

Chapter Four

Theorising service user involvement from a researcher perspective

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Introduction

There has been growing momentum concerning patient and public involvement (PPI) in research over the last decade in the United Kingdom (UK), with concomitant establishment of appropriate infrastructure, in particular, the development of INVOLVE (Hanley et al., 2004), which is supported by the Department of Health (DH) expressly to promote PPI in research. In 2005, the DH explicitly stated that members of the public, including service users (patients) and carers, should be actively involved in 'design, conduct, analysis and reporting of research' (DH, 2005), while the National Institute for Health Research (NIHR) increasingly requires evidence of active public involvement when commissioning healthcare research (NIHR, 2012). The NIHR is one of two main public bodies (the other being the Medical Research Council) through which healthcare research is funded in the UK, and therefore hugely influential in this area. Principles for good practice when involving service users in research have also been published in different areas of healthcare, in particular mental health (UK Mental Health Research Network, 2011).

Over a similar period, theorists and other academics have started to develop and codify knowledge concerning issues arising from PPI in research. These have included definition of different models of participation, and discussion of different conceptions of knowledge itself (Nolan et al., 2007; Oliver et al., 2008; Morrow et al., 2010). In this chapter, we intend to discuss some of these issues in relation to our real-world experience of leading and working on academic funded projects in which service users have played active roles to varying extents.

At the University of the West of England (UWE), over the last five years, we have had a particular focus on working with service users

across a range of activities within the institution, including research. We have assigned the term 'service user research partner' to those individuals, neither academics nor health or social care practitioners, who have been active within research projects. In 2010, we produced a guide for good practice for involving service users in research, developed jointly by services users, carers, academics, practitioners and members of the public (UWE, 2010). In this chapter we will refer to 'service user researchers' to denote service users, carers or members of the public who are actively involved in research projects; and to 'researchers' to denote academic or clinical researchers.

Some of our service user research partners have been or are users of mental health services, and some of our projects have been located within the area of mental health. However, many of our service user research partners and research projects have been situated within other areas of health and social care. Our experience across all these projects has led us to recognise that there are issues arising from PPI in research which are unrelated to the area of care or service delivery; it is from this recognition that we approach our task of theorising service user involvement from a researcher perspective.

It should be noted that care for mental health is unlike other healthcare areas in the United Kingdom, as it is the only area where service users can be treated without their consent, a course of action enshrined in law since the early 1840s (Fennel 1996). There has consequently been a relatively high and longstanding degree of activism among mental health service users (Crossley 1999), accompanied by a drive for PPI in service design, delivery and research. Researchers in this area have therefore a longer history of considering and engaging with PPI in research than researchers in many other areas of health and social care. By contrast, in our experience, professionals in some other areas of healthcare and research are still not aware of PPI, despite recent developments and the growing literature.

Researcher attitudes to PPI

An important starting place is to ask what we already know about researchers' attitudes to PPI in research, both generally and in terms of attitudes in mental health research. There is an emerging evidence base on the impact of PPI on research which has been collated and synthesised in two recent literature reviews (Staley 2009, Brett et al., 2010). Both reviews consider the impact of PPI, which gives some insights into researchers' attitudes. The reviews found that PPI has been reported to have both positive and negative impacts on researchers.

Positive impacts included increased enjoyment and satisfaction from working in partnership with the public, career benefits and most relevant to this discussion, positive challenges to their beliefs and attitudes (Hewlett et al., 2006). One team of mental health service researchers reported:

“Having a service user as part of the team made other team members try to consider how users would think and feel in mental health services and when reading our report. It made us challenge our own assumptions, consider our language and to be very honest and open with ourselves about our attitudes and values.” (Clark et al., 2004, p.34)

However, researchers have also reported that involving the public often requires significant time, energy and/or financial resources, which can lead to frustration on their part. Some researchers are sceptical about the value of PPI or have negative attitudes because of what they regard as negative previous experiences of involvement. Researchers may also find it difficult to relinquish control or share power in research (Brett et al., 2010).

There have been a number of articles about PPI in research in which researchers already committed to involvement demonstrate their positive attitudes towards it (e.g. Hewlett et al., 2006; Staniszewska et al., 2007). There are of course a number of service user researchers, particularly in mental health, who unsurprisingly express very positive attitudes towards PPI in research (Rose, 2004; Beresford, 2007). We have much less concrete information about researchers who are sceptical or hostile towards PPI in research (for they do not tend to write articles about it), although stories of such attitudes are commonly recounted by the advocates of involvement. There have been relatively few research studies specifically on researchers' attitudes towards PPI in research. The most significant contribution in this area has been the two papers by a team of researchers mainly based in Sheffield, UK who undertook a study specifically on health researchers' attitudes towards involving the public in research (Thompson et al., 2009; Ward et al., 2010). They conducted a qualitative study with fifteen purposively sampled UK-based university health researchers and found a mixed picture of positive beliefs in the benefits of involving the public alongside some feelings of apprehension and discomfort. Although based on a small sample, this mixed picture of researchers' attitudes towards involvement is consistent with the literature discussed above and our own experiences. In particular Ward et al. (2009) identify

the issues of 'epistemological dissonance' (a lack of recognition that service users can bring valid forms of knowledge to bear on research) and the 'know-do gap' (between researchers' stated belief in the value of PPI and their actual practices). They link these issues to researchers' professionalisation strategies for privileging their 'expert' knowledge over service users' lay knowledge based on lived experience, thus maintaining their power and status as researchers relative to service users. However strong our personal commitments to PPI and however good our relationships with service users, as academic researchers we have to acknowledge and reflect upon these power/knowledge dynamics which inevitably shape our relationships with service users in research, whether we are conscious of them or not.

Implications of PPI for research and researchers

Much has been written about the benefits accruing to service users and members of the public when authentic PPI occurs in research projects (e.g. Faulkner, 2009; Lowes et al., 2011). There is also evidence that suggests that PPI enhances the quality of research (Faulkner, 2009; Staley, 2009; Lowes et al., 2011). The need to establish whether this is or is not the case, and to determine what conditions are necessary for a favourable outcome in this regard, has resulted in the NIHR's funding three projects and the Medical Research Council one, all ongoing at the time of writing, to measure the impact of PPI in research. However, as stated above, relatively little has been written about the researcher experience in the context of PPI.

It is a truism to state that research needs researchers; equally, researchers need research. For many researchers, a lack of funded projects can mean lack of employment and even the end of a career. These researchers must therefore keep abreast of, and comply with, changing imperatives in conducting research, in order to remain employed. The necessity for gaining ethical approval is an example of such an imperative; surprising though it may seem, it is only relatively recently that ethical review became mandatory for research projects within healthcare (DH, 2001). Similarly, researchers applying for many funding schemes now must engage with PPI in their projects. It is important to recognise this element of compulsion in the current context; while most service users and carers who become actively engaged in research do so from conviction and a passionate wish to have their voice heard, it cannot be assumed that all researchers are equally passionate about PPI in research. While there are undoubtedly many who have strong commitment to providing opportunities for the

service user voice to be heard, it should also be recognised that there are considerable numbers of jobbing researchers for whom PPI is merely one imperative among many others with which they must comply. This situation can be compounded by a researcher's academic discipline, which may focus entirely on a research paradigm which is not necessarily easily aligned with PPI principles.

Theoretical framing for research

There are differing perspectives and differing paradigms of research, and PPI fits more easily into some than others. Different research paradigms can be conceptualised along a continuum with approaches grounded in positivistic enquiry (for example, randomised controlled trials) at one end, and those recognising the shifting complexity of the self and of social situations (for example, participatory enquiry) at the other (Guba & Lincoln, 1994; Heron & Reason, 1997). Unsurprisingly, PPI in research has grown from approaches such as participatory enquiry (Nolan et al., 2007). It is fairly obvious that PPI can easily be incorporated into an approach which values, even demands, active contribution from all those involved (Heron & Reason, 1997). For example, in participatory and many qualitative approaches, with appropriate support, service users can be involved in all the research processes, including study design and collection and analysis of data (Hopper & Lincoln, 2009; Moule et al., 2011). In these approaches, it is also possible to adopt a relatively flexible attitude to the conceptualisation and construction of knowledge, since any assumption that knowledge is necessarily objective and value-free is itself called into question (Nolan et al., 2007). It therefore becomes congruent to accord value to 'situated' knowledge, that is, knowledge that does not derive from professional or academic sources.

It is more difficult to incorporate more participatory types of PPI into positivistic research approaches. Although service users can certainly be involved in framing research questions, identifying outcomes relevant to service users and selecting study instruments (Campbell, 2009; Del Vecchio & Blyler, 2009; Edwards et al., 2011), the data collection and processing methods employed often require specialised knowledge and skills. It is generally unrealistic to expect service users to acquire these skills; or to expect researchers to involve service users without the prerequisite skills actively in these processes. In addition, positivistic enquiry assumes that 'real' knowledge is objective and derived from measurable sources, and is the domain of professional or academic 'experts'; this assumption results in subjective experience,

such as the service user voice, being accorded relatively less value or compartmentalised to only specific parts of the research process.

Despite increasing recognition of the validity and usefulness of a range of different research paradigms, the belief persists in some circles that research results from positivistic enquiry, assumed to be neutral and objective, and underpinned by statistical theory, are intrinsically of more value than those derived from 'softer' approaches, such as participatory enquiry; that this is the case in healthcare research is evidenced by the format of application forms for research funding and for ethical review, many of which still ask direct questions about the statistical and scientific methods to be employed, regardless of which research approach has been chosen. Given the comparative limitations of organising PPI in positivistic enquiry, this inherent bias in its favour in practice mitigates against service user involvement in the conduct of a large body of healthcare research, other than within narrowly defined and limited parameters such as the design stage or assisting in dissemination.

Power issues

As has been mentioned in various chapters in this volume, the exercise of power in research incorporating PPI is an obvious issue for consideration. There is no doubt that unequal power relationships can have a major effect on the quality and extent of PPI in a project. Extreme cases of power imbalances can result in only tokenistic PPI, where service users are not given genuine opportunities for active involvement in a project, but are included simply as 'window dressing'. However, there has been little recognition of the way that power issues in PPI research can also affect researchers negatively. As stated above, service user researchers usually want to be involved in research projects due to their own strong feelings about the area of care, arising from personal experience, or the experience of someone close to them. In our experience, it can therefore be quite disappointing for them to discover how long research findings can take to get into the public domain; and also that there is no guarantee, and in fact, often little likelihood, that findings from a project will be implemented in a service area.

Barriers to implementation of research findings in practice have been well documented (e.g. Mantzoukas, 2008; Greenhalgh & Russell, 2009). Service users often do not realise that many, if not most, researchers are powerless in this area. Consequently, researchers working on PPI projects often have to engage in considerable emotional work in order to support service users to manage the disappointment arising from

realisation of the reality of the relationship between research and practice in health and social care. As it is common for funded research projects to be conducted with barely adequate time and resources, and with the deadlines and demands of funders to meet, this emotional work can add considerably to the stress experienced by researchers who are responsible for ensuring that a project is conducted to sufficiently high academic standards within the time specified.

Skills

Any individual involved actively in a research project must have the skills required to fulfil their role. In a PPI project, researchers must ensure that this is the case for all the service user researchers. When researchers are recruited to work on a project, it is common for them to have to provide a curriculum vitae which details their research skills and experience. While service user researchers may be asked to provide similar information before being invited to a project, there is often a process of negotiation that needs to be completed, in order to ensure that they are equipped for particular research tasks.

The senior researchers in the project need firstly to ascertain to what extent service user researchers wish to be involved; this can range along a continuum from providing advice on particular topics, to undertaking a variety of research tasks, including data collection and analysis, and contributing to writing project reports. Training for service user researchers in particular aspects of research often needs to be arranged externally, or provided within the project, in order to enable them to function adequately. Allowing this level of flexibility, if possible, is important to allow service user researchers to grow as researchers. In turn, this can be beneficial for current and future projects. However, it should be remembered that not all service user researchers want to develop involvement in research. In particular, some service user researchers may feel overwhelmed by perceived expectations concerning their own skills, performance and responsibility (Shields et al., 2007). Researchers need to be sensitive to this situation, and may have to depart from agreed allocation of tasks within the project as it progresses, in order to support the service user researchers. This process obviously requires that researchers have sufficient sensitivity, and are able to communicate with the service user researchers about these issues. They also need to be able to negotiate satisfactory ways forward, and be prepared to increase their own task commitments in order to facilitate the service user researchers' input into the project.

Running a project

Even for researchers such as ourselves who are strongly committed to involving the public in research, there often remain fundamental tensions between including members of the public fully in research and having to deliver the research outputs and outcomes required by funders and employing institutions. The benefits are increasingly recognised in the literature (Staley, 2009; Brett et al., 2010) but it is important also to reflect on the costs, particularly the emotion costs and tensions which are not often discussed. Often the catalyst for these is the conflicting pull between the efficiency/quality drives (getting the research done to the necessary standards for funders and academic publication) and the empowerment agenda (giving service users a real voice in decision making). National policy and the literature imply the two drives are complementary but in our experience they often conflict, and this can lead to emotional work for the researcher who has to try to find a compromise that balances the competing drives. Similarly researchers often have to balance and mediate between service users' individual needs (both practical and emotional) and often inflexible institutional policy, procedures and practices. In the best case scenario, where the research is well funded, there may be a PPI co-ordinator or administrator who will take some of the pressure off the researcher and sort out the practicalities. Often, however, it will be the principal investigator or another researcher in the team who has to take responsibility for managing this tension.

A key question, particularly relevant when working with service users with long-term conditions, is how you deal with illness, particularly episodic illness which means that as a researcher you can never be sure when a service user will be in a position to contribute. This is less an issue when they are one of several individuals contributing in an advisory capacity, but becomes more intense when they are a core member of the research team and may have significant responsibilities including data collection and processing. This raises a fundamental issue about the nature of the 'contract' between the university, the researcher and the service user. Assuming as is good practice, and as our institution does, that service users are paid for their time, do you agree a formal contract with them, and if so, how do you contract for potential episodic illness? Our approach has been to avoid formal contracts and pay for hours worked on a 'casual claim' basis. This allows the service user some flexibility to balance their work and illness, and avoids committing all the institutional resource where the work may not materialise, but it does mean the potential casualisation of the

service user contribution. Moreover, if a service user is ill long-term it still leaves the researcher with a conundrum of whether to wait for their health to improve (with possible deadlines looming) or seek to involve a 'replacement' service user. In our experience, it is best to broach the possibility of a service user's having to withdraw completely from a study, and to negotiate and plan for this eventuality at the start of a project.

There is often a large amount of emotional work for the researcher in these situations, both in terms of seeking to support the service users and in managing institutional policies and practices into which the service user researcher does not easily fit. As a member of staff you are often the face of the institution to the service user, and therefore may be the recipient of their frustration (and sometimes anger) at non-service user-friendly institutional systems and practices. Many of these frustrations and tensions relate to payment and expenses issues, where university finance departments do not have a service user category of employment. As researchers we sometimes need to do things 'under the radar', adapting and reinterpreting university procedures. Such work can be time consuming and frustrating, and the researcher is never quite sure when she or he may be 'caught out' and criticised for bending the bureaucratic rules. Often this emotional work is equally hidden from institutional managers and from service user researchers. Similarly, negotiating service users' access to NHS Trusts as researchers can prove lengthy and difficult, as Trust processes are not generally structured to allow for service users in that capacity.

A final area of emotional work can be managing meetings with service users. Researchers and service users may have a common interest in research projects succeeding, but they often come with very different assumptions, aims and world views which may be difficult to integrate (Del Vecchio & Blyler 2009). Sometimes we as researchers can find it very frustrating when from our perspectives, service users digress wildly from the agenda, but we feel inhibited to challenge them directly in the same way that we would with an academic colleague. There are complex power issues in the relationship between researchers and service user researchers, but, as mentioned above, not all the power is exercised by the former; the authority to speak as a service user and dominate proceedings is a potent power for some service user researchers. In these situations, particularly when deadlines draw near, the temptation for researchers can be to take the line of least resistance to produce work that will sufficiently satisfy both the funders and the service user researchers. This can result in researchers producing outputs with which they themselves are not satisfied, as they have prioritised

the lack of tension in the research team and delivery to deadlines above academic considerations.

From the preceding, it should be evident that, even when you are genuinely committed to fully involve service users in a project, it can be hard always to do so well in practice.

Deadlines are tight, and academic colleagues are often on hand for corridor conversations, or at least they are likely to be checking emails regularly, sometimes late at night or at weekends, when service users are less likely to be available online. With the best will in the world, you cannot always manage to keep service user researchers equally in the loop with academic colleagues; and you then face the additional emotional work of the guilt that you are not living up to your own values. This emotional work for researchers in involving service users needs to be weighed in the balance along side the 'epistemological dissonance' and professionalising strategies to maintain researchers' power and status identified by Ward et al. (2009), in order to come to a more nuanced understanding of the different drivers and challenges facing researchers in this area.

However, whatever problems occur, when a project has been completed satisfactorily, it is often the case that a positive relationship has developed between all those involved. At this point, service user researchers may be keen to get involved in other research, particularly where they have acquired particular skills sets which they wish to maintain or develop further. In this situation, researchers may have to consider how to support the service users in subsequent activities. It can be argued that, having invited service users into a project, which has subsequently benefited from their particular perspective and their acquired skills, researchers have a moral imperative to be involved to some extent in their further development. Where researchers acknowledge and accept this responsibility, there are obviously further time and resource implications for them which they then need to manage.

Conclusion

PPI in research, while of undoubted merit and productive of benefit to researchers and service users, is actually more difficult and problematic to manage in the real world than discussion in the guidance and most of the literature implies; it is a classic case of dissonance between theory and practice. Researchers tend to report the positive aspects of PPI, and not the difficulties and emotional work. Academic, clinical and service user researchers need to create space for reflection on, and honest dialogue about, these 'wicked issues' within research projects and programmes, and the research community as a whole needs to

reflect more honestly on this if PPI in research policy and practice is to advance. In particular, bureaucratic academic and care systems and the expectations of both researchers and service user researchers need to be managed effectively, so that projects are not hampered by conflicting perspectives, frustrating red tape and unrealistic goals; but rather enhanced by the inclusion of diversity and the acceptance of individuals' differing degrees of engagement, capacity and skills sets.

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