Health Expectations,* 2011; 15: 229-241.

I wish to include this work as part of my submission for a PhD by Publication. I am also required to submit an electronic version of my thesis, which I am required to deposit in White Rose eTheses Online repository (http://etheses.whiterose.ac.uk/). The repository is non-commercial and openly available to all.

I would be grateful if you could advise if this will be acceptable to you, subject to the journal's agreement.

In addition I am required to provide an accurate summary of the nature of my contribution to this paper. I would be grateful if you would review the following for accuracy, making any alterations you feel necessary.

Contribution of the candidate:

As the principal investigator, I designed the study, wrote the research bid, applied for ethical approval, conducted the research, all with assistance from my co-authors. I was responsible for taking all the important decisions in the study.

I pre-selected a consensus level of 80% for the Delphi process. I selected the Delphi panellists. The Delphi quantitative analysis was carried out by my co-author, Jonathan

Boote. I carried out interviews of a purposive sample of Delphi panellists, arranged for the transcription of the interviews, and sent the interviewees the transcripts for any necessary corrections.

Qualitative analysis of responses in the text boxes of the Delphi questionnaires and of the interviews, was conducted by my co-author Jonathan Boote and me. I presented our analysis to the research team and Advisory Group for further discussion and interpretation at different stages, re-analysed the data. I produced a first draft of the publication, to which my co-authors contributed revisions. All three authors approved the final draft.

Many thanks for your help

With best wishes

Rosemary"

Replies from co-authors

From: Jonathan D Boote <j.boote@sheffield.ac.uk>
Date: 9 April 2013 19:20
Subject: Re: PhD by publication - permssions to publish - Publication 5
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary

I am happy as a co-author of this paper for you to include it in your PhD by publication. I am also happy with the description of your contribution to this work.

With best wishes
Jonathan

From: Glenys Parry <g.d.parry@sheffield.ac.uk>
Date: 24 April 2013 11:01
Subject: Re: PhD by publication - permissions from co-authors to publish - Health Expectations paper
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary, I am of course very happy for you to publish this Health Expectations paper in your thesis (printed and electronic) and the White Rose depository.

Best wishes Glenys

On 24 Apr 2013 09:48, "Rosemary Barber" <rosemary.barber@sheffield.ac.uk> wrote:

Dear Glenys

From: Glenys Parry <g.d.parry@sheffield.ac.uk>
Date: 16 April 2013 14:11
Subject: Re: PhD by publication - permissions from co-authors to publish - Health Expectations paper
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary

I have read your email about your article **Barber R, Boote J, Parry G, Cooper C, Yeeles P, Cook S. Can the impact of public involvement on research be evaluated? A mixed methods study. *Health Expectations*, 2011; 15: 229-241.**

I am in full agreement with your description of your contribution and confirm that the research was your own work, and that advice I offered as co-author was less that usually available through PhD supervision.

Please let me know if you need me to sign anything or provide further information.

All best wishes

Glenys

From: Cindy L Cooper <c.l.cooper@sheffield.ac.uk>
Date: 8 April 2013 12:04
Subject: Re: PhD by publication - permissions to publish - publication 5
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Rosemary

Yes I'm happy for you to include the paper and can confirm that the summary of the nature of your contribution is accurate

Best wishes

Cindy

From: Philippa Yeeles <Philippa.Yeeles@nihr-ccf.org.uk>
Date: 10 April 2013 21:28
Subject: RE: PhD by publication - permissions to publish from co-authors - Health Expectations paper

To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary

I am really pleased to hear about this work and look forward to reading your thesis in due course.

I agree with your description of the work that you undertook in relation to the paper that we co-authored and that you reference below.

I would be delighted if you were to include it in your thesis.

Best wishes

Philippa

From: Cook, Sarah <S.P.Cook@shu.ac.uk>
Date: 16 April 2013 12:52
Subject: RE: PhD by publication - Permissions from authors to publish
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary

I would like to confirm that the statements below are acceptable to me and I find them to be a correct summary of your contribution to this paper.

Best Wishes

Sarah Cook

Publication 6

Permission from co-authors to publish, and agreement about the nature of my contribution to the publication

Barber R, Boote J, Parry G, Cooper C, Yeeles P. *Evaluating the impact of public involvement on research*. In: Barnes M, Cotterell P (eds) *Critical Perspectives on User Involvement*. Bristol: Policy Press, 2012: 217-223.

Letter to co-authors:

"I am registered as a postgraduate research candidate at the University of Sheffield working towards my PhD by Publication thesis on: **Exploring the meaning and impact of public involvement in health research**. Regulations for the thesis require the inclusion of the following published material and, in addition to contacting the relevant journal, I am contacting you as co-author of:

Barber R, Boote J, Parry G, Cooper C, Yeeles P, Cook S. Can the impact of public involvement on research be evaluated? A mixed methods study. *Health Expectations,* 2011; 15: 229-241.

I wish to include this work as part of my submission for a PhD by Publication. I am also required to submit an electronic version of my thesis, which I am required to deposit in White Rose eTheses Online repository (http://etheses.whiterose.ac.uk/). The repository is non-commercial and openly available to all.

I would be grateful if you could advise if this will be acceptable to you, subject to the journal's agreement.

In addition I am required to provide an accurate summary of the nature of my contribution to this paper. I would be grateful if you would review the following for accuracy, making any alterations you feel necessary.

Contribution of the candidate:

As the principal investigator, I designed the study, wrote the research bid, applied for ethical approval, conducted the research, all with assistance from my co-authors. I was responsible for taking all the important decisions in the study.

I pre-selected a consensus level of 80% for the Delphi process. I selected the Delphi panellists. The Delphi quantitative analysis was carried out by my co-author, Jonathan Boote. I carried out interviews of a purposive sample of Delphi panellists, arranged for the transcription of the interviews, and sent the interviewees the transcripts for any necessary corrections.

Qualitative analysis of responses in the text boxes of the Delphi questionnaires and of the interviews, was conducted by my co-author Jonathan Boote and me. I presented our analysis to the research team and Advisory Group for further discussion and interpretation at different stages, re-analysed the data. I produced a first draft of the publication, to which my co-authors contributed revisions. All three authors approved the final draft.

Many thanks for your help

With best wishes

Rosemary"

Replies from co-authors

From: Jonathan D Boote <j.boote@sheffield.ac.uk>
Date: 9 April 2013 19:20
Subject: Re: PhD by publication - permssions to publish - publication 6
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary

I am happy as a co-author of this paper for you to include it in your PhD by publication. I am also happy with the description of your contribution to this work.

With best wishes
Jonathan

From: Glenys Parry <g.d.parry@sheffield.ac.uk>
Date: 24 April 2013 11:04
Subject: Re: PhD by publication - permissions from authors to publish
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary, I am of course very happy for you to publish this book chapter on evaluating public involvement on research in your thesis (printed and electronic) and the White Rose depository.

Best wishes Glenys

From: Glenys Parry <g.d.parry@sheffield.ac.uk>
Date: 16 April 2013 14:08
Subject: Re: PhD by publication - permissions from authors to publish

To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary

I have read your email about your article **Barber R, Boote J, Parry G, Cooper C, Yeeles P. *Evaluating the impact of public involvement on research,* pp. 217-223. In: Barnes M, Cotterell P (Eds.) *Critical Perspectives on User Involvement,* 2012. Bristol: Policy Press.**

I am in full agreement with your description of your contribution and confirm that the research was your own work, and that advice I offered as co-author was less that usually available through PhD supervision.

Please let me know if you need me to sign anything or provide further information.

All best wishes

Glenys

From: Cindy L Cooper <c.l.cooper@sheffield.ac.uk>
Date: 8 April 2013 12:04
Subject: Re: PhD by publication - permissions to publish - publication 6
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Rosemary

Yes I'm happy for you to include the paper and can confirm that the summary of the nature of your contribution is accurate

Best wishes

Cindy

From: Philippa Yeeles <Philippa.Yeeles@nihr-ccf.org.uk>
Date: 10 April 2013 21:28
Subject: RE: PhD by publication - permissions to publish from co-authors - Policy Press chapter
To: Rosemary Barber <rosemary.barber@sheffield.ac.uk>

Dear Rosemary

I am really pleased to hear about this work and look forward to reading your thesis in due course.

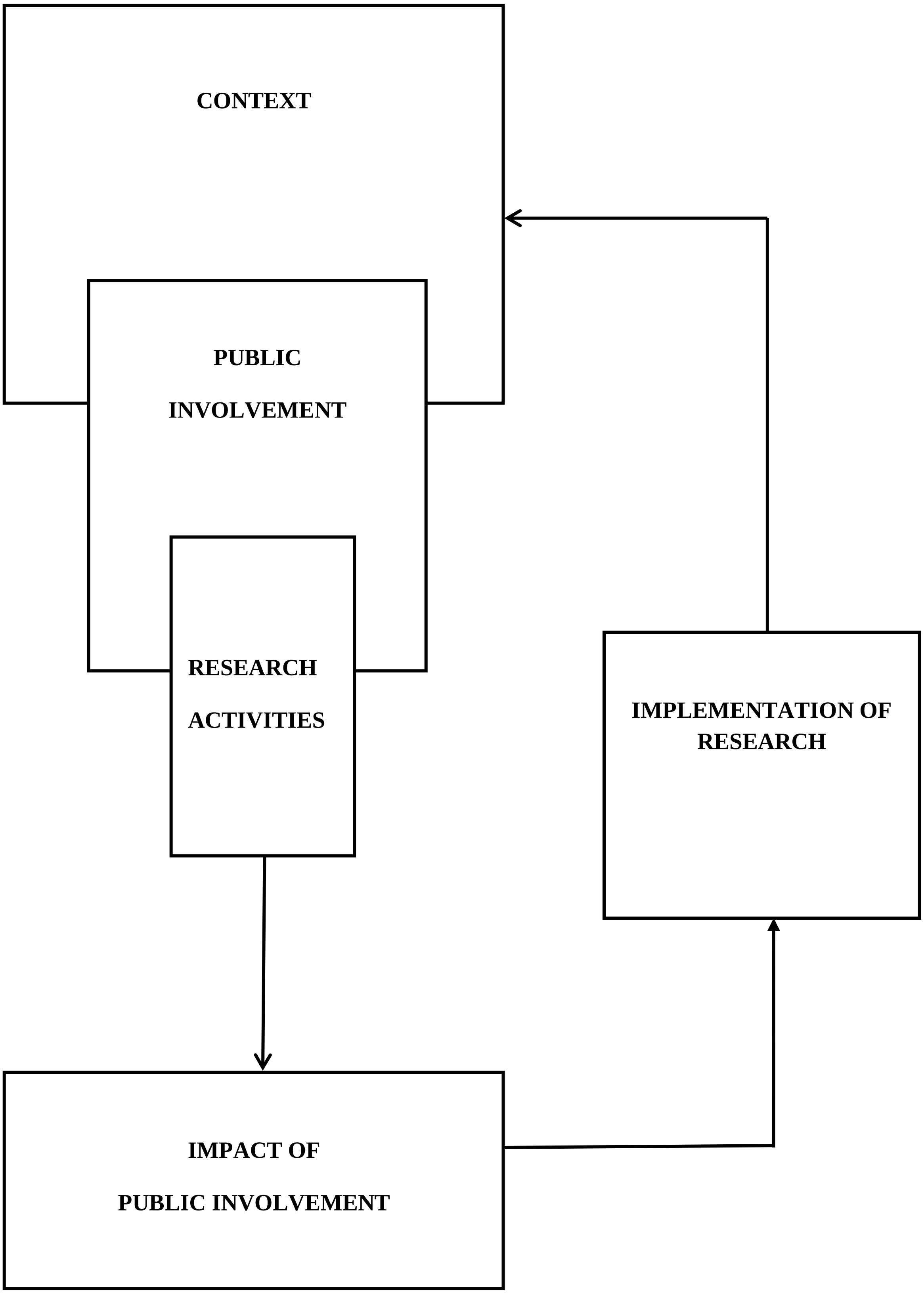
I agree with your description of the work that you undertook in relation to the book chapter that we co-authored and that you reference below.

I would be delighted if you were to include it in your thesis.

Best wishes

Philippa

APPENDIX 3: A CONCEPTUAL FRAMEWORK OF PUBLIC INVOLVEMENT



Fuller details of the context, type(s) of public involved, research activities, impact issues and implementation

The figure above can be populated by the information suggested in the boxes below.

CONTEXT

Details should be provided in this space that take account of the wider and proximal context for public involvement, and include political, organisational, practical, conceptual and interpersonal issues, for example:

- The political context
- Type(s) of organisation and/or research networks
- Resources/funds available for public involvement
- The availability/absence of training/mentoring and support
- The type of research project e.g. RCT, qualitative exploratory study
- Conceptual view of public involvement e.g. emancipatory research
- Attitudes of funders/commissioners/researchers to public involvement
- Type of working relationships e.g. consultation, collaboration or user-led
- Quality of working relationship e.g. trusting or neglectful.
- Aims/motivations of the funders/researchers to involving the public in the research
- Aims/motivations of the public in being involved in the research.

TYPE(S) OF PUBLIC INVOLVED

Information should be provided relating to the characteristics of the public involved, for instance:

- Member of an advisory group, committee, research panel or individual advisor
- Type of member of the public e.g. patient, carer, member of a charity/voluntary organisation
- Specific attributes brought to the research activities, e.g. person with experiential knowledge and/or research experience.

RESEARCH ACTIVITIES

Information should be provided in the lower square, giving details of the type of public involvement in research activities (including if possible the level and intensity of the task) such as:

- Advising on research programmes or projects
- Initiating or prioritising research topics
- Developing a bid
- Designing a study
- Writing a protocol
- Drafting a topic guide
- Interviewing participants
- Analysing and /or interpreting the data
- Writing reports
- Disseminating the findings.

IMPACT ISSUES

Details can be given of the various ways in which public involvement has made a difference to the specific aspects of research, for instance:

- On research processes
- On research outcomes
- On members of the public
- On researchers.

IMPLEMENTATION

Details should be given of any ways in which the public contributed to implementing research findings. The results of implementation will be fed back into the wider context:

- Ways in which members of the public were involved in implementing the research findings
- How the findings were implemented.

The conceptual framework can be used for two purposes. Firstly, it can help to clarify the meaning of public involvement. By providing details of the different aspects of public involvement, the complexity will be highlighted, and this may also help to clarify the aims of involving the public.

Secondly, it can be used as a tool to evaluate the impact. The inter-relationships between the different dimensions in the framework can be explored, showing the various possibilities for evaluating the impact of public involvement.

APPENDIX 4: CITATIONS OF PUBLICATIONS

A selection of citations for the six included publications is presented here.

Selected citations for publication 1

Relating to the meaning of public involvement in research

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.

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Selected citations for publication 2

Relating to the meaning of public involvement in research

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Table 1. Publications relating to the meaning and impact of public involvement in research. The included publications are in bold.

RESEARCH CONCERNING THE MEANING OF PUBLIC INVOLVEMENT IN RESEARCH	
Activity	**Publication**
Conducted a critical review of the literature and recommended a future research agenda.	Boote J, Telford R, Cooper C. Consumer involvement in health research: A review and research agenda. *Health Policy,* 2002; 61: 213-236.
Carried out scoping survey of the extent of public involvement in one NHS region.	Telford R, Beverley C, Cooper C, Boote J. Consumer involvement in health research: fact or fiction? *British Journal of Clinical Governance*, 2002; 7: 92–103.
Held a workshop to explore the potential for local public involvement in research.	Telford R, Repper J. *Developing Research Partnerships in Adult Mental Health: Report of a Day Conference.* 18 June 2002. Sheffield Health and Social Research Consortium: Sheffield. ISBN 1 900752 808, 2002.
Wrote a joint critical review of public involvement in mental health research.	**Telford R, Faulkner A. Learning about service user involvement in mental health research. *Journal of Mental Health,* 2004; 13: 549-559.**
Conducted a consensus study to develop principles of successful public involvement in research.	**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.**
Conducted a workshop to determine regional priorities of members of the public for mental health research.	Jones A, Lovell J, Lucock M, Telford R, Barczi M. *Service User Self Help Initiative (SUSHI). Report for participants from a meeting held on 2 July 2004 at York*. PsyReNN/NIMHE: Huddersfield University, 2005. Lucock M, Barber R, Jones A, Lovell J, Barczi M. Service users' views of self-help strategies and research in the UK. *Journal of Mental Health,* 2007; 16: 795-805.
Conducted a subgroup analysis of participants in the consensus study.	Boote J, Barber R, Cooper C. Principles and indicators of successful consumer involvement in NHS research: results of a Delphi study and subgroup analysis. *Health Policy,* 2006; 75: 280-297.

Commissioned to carry out a survey on public involvement in MRC Research Units.	Barber R. *Survey on Public Involvement in MRC Research Units.* A report prepared on behalf of the Advisory Group on Public Involvement. London: Medical Research Council, 2006.
Carried out a large scale survey of UK researchers to find out how they were involving members of the public.	**Barber R, Boote J D, Cooper C L. Involving consumers successfully in NHS research: a national survey. *Health Expectations,* 2007; 10: 380-391.**
Supervised a PhD thesis that involved people with a visual impairment as advisors in a study.	Beverley CA, Bath PA, Barber R. Can two established information models explain the information behaviour of visually impaired people seeking health and social care information? *Journal of Documentation,* 2007; 63: 9-32. Beverley C, Bath P, Barber R. Health and social care information for visually-impaired people. Aslib Proceedings, 2011; 63: 256-274.
Investigated the attitudes of researchers to public involvement.	Thompson J, Barber R, Ward P R, Boote J D, Cooper C L, Armitage C J, Jones G. Health researchers’ attitudes towards public involvement in health research. *Health Expectations,* 2009; 12: 209-220. Ward P R, Thompson J, Barber R, Armitage, C J, Boote J D, Cooper C L, Jones G L. Critical perspectives on ‘consumer involvement’ in health research: epistemological dissonance and the know-do gap. *Journal of Sociology,* 2009; 6: 63-82. Thompson J, Bissell P, Cooper C, Armitage C J, Barber R. Credibility and the ‘professionalized’ lay expert: reflections on the dilemmas and opportunities of public involvement in health research. *Health,* 2012; 16: 602-618. Thompson J, Bissell P, Cooper C, Armitage C J, Barber R. Exploring the impact of patient and public involvement in a cancer research setting. *Qualitative Health Research,* 2013; doi: 10.1111/hex.12158.
Explored outcome measures acceptable to mental health service users.	Crawford MJ, Robotham D, Than L, Patterson S, Weaver T, Barber R, Wykes T, Rose D. Selecting outcome measures in mental health: the views of service users *Journal of Mental Health,* 2011; 20: 336-346.

RESEARCH CONCERNING THE IMPACT OF PUBLIC INVOLVEMENT IN RESEARCH	
Contributed to an evaluation of the North Trent Cancer Research Network Consumer Research Panel.	Cooper C, Moore J, Telford R, Boote J, Repper J. *Evaluation of the NTCRN Consumer Research Panel*. ScHARR Report Series No: 14. Sheffield School of Health and Related Research, University of Sheffield: Sheffield. ISBN 1 900752 31 X, 2005.
Conducted an expert workshop as part of a mixed methods approach to investigate the impact of public involvement.	Barber R, Parry G, Cooper C, Boote J. *Report of the Expert Workshop on the Impact of Public Involvement on Health and Social Care Research.* ScHARR Report Series. University of Sheffield: Sheffield. ISBN 1 900752 66 2, 2007.
Conducted a prospective longitudinal study of the impact of public involvement.	**Barber R, Beresford P, Boote J, Cooper C, Faulkner A. Evaluating the impact of service user involvement on research. A prospective case study. *International Journal of Consumer Studies*, 2011; 35: 609-615.**
Explored the feasibility of evaluating the impact of public involvement in research.	**Barber R, Boote J, Parry G, Cooper C, Yeeles P, Cook S. Can the impact of public involvement on research be evaluated? A mixed methods study. *Health Expectations*, 2011; 15: 229-241.**
Wrote a critical review of the impact of public involvement.	**Barber R, Boote J, Parry G, Cooper C, Yeeles P. Evaluating the impact of public involvement on research. In: Barnes M, Cotterell P. (eds) Critical Perspectives on User Involvement. Policy Press, 2012: 217-223.**
Contributed to a call to develop the evidence base for public involvement.	Staniszewska S, Adebajo, A, Barber R, Beresford P, Brady, L-M, Brett, J, Elliot, J, Evans, D, Haywood, KL, Jones, D, Monkford, C, Nettle, M, Rose, D, Williamson T. Developing the evidence base of patient and public involvement in research: the case for measuring impact. *International Journal of Consumer Studies,* 2011; 35: 628-632.
Contributed to a call to strengthen the reporting of public involvement in research.	Staniszewska S, Brett J, Mockford C, Barber R. The GRIPP checklist: Strengthening the quality of patient and public involvement reporting in research. *International Journal of Technology Assessment in Health Care,* 2011; 27: 391-399. doi: 10.1017/S0266462311000481.