

# Evaluating the impact of service user involvement on research: a prospective case study

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## 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 criticized 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 recognized 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; Telford *et al.*, 2004; Faulkner, 2004a; McKenzie and Hanley, 2007; Morrow *et al.*, 2010).

Why involve service users in research? Pragmatic, moral and political cases have been put forward (Entwistle *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 prioritizing 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 prioritizing 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 used 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 *et al.*, 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 organizational 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; Lindenmeyer *et al.*, 2007; Fudge *et al.*, 2008; Caldon *et al.*, 2010; Elberse *et al.*, 2010; Williamson *et al.*, 2010). 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 categorization (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 organizations 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 characterized 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 changes (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 categorized. 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 familiarization 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). Andejski *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 organizational 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 (e.g. 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 provided 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.

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