

# Challenges and Strategies in Collaborative Working with Service User Researchers: Reflections from the Academic Researcher

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## Abstract

*In this article, the authors consider the lessons to be drawn from a collaborative two-year research project involving academic researchers working alongside three service user research organisations. The joint working on the project involved designing a research tool and conducting interviews with users of services that were provided by health and social services partnerships. Questions arising from this project involved consideration of the advantages and challenges of collaborative work. Our experience has highlighted the necessity of carefully considering a range of factors, including the ethos and goals of each organisation, as well as the skills and experience of the individuals involved, in relation to the specific purpose of the research. The challenge for academic researchers is to find ways to meet a range of research aims and objectives, while negotiating roles in ways that avoid reinforcing power relations and disempowering service user researchers. Alongside consideration of the challenges involved, this reflective account also highlights some of the advantages of working with user researchers, and suggests ways of harnessing the enthusiasm and skills of service users, with the aim of capturing the unique perspective they bring to research.*

## Keywords

Research methods, user involvement, user led research, partnership, research ethics.

## Introduction

In this article, the authors consider the lessons to be drawn from a collaborative two-year research project involving academic researchers working alongside three service user research organisations. We use the term ‘academic researcher’ to refer to the academically qualified researchers who were based at the University of Glasgow, and who are not service users. We refer to ‘service user researchers’ as users of health and/or social care services who are actively involved in research. This distinction is

blurred with one of the user research organisations, as will be explained in the text. The collaboration involved designing a research tool and conducting interviews with users of services that were provided by health and social services partnerships. This article represents the perspective of the academic researchers, although the text has been shared with the service user research partners. The research which informs this paper was conducted as part of a wider research programme (Modernising Adult Social Care research initiative, DH 2003-6). It is consistent

with the UK government's modernisation agenda, that service users were involved in this project as active participants rather than simply research subjects. Questions arising from this project have involved consideration of the advantages and challenges of such collaborations, and what the process tells us about the optimum way of harnessing the enthusiasm and skills of service users.

Walmsley (2004a; Walmsley, 2004b), Rose (2003), and Beresford (2004) argue there is an urgent need to move on from anecdotal and biographical accounts of service user involvement in research to developing the evidence base. It is worth acknowledging from the outset that different philosophical and methodological issues have influenced the parties to this research, as well as the research process, with some tensions emerging in the shared research journey. The main questions being addressed (from an academic perspective) concern the advantages and challenges in involving service users as more than research subjects. The purpose here is to consider constructive strategies for future involvement.

### Context

There is considerable emphasis in current policy initiatives in the UK on involving service users in shaping services (Department of Health, 2001; NHS Executive, 1999; Secretary of State for Health, 2000). This development is based on a common-sense assumption that services cannot meet the needs of service users unless users' views are incorporated into service design. UK government policy documents state that involving patients leads to 'more responsive services and better outcomes of care' (NHS Executive, 1999). The agenda of involvement, according to one government source, is anticipated to

'shift the balance of power' so that service users as opposed to health and social care professionals dictate what services are needed and how they are delivered (Department of Health, 2001)

With regard to research specifically, the Director of Research and Development in the Department of Health set up Consumers in NHS Research in 1996, as a standing advisory group on consumer involvement in the NHS. In 2001, the Group widened its remit to cover public health and social care research commissioned by the Policy Research Programme of the DH. The Group has now been renamed *INVOLVE - promoting public involvement in NHS, public health and social care research*, to better reflect its extended remit. *INVOLVE's* briefing for researchers (Hanley *et al.*, 2004) argues that the involvement of service users in the research process as co-researchers can help to 'empower' service users. Involvement can mean a range of activities in various settings. There is an established tradition of representing user involvement which can be equated with a 'ladder' of participation (Arnstein, 1969). Involvement ranges from fairly low levels of participation characteristic of traditional professionally led services, to user led approaches. However, in practice, the involvement of service users does not necessarily result in their views being taken on board. There is extensive literature on the subject of service user involvement in the health and social care field, often with an assumption that this will lead to the development of more responsive and effective services that in turn, will improve quality of care. Evidence to support this assumption, however, still remains elusive (Hubbard *et al.*, 2004).

### Service user research organisations

Three user research organisations participated in this project. Their distinct origins, structures and levels of experience indicate the diversity of the organisations. They are also distinguished by their different approaches to research, which they have contributed to the literature on involvement, highlighting some of the challenges and recommendations for involving user researchers.

#### *Older People Researching Social Issues (OPRSI)*

Older People Researching Social Issues (OPRSI) is a co-operative of older people who trained in research methods for two terms at the University of Lancaster in 2002. They have subsequently been operating as a research consultancy, primarily carrying out research interviews and focus groups. OPRSI started out as *The Interviewers*, but changed their name as their interest in expanding their research experience has developed. OPRSI have recently documented their experiences of becoming researchers (Clough *et al.*, 2006), providing a useful reference guide to the ‘potential, practicalities and pitfalls’ (p47) of becoming involved in research. Their account details the challenges faced by individual members of the group on their journey to becoming researchers, as well as their development as a team:

*Individual competence depends on how effectively group members work together and support each other.*

(Clough *et al.*, 2006, p41)

Part of the journey for OPRSI continues to involve working out where the strengths and capacities of individuals and the collective lie. Much of this account is an honest reflection on the challenges faced in general in becoming a qualitative researcher.

The academic mentors for OPRSI, Roger Clough and Mary Leamy, who trained them as well as continuing to provide support to the group, have also written about working with them. They have referred to the requirement to demystify the research process and share knowledge of research with the students. As teachers, their ‘expert role’ needed to be balanced with an ‘empowering or facilitative’ role, where students felt able to challenge their mentors (Leamy & Clough, 2006, p21). They also describe the need to make the specific set of skills required for qualitative interviewing understood by a group of students with diverse educational and life experiences. While this research method is designed to allow and encourage interviewees to tell their stories and retain some control over the interview, the interviewer’s role is to gently guide the discussion so the interviewee maintains a focus upon the research topic:

*This is a very skilful, complex task and many older interviewers reported difficulties in keeping the interview focused.*

(Leamy & Clough, 2006, p25)

However, the authors concluded that OPRSI had brought a distinctive perspective to the research and that interviews by OPRSI resulted in enhanced levels of disclosure by older interviewees.

#### *Service User Research Enterprise (SURE)*

Service User Research Enterprise (SURE) is a collaborative project between academic service user researchers and clinical academics at the Institute of Psychiatry in London, staffed mainly by people who are using or have used mental health services. SURE differs from the other user research organisations in this project in that it shares a similar academic status with the University of Glasgow research team.

The two research staff from SURE involved in this project both have personal experience of distress and of treatments and services that they bring to bear on their research. They are also both academically qualified researchers, one tenured and one contracted specifically for this project. Diana Rose, the co-director of SURE, who worked with us on this project, has previously outlined some of the peaks and pitfalls of collaborative research (Rose, 2003). Rose's account indicates that SURE adopt a broad-based approach to conducting research, advocating an increase in user-led research, while also participating in collaborative and consultative research. Acknowledging that scepticism continues to exist with regard to the value of involvement, Rose emphasises the importance of avoiding tokenism. Further, she highlights that even when a user-researcher is academically qualified, their mental health can result in reduced status due to career interruptions and because of discrimination. She, therefore, strongly advocates moving to maximise the potential for the fresh insights user researchers can bring to improve services.

#### *Central England People First*

Central England People First (CEPF) is primarily a self-advocacy organisation for people with learning difficulties. The term learning difficulties is preferred by some disability organisations in the UK to learning disabilities. The international term is intellectual disabilities. Formed fifteen years ago, People First has been involved in various research activities over the years. CEPF members are supported in their research activities by staff from the Open University. Some of their academic supports are among those who have attempted to adopt an 'emancipatory' approach to doing research with people with learning

difficulties (Smith, 2004; Walmsley, 2004a; 2004b). Jan Walmsley has acted as academic support to CEPF over a number of years and has reported a number of practical considerations in research with people with learning difficulties, including the extra time required and the importance of producing accessible information (2004b). In distinguishing between approaches to research, Walmsley (2001) suggests that in the case of 'participatory research', the researcher works in partnership with participants, using qualitative methods to interpret and explain the experiences of people with learning difficulties. Ultimately however, the researcher remains accountable to the funding body. Conversely, emancipatory approaches draw attention to power differentials between the 'researcher' and the 'researched'. Emancipatory research is viewed as a process of producing knowledge that will benefit oppressed people, using qualitative or quantitative methods where the researcher's expertise is placed at the disposal of people with disabilities (Barnes, 2003).

Walmsley (2004a) has also written about her own position with regard to emancipatory research with people with learning difficulties. She includes herself among many academic researchers who have endeavoured to take on board the emancipatory agenda, striving to be viewed as supporting rather than directing research. There is a tendency in some academic accounts to enhance the role of service users in research, with less attention paid to the input of the academic researcher. While this can be done with the good intention of enhancing the image of disabled researchers, Walmsley cautions against 'the naïve belief that if conditions are right somehow the effect of the impairment will disappear' (pp61-62). Walmsley is clear however about the

need for involving service users in research, highlighting that if such work is to be effective, and if the risk of paternalism is to be minimised, some of the work must be done with people with learning difficulties.

### **Background to the project**

In May 2004, we embarked on a research project that aimed to investigate service users' views of services delivered by health and social services partnerships. This project was committed to the inclusion of service users' views; the premise was that although there had been much research on the subject of partnerships between health and social services, the focus had tended to be on the outcomes identified by professionals. The project began from the position that service users' views were necessary to assess whether partnership is delivering, and that this had to be assessed by considering the outcomes important to service users. This project set out to develop a tool for this purpose, and as a basis for conducting 300 interviews with five groups of service users in each of three types of service: mental health services, older people's services and services for adults with learning difficulties. The university research team consisted of seven individuals; three tenured academic researchers, one contract academic researcher, one NHS manager (the project grant holders) and two contracted research fellows.

### **When and why we included users as co-researchers**

The decision to involve service users as co-researchers in this project was in part a response to the remit of the funding body, the Department of Health (DH), which encourages the involvement of service users as more than the 'subjects' of research in White Papers such as the *NHS Plan* (Secretary of State for Health,

2000). This project was one of nine commissioned by DH under the Modernising Adult Social Care research initiative (MASCri). The DH required explicit statements about plans for active user involvement in the research process from all applicants under the MASC initiative; they advised applicants that this would be a criterion in the assessment process and that service users would be involved in assessing the bids. In other words, involvement was partly in response to a top-down policy directive. While several of the other projects were committed to obtaining service user views on aspects of the modernisation programme, this project is the only one in this programme to actually involve user researchers in gathering data and analysis as well as developing research tools. This indicates that active participation of users in research is not yet mainstream or necessarily perceived as essential. Further, it is not clear the extent to which service users' views were influential in setting the MASCri research agenda, before the call for proposals went out. A decision was made by the project grant holders to involve user organisations to represent the three groups of service users to be interviewed in the project.

The second reason for involving service users as co-researchers was an expectation that their involvement could enhance the research and make it more relevant to service users, particularly given the project's focus on outcomes for service users. This was premised on the assumption that the personal experience of being a service user could enable persons to be effective interviewers of other service users, which in turn, would add value to the project (Rose, 2001). The notion that sharing an experience with the interviewee brings the researcher unique *epistemic privilege* fundamentally

influencing the quality of the data was first championed by feminist writers and has been embraced by researchers working with a range of oppressed communities (Fine, 1994).

The view of the University of Glasgow team at the contracting stage, based on initial communications, was that each organisation included expert user researchers, experienced in conducting the type of semi-structured interview anticipated in this research. Beyond the contracted agreement that such interviews would be conducted, it was anticipated that research roles would be negotiated separately with each of the three organisations, attempting to equalise relationships where possible, and to share knowledge and experience along the way. With hindsight, it would have been useful to have explicitly developed a shared value-base. In this way, we would have collectively developed value-driven ground rules for negotiating and carrying out the practical tasks.

### **Challenges and strategies**

In this section, we consider the key challenges that emerged during this research collaboration. While a variety of obstacles/barriers to be overcome emerged during the course of the project, these mainly related to more routine project management issues. This discussion is focused on challenges emerging from the involvement of service users as researchers.

#### *Negotiating roles*

The two contract researchers at the University of Glasgow took up their posts in May 2004. One of the key tasks at this stage was to re-establish contact with the three service user organisations, to begin to negotiate how interviews would be organised and agree the extent of involvement of each organisation.

In this project, we sought to maximise the involvement of our service user research partners within the bounds of the existing protocol. The protocol that was agreed in principle with the DH prior to the recommendation to involve service users, was based around qualitative interviews with users of services provided in partnership. On reflection, the design of the research should have been altered following the requirement of the DH to involve users as researchers, to allow for the training and other requirements of user researchers. In practice, our experience supports the position that roles need to be continuously negotiated and subject to change in light of the user researchers' skills development, confidence and willingness to participate in different stages of the research (Carr, 2004; Elwyn *et al.*, 2005; Hanley *et al.*, 2004).

At the start of the project the contract researchers conducted face-to-face meetings with individuals in all three service user research organisations to negotiate the extent of involvement in the research. At this point all three organisations agreed to be involved in the development of the interview schedule and to carry out interviews. In addition, CEPF agreed to lead a focus group with people with learning difficulties to determine the outcomes on which our interview schedule would be based and OPRSI agreed to be involved in piloting the interview schedule with older service users. SURE did not have the capacity to take part in this early development work, other than to briefly comment on the schedule, but did commit themselves to analyse the data from the interviews with mental health service users that they had carried out. The input of OPRSI and CEPF in developing the tool was significant and considerably influenced its final form and content.

As the project progressed some members of OPRSI expressed an interest in becoming involved in the analysis of the data. Agreement was reached with the academic mentor that she would work with those who were interested, to demonstrate how to use the selected qualitative research analysis programme used by the university researchers. The university researchers produced a list of all the terms they were using to code the interview transcripts, with explanations for each term. The academic support then used this information to train the user researchers, using transcripts of their own interviews. This exercise was highly valued by the OPRSI researchers, who reported that the exercise significantly improved their understanding of the purpose of the research. Furthermore, they informed that this understanding improved their interview skills as they felt they were more able to obtain relevant information from the interviewees.

Another aspect of the research process that was influenced by user researchers was the methods used to capture their reflections. Researchers from CEPF wanted to work with us to disseminate findings of the project and, following a discussion which took place on completion of their first interviews, we developed a mechanism to capture their thoughts on analysis of the data. Listening to their comments on the service, including their observations on the relationships between staff and service users, it was clear that capturing these reflections could harness the added value of user involvement in a way that qualitative interviewing might not. Following from this development with CEPF, we subsequently suggested to the other two organisations that they might similarly want to record their reflections on each site, using the method of their choice. In practice, SURE, CEPF and OPRSI provided written notes of their

observations and we also facilitated a discussion with OPRSI. This provided valuable additional data, from the unique perspective of service users.

It should be emphasised that although all members of the University of Glasgow research team had previous experience of working with service users, none of us had worked with users as researchers before. Furthermore, whilst the service user researchers were experienced, we ascertained later in the process that neither CEPF nor OPRSI had been involved in interviewing studies of this scale before. There is an extent to which it could be argued that both the academic and service user researchers approached their work together on the study with optimistic naivety, with all partners preferring to trust in the expertise of the others rather than ask difficult questions or face difficult issues at the start of the working relationship.

#### *Research skills and methods*

All three user organisations involved in this project have acquired specific skills and knowledge through experience of research and/or experience as services users, or in the case of OPRSI, of being older people. However, as indicated by this account, there are significant variations between the types and levels of skill and experience of the organisations and of individuals within the organisations. Although each organisation can justifiably claim significant levels of research experience, our collaboration has indicated that it is vital to consider each user organisation and indeed each user researcher individually, and to negotiate the methods of involvement in ways which maximise the potential added value of the involvement of service users as researchers.

In addition to the need to consider skills and experience, the purpose of the

research may influence decisions on how best to involve user researchers. The principal method employed in this project was semi-structured qualitative interviewing. Qualitative policy-oriented research requires very specific skills, as well as knowledge of the research topic and an understanding of the policy context. Ideally, all of these factors should be present in a qualitative interviewer. The personal qualities required from an interviewer to protect the well-being of the interviewee include the ability to negotiate and obtain informed consent, good listening skills, empathy, and discretion. Some of the features outlined here can be developed by training. However, regardless of whether a researcher is a service user or not, some individuals may not be inclined or able to obtain all of these skills and attributes. In such circumstances, it may be appropriate, as OPRSI (Clough *et al.*, 2006) recommend, to consider how each individual may best contribute to the research team. A recent DH sponsored, user led study of involvement drew the following conclusion:

*In some circumstances, it might be appropriate to interview people for research roles, if they require specific experience or approaches.*

(The Learning Difficulties Research Team, 2006, p24)

A fundamental consideration here is a potential conflict of interest between research goals, and our responsibilities to the least powerful actors in the research process, the research 'subjects'. To comply with the emancipatory model, the primary goal of this research would have been to empower the user researchers. However, in research with service users, the interests and well-being of the individual research 'subjects' must be paramount. This is an ethical consideration. We are asking after all, that interviewees discuss

personal and often sensitive information about their lives. As well as the inherent responsibilities towards the researched, to ensure that they are not harmed in any way by the research, there is a further responsibility to ensure that the data generated is gathered effectively and used purposefully for the research aims, as explained to the subject in obtaining consent to participate. The integrity of the research itself has to be a consideration.

Where different value bases are brought to research collaborations, there is potential for tensions to arise when values are not made explicit at the outset. In this project, a decision was made fairly early on by the University of Glasgow staff not to include everyone who wanted to be involved in interviewing from one of the organisations, in the qualitative interviewing task. This decision followed a pilot interviewing exercise which highlighted the skills needed to conduct semi-structured interviews. This included interviewers who could not read the questions themselves, using support staff to prompt them by reading the questions first. The interviewers then repeated the questions, sometimes broken into short phrases, which the university researchers perceived to significantly affect rapport building with the interviewee. This presented a dilemma.

The university researchers tried to negotiate a diverse range of goals in this project. We were conscious that part of the rationale for user involvement in research is about ensuring that that research is more clearly grounded in the reality of users' lives and experiences, and some parts of this collaboration with user researchers, particularly the design of the research tools, undoubtedly resulted in more effective engagement with the lives of users. However, a



further aim of user involvement, particularly in policy-oriented research, is to move towards providing the kind of services users want (Department of Health, 2001; NHS Executive, 1999). This aim is emphasised by OPRSI:

*Consultation is not enough, people want to influence.*

(Clough *et al.*, 2006, p5)

Where the aim is to influence policy using qualitative methods, questions arise about potential impact if the user researchers do not possess, or have not had the opportunity to develop the necessary skills to effectively garner the views of other service users. For a research project that set out to conduct in-depth interviews in ways recommended by qualitative experts (Patton, 2002; Punch, 2005; Silverman, 2001), this created a tension. The challenge facing us was to elicit in-depth accounts of people's experiences of using a service at the same time as enabling service user researchers to conduct some of the interviews within the constraints of the research grant award.

Following the decision by the university researchers, the service user researchers agreed to continue on the basis of two of their five researchers conducting interviews, with the others taking on co-ordinating and organisational roles. However, although a further aspect to the rationale for involving users as researchers is to redress power imbalances between academic researchers and service users (Smith, 2004), these user researchers felt disempowered because control was taken away from them, in conflict with their organisational ethos. For the university staff, this decision represented a very uneasy compromise between the various goals of this research project. This experience also highlighted the necessity of considering and negotiating

a range of methods, in order to effectively involve user researchers.

## Discussion

Our experiences in this two-year project have indicated a range of ways in which research is enhanced by the involvement of service users as active participants in the research process. Not least amongst these was the contribution of the service users to making sense of the data generated from the project and the face validity of the research tools. The unique perspective of service users was harnessed by their recording of their reflections on interview sites. Despite the heavy demands made on all the researchers involved, and sometimes tense negotiations between the research partners, each user research organisation delivered its contracted input for this project.

The position taken in this article is that research should support positions challenging oppressive practice, address the marginalization and exclusion of service users, and seek to drive services in the directions identified by service users. We endeavoured to adhere to these goals in this research project, in our negotiations over roles with the user researchers. The university researchers are conscious however that some parties to the research were frustrated and disappointed by the research process and to a large extent these difficulties arose over differing approaches to effectively harnessing research skills and selecting methods.

Where the goal of research is the empowerment of the user researcher, considerable latitude exists for consideration of research methodology. However, our experience has indicated that the emancipatory approach does not necessarily easily coexist with attempts to deliver on policy research. A key consideration in doing research with

vulnerable people is whose interests are paramount. This can become complicated when service users are both actors and subjects in a project, but ultimately, the research subjects are in the more vulnerable, less powerful position. It is our view therefore, that it is essential that user researchers who move beyond advisory capacities in research, to qualitative interviewing, must have the necessary research skills in order to ensure the well-being of the research subject is not in any way jeopardised, and to avoid compromising the quality of the research. The challenge for future research teams is to find ways to work with individuals and organisations to negotiate roles in ways that avoid reinforcing power relations and disempowering service user researchers.

Where service user researchers are engaged in collaborative projects with academic researchers, a flexible approach by both can considerably enhance the quality of the research, and the research experience of all participating researchers as well as the research subjects. In the group discussion held with OPRSI at the end of the project, some of the researchers were clear that they wanted to continue building their skills as qualitative interviewers. Others acknowledged that they were less comfortable with semi-structured qualitative interviewing as a method, preferring to carry out unstructured life history interviews. A few responded very positively to the idea that they might more productively have spent time in the research sites, speaking informally to users and staff, observing the environment in which they lived and worked, and the interactions between them. Although this project was undoubtedly enhanced by the involvement of service users, it is our view that a more ethnographic approach could have more effectively harnessed

the added value of user researchers in some cases, capturing the unique perspective of user researchers.

### **Practical recommendations**

- To avoid tokenism, service users should be involved from the start in identifying research priorities and setting research questions.
- Extra time should be allowed to develop value-based ground rules prior to the project work commencing, as well as ascertaining the values of each organisation involved.
- Agreement about the aims of the research should be established at the outset. The aims should be taken into consideration in negotiations about methods.
- Discussions should take place at the outset to ensure that everyone understands that there are different types of research and identify which type best suits the organisations involved. Different types of research activity, including focus groups, interviews, analysis, commentary on research tools and results should be considered, to identify who does what according to preferences and aptitude.
- Ethnographic approaches to research offer particularly rich sources of harnessing the unique perspective of user researchers.
- It should be understood that in collaborations with organisations adopting an emancipatory agenda, compliance with this agenda requires that the methods and approach to research should be decided by the organisations.
- Extra time should be built in for regular intermissions during the

project. This would allow for taking stock of progress and to identify and alleviate pressure points.

- Regular intermissions would also allow space to renegotiate roles throughout the project. User researchers who are developing their confidence and skills in a specific area could be enabled to build on those skills. User researchers struggling with one area of research could similarly be offered the opportunity to undertake alternative tasks. In both cases, appropriate training should be provided.

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