Telling Different Stories: User Involvement in Mental Health Research

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Abstract

The paper looks at the developmental process of a user researchers unit based within a prestigious academic institution and the issues raised by this placement. It highlights the process by which user researchers can be effective in enabling other user voices to be heard in the context of undertaking good quality research, aimed at optimising opportunities for user participation. The key relationships with academic researchers are looked at within the context of the examples of research methodology which allows users' testimonies to be considered as evidence. The nature of evidence is discussed in the light of Foucault's theoretical position on power and knowledge, as well as that of feminist research.

Keywords: user involvement, user research, mental health services, research ethics

Introduction

This paper seeks to describe the work of the Service User Research Enterprise (SURE) and some of the challenges it faces. SURE is located at the Institute of Psychiatry in London. It is a collaborative research endeavour where user researchers and clinical academics work together. Currently, SURE comprises five researchers who have experienced distress and/or used mental health services. SURE is the only unit in UK universities to employ service users in this way. Our Director is a professor of psychology and the unit has been in existence for three years now.

It is important to note that user-focused research is grounded in the user movement. For example, this is where we hope to get our research questions and some of our methodologies. It has been estimated (Wallcraft et al, 2003) that the user movement has grown from some 15 groups in the mid-1980s to over 700 today. Over the past five years, user research has 'grown wings and begun to fly' (Strategies for Living, 2003) and this development is part of the user movement itself. Nevertheless, local service users who do not have a background in research can be suspicious of service users who have secured jobs at an institution like the Institute of Psychiatry. This suspicion needs to be taken seriously.

In this paper, I will look at user involvement in research committees, an example of collaboration that worked well and the model of participatory research that is often used in our research at SURE. The latter part of the paper looks at some of the challenges faced by SURE and the paper ends with some more theoretical questions.

User Involvement in Research Committees

The NHS Trust affiliated to the Institute of Psychiatry is the South London and Maudsley NHS Trust. The two institutions together have a Research and Development Steering Group (RandD SG) which allocates funds, sets research priorities and oversees research done in the Trust and the Institute.

When SURE was first mooted, an application was put to the RandD SG that it should include user representation. We were very anxious to avoid tokenism in the sense of one or two users sitting on the Committee completely unsupported. To do this, a reference group was set up to support the two representatives who would attend the RandD SG. This reference group is known as the Consumer Research Advisory Group (CRAG) and it has 15 members. It has been in existence for two years and has had representation on the Committee for that time. Two SURE workers support the CRAG. In addition, one of these is a full member of the Committee and part of their remit is to support the CRAG representatives. The full CRAG has the opportunity to see all Committee papers and to discuss what are the most important points for the representatives to raise. The representatives then feed back the discussions on the RandD SG to the full CRAG meeting. As far as we are aware, this structure is unique in user involvement in RandD both inside and outside mental health.

In December 2002, the CRAG held a conference for local service users to identify their priorities for research. Many of the identified priorities lay at the social end of the care spectrum rather than the health end. The CRAG was successful in making 'psychosocial interventions' the number one priority for research in the Trust and the Institute.

However, this structure is not without problems.

Knowledge of research is variable amongst CRAG members and even more so amongst those who attended the conference. This introduces a power imbalance between service users who are not primarily researchers and those who are. 'Support' is not always benign. Imbalances of power occur in many ways in user research and will be a central theme in this paper.

An Example of Successful Collaborative Research

Much collaborative research, or user involvement in research, is fraught with difficulties. Here again there are issues of power and control, this time between user researchers and professionals. I will return to this. However, at this point in the paper I would like to give an example of a piece of work where collaboration between service user researchers and clinical academics worked well. The work was a Review of Consumers' Perspectives on Electroconvulsive Therapy (ECT) (Rose et al, 2003). This was commissioned by the Department of Health alongside a meta-analysis of trials of the effectiveness and safety of ECT (UK ECT Review Group and John Geddes, 2003). The two empirical researchers on the Consumer project had themselves experienced ECT. The team also included a psychiatrist and a psychologist and their role was to help with the analysis and the write-up.

The Review relied on existing materials - we did not gather any new information, for example, in the form of interviews. We collected 26 articles written by clinical academics and 9 authored by consumers or in collaboration with consumers. We also collected 139 'testimonies' or first-hand accounts of receiving ECT and most of these were in electronic form, for example, from the Internet.

The academic articles reported much higher levels of satisfaction with ECT than either the user-led research or the testimonies. The standard response to this is that the user-led research and the testimonies relied on biased sampling. However, because the user researchers on the project had experienced the treatment and also experienced being in hospital and being interviewed as to whether this treatment had helped, it seemed to us that something else was going on. The academic articles that reported the highest levels of

satisfaction studied this in a very particular way. Satisfaction interviews were conducted as soon as treatment ended, or even during it, and the interviewer was the treating doctor who asked a few simple questions. From our own experience, we thought that, under these circumstances, users would not want to complain or might not tell the truth in order either to avoid more treatments or simply to get rid of the doctor who was asking yet more questions! We therefore argued that these academic papers were over-estimating user satisfaction with ECT. This use of our experience led to novel results, in contrast to received psychiatric wisdom, being distilled from the material we had to hand.

The academics in our team helped with the analysis and the write-up and this was very useful. Another of our findings was that even where people had signed a consent form for ECT, up to a third felt there was pressure to do so and so they did not freely choose to have the treatment. We had a lot of help from our academic colleagues in respect to mental health legislation and case law and the psychiatric literature on 'perceived coercion'. The psychologist on the team also provided considerable help with the issue of memory loss. According to a significant number of users, persistent memory loss is a very detrimental side-effect of ECT. This collaboration, then, was a successful one.

This piece of work has also had policy implications. At the same time as we were conducting the study, the National Institute for Clinical Excellence (NICE) was carrying out an appraisal of ECT. NICE used our report in their appraisal and the criteria for giving ECT are now much more restrictive.

Participatory Research

Participatory research has a relatively long history and takes various forms (De Koning and Martin, 1996; Kemshall and Littlechild, 2000). Its fundamental tenet is that participants are not passive subjects (Trivedi and Wykes, 2002) but are involved throughout the research process. It must be said that in mental health research, participants are rarely anything but passive subjects.

In pure participatory research, the research question comes from the participating community and the object is to bring about social change. The first of these is difficult to achieve in a funding context where the funder decides what the subject of the tender is to be. It is also sometimes a hope rather than an actuality that social change will be brought about. However, when participatory research is inflected by a user model there is one way in which the participants are brought closer to the research process. This is because the researcher is a mental health services user themselves. In this way, there is a leavening of the power relations between researcher and researched as both have experience with mental health services and there is an immediate understanding on both sides that experiences are shared.

To give an example of participatory research from SURE's work, I will take a project on continuity of care. This was commissioned as part of a group of projects on continuity of care for vulnerable groups. The funders specified that for each project there should be an investigation of users' and carers' perceptions of continuity of care from their own perspective. As part of a larger project, this investigation is being carried out by SURE. Prior to this project, only academic and managerial views of continuity of care had been considered and users and carers were never asked what their experiences might be.

The methods used were qualitative and the researchers introduced themselves as users of psychiatric services. There were eight focus groups - three for carers and five for users - and each met twice. In the first meeting, participants were invited to 'tell their story' of their contact with psychiatric services. This was followed by the introduction of the idea of continuity of care. No participant was familiar with this term but astute probing meant it was possible for them to relate it to their own experiences. At the second meeting of the focus groups, a great deal of time was spent feeding back what we had gleaned from the first meeting. This was to check that we had fully captured what people meant to say and to give them the opportunity to retract, add or change statements.

Later in the second meeting, participants were asked to rank elements of continuity of care. Some of these had been taken from the academic and clinical literature, re-written to make them more accessible. The rest had been distilled from what participants had said at the first meeting. We asked participants to rank these elements both individually and collectively. Throughout the process, the main researcher kept in touch with participants both by phone and by writing thank you cards. Participants were paid for their time. Only one person dropped out between the first and second round of focus groups.

From these exercises, we derived two measures of continuity of care - one for users and one for carers. Participants were then invited back to be part of an expert panel, which scrutinised the measures. They made many comments. The measures were then taken to expert panels made up of people who had not been part of the focus groups and they were asked to comment as well. It is important that these were called *expert* panels as we see participants as experts in their own experience. We showed the final questionnaires to the original participants. In an effort to find out whether the measures accurately reflected what they thought about continuity of care we simply asked whether they felt ownership of the questionnaires. They unequivocally did so and we hope that this means that the process was an empowering one for them.

The participants in the focus groups will be kept in touch with developments in the project through newsletters and meetings. This, together with the fact that the researchers were themselves service users, means that the research model approaches that of participatory research. Nonetheless, we have to say 'approaches' as the research question came from funders rather than the community and it is as yet unclear what concrete policy changes may be brought about as a result of this work. On the other hand, what is novel about our approach is that the researchers come from the same 'community' as the participants.

Challenges

Many challenges face the endeavours of user-focused and collaborative research. Some professionals are openly and frankly sceptical

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about the developments we have been describing. Tyrer writes:

> *There is a real danger that the engine of user initiatives in mental health services, although positive in principle, will accelerate out of control and drive mental health research into the sand.* (Tyrer, 2002: 406)

The only way in which user-focused and collaborative research can withstand such a 'heading into the sand' stance is by delivering good quality research outputs with a demonstrable benefit to the research community, the practitioner community and, most importantly, to users and the user movement.

Another problem arises now that funders are asking for user involvement in research projects. This can lead people preparing proposals for funding to approach units like SURE to rubber stamp the proposal. This we refuse to do. In an attempt to overcome this difficulty, we now run a 'SURE clinic' every week where clinical academics from the Institute of Psychiatry can come and get advice on involving service users in their research.

We can now return to the issue of power differentials between user researchers and professionals. There are many ways in which professionals can have more power than user-researchers in a collaborative project. First, even if a user-researcher has all the required degrees, it is likely that they will not have same career track record. Mental health problems can interrupt careers but there are also issues of discrimination and stigma, which may prevent people getting jobs. For example, Occupational Health departments may need some persuading that having a diagnosis is a qualification for user-led and collaborative research.

Linked to this, there are salary and status differentials so that even experienced user researchers in a collaborative project will be perceived as 'junior'. Of course, some user-researchers acting as consultants to research projects do not get a salary at all. They receive money under 'permitted work' rules despite putting in enormous amounts of effort. There are, of course, problems with the benefits system here.

Finally, a situation may arise where the user/ professional research relationship is overlaid by an implicit patient/doctor *clinical* relationship. It is as if some collaborators are regarding you through two mirrors - one as a researcher and one as somebody's patient. We have occasionally been in research meetings that suddenly felt like a ward round. It must be said though that this has not happened in the context of SURE itself. All these things mean not only that users have less power but that their knowledge and research may not be accorded the same status as professional work. It is because of this that full 'partnership' in research between users and clinical academics is very difficult to achieve.

The Future

The main problem we face in doing user-focused or collaborative research is that it is fashionable now but may soon pass into obscurity. What we need are strategies to avoid this and to give such research credibility so that it is taken seriously without diluting its political agenda - to change things, and not just services, so that people with a mental illness diagnosis can live the kinds of lives they want.

First, and most simply, we have to deliver. There is no point in getting in large grants if you cannot deliver on them. Of course, this is not simple because what counts as delivering a good piece of work may have different criteria for users, professionals and funders. We think that an important issue here is that we need to make our assumptions explicit - actually, we think all research should do that because all research has assumptions. But because we are arguing from a different standpoint to mainstream research we need to be very explicit about that standpoint, its assumptions and how it affects both process and outcomes. This point is developed below.

Second, and related to this, we need a programme of evaluation of user-focused and collaborative research. We need to know whether it complements or even challenges mainstream research. We need to know whether it leads to different processes and outcomes. Importantly, what are the policy implications of this kind of research? Is it value for money? I am pretty

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confident that all these questions can be answered in a way that shows user-focused and collaborative research is not only a valuable but a *necessary* complement and balance to professional research. But there is no point in just saying it - it has to be demonstrated.

Third, we need to build research capacity amongst those service users who are interested. We have mentioned already the difficulties in education and in careers that may beset people with mental health problems - and discrimination has not gone away, despite the Disability Discrimination Act. So one of the things needed is just to give people confidence that they can do this if they want to. Of course this is not to imply that the majority of service users wish to put their energies into research. Nevertheless, at the moment, SURE is trying to build research capacity - by employing service users and registering them for PhDs, by training local service users, by having users as co-facilitators in research or as members of Reference Groups and so on. We have started but have a long way to go. Of course professionals need their capacity built too. And professionals need to learn what user involvement in research can and should amount to. They need also to think about their own role and the possibility that they will have to relinquish some power and control.

The rest of this paper is devoted to more theoretical issues. User-research is now sufficiently established that we can go beyond the nuts and bolts of doing research and consider some wider questions.

Criticisms We Can Anticipate

As must be clear, user-focused research concentrates on the *experience* of participants. Increasingly we are coming to be called 'experts by experience' (Faulkner and Thomas, 2002). But this can provoke criticisms from mainstream thinkers. They are likely to say that the kinds of knowledge that are based on, or influenced by, direct experience are 'subjective', 'biased' and produced by people who are 'over-involved'. It will be said that we are too close to the subject and so cannot be objective, that we use methods such as participatory research which will never guarantee an unbiased approach and that relying on one's own experience in the process of producing knowledge is a recipe for unscientific disaster. Indeed, these are the criticisms of participatory research made by Frideres (1992).

These criticisms rest on a certain view of knowledge production which broadly can be described as positivist. It is held that scientific knowledge is generated in an unbiased and objective way and that the subjectivity of the scientist exerts no influence on the knowledge that is produced. Randomised controlled trials are held to be the apex of this method in medicine because there are no biases in the selection of subjects and the outcome measures have been tested for their reliability and validity.

We can question whether this image of science is an accurate reflection or more like a 'myth'. Outcome measures always originate with a scientist or group of scientists and so their individual and collective ideas are what produce these measures. Reliability only means that results are replicable between individual investigators, which is hardly surprising as all will have been trained to use them in the same way. Validity is notoriously difficult to assess. The process of 'blinding' where the investigators are supposed not to be aware of who has had an intervention and who has not often does not work as both 'subject' and investigator can guess who falls into which class.

Standpoints

It can be argued that mainstream research is not the universal rationality that Enlightenment thought promised but that it comes from a particular standpoint. In psychiatry, that standpoint is the perspective of those who deliver services and treatments and who research them (usually the same people). If this is so, user-focused research is not biased and subjective but comes from a different standpoint - that of those who receive services and treatments.

The standpoint of mainstream research may also be thought of as not universal but as partial and incomplete. It derives research questions and supplies answers from its own theoretical and methodological perspectives and the clinical issues that preoccupy mainstream researchers and funding

bodies. This argument is anathema to some mainstream researchers because it smacks of relativism. There is no 'universal knowledge' but only particular or situated knowledge produced through different standpoints. Different standpoints produce 'different truths'.

Here power arises again but in a different way. Mainstream knowledge can seem like 'common sense' and so it is elevated to the dominant discourse. In this way the knowledge productions of other groups and other perspectives are undermined. Foucault calls this the 'power/ knowledge axis' in an attempt to explain power relations at the level of knowledge itself.

Different Knowledges

So, in this case we have different knowledges, one based on science and one based on experience. The next step is how we evaluate these different knowledges. Are all equally valid? Is this really relativism?

We can learn here from feminist epistemology. Epistemology simply means protocols or theories for producing valid truths. Feminists such as Sandra Harding (1993, 2004), Nancy Hartsock (1998) and Hilary Rose (1994) have argued that women have been marginalized from science. Lakoff and Johnson (1981) were the first to point out that Enlightenment thought rests on certain oppositions: reason/unreason, rational/irrational, culture/nature, intellect/emotion, mind/body. Science has elevated the first set of these oppositions and, of course, these are attributes traditionally ascribed to men. By making male attributes the acme of science, women and women's experiences are excluded. But this is a sleight of hand as it pretends that male attributes are the universal attributes of thought. In this way, mainstream research produces knowledge that is partial and incomplete. It only looks like 'common sense' because it has elided and hidden the knowledge of marginalized groups.

It seems to me that these oppositions also describe the power relations between psychiatrists and service users, probably more so than in the case of power relations between men and women. We are defined by our unreason or irrationality, closeness to brute nature and overwhelmed by our emotions.

Rationality and intellect are the province of those who help us and who do research 'into' our condition.

It is obvious that the structuring of social life between men and women is not the same as the structures that characterise power relations in mental health. Service users are a particular group of people and so are mental health professionals. Most of social life takes place outside this world. But we can say that psychiatry and psychiatric knowledge have power over users' knowledge and we can also point out that there is a societal dimension to this. That is the existence of stigma and discrimination and the pervasive fear of madness in society.

Of course, sometimes we *are* irrational and emotional. But this only matters if the rationalist/ intellectual model of science is taken as the only and universal way of producing knowledge. We need to reclaim our voice. Doing this means critiquing a science which rests on a false universality and producing our own knowledge based upon the meanings which we inhabit. We will not produce the same truths as mainstream research: that much is clear. However, there are two things. The designated irrationality of mad people must not be allowed to downgrade the knowledge we produce. As feminist epistemologists have shown and I have already said, such downgrading rests on a false view of Enlightenment thought as universally true and its epistemologies as the only way of producing valid truths.

The second point applies mainly to 'collaborative' research. We need to try and open up a dialogue with mainstream researchers. Foucault has written that psychiatry is a 'monologue of reason *about* madness' (Foucault, 1967, p.ix, italics original). He argues also that this monologue has silenced the voice of madness. We must try and turn this monologue into a dialogue with mainstream researchers. At an abstract level there would be little common ground between what is written here and mainstream thought. But in specific projects, there is more room for negotiation and seeing where the lines of agreement and disagreement emerge.

There is a way in which research by mental health

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service users may produce a more complete knowledge of the world than mainstream research. In terms of feminism, the argument is indicated in the work of Nancy Hartsock (1998) but it is not developed. The argument is that women have access to both the dominant discourse and the discourse of the disadvantaged. In that case, their knowledge of social life is richer and more complete than the notion of a universal knowledge based on one perspective only would imply. It can be argued that these ideas could be applied to the field of mental health.

Whether we like it or not, mental health service users are exposed to the discourse of mainstream psychiatric practice. We cannot help but know about it - it surrounds us. Most users may not know the world of mental health research but they certainly know about its consequences. The treatments and services they receive are based on this knowledge. But users also have access to the world of our own experience and often combine the two either happily or in a discontented way.

This access to both kinds of knowledge is especially relevant when users are doing research, although it is not confined to research. We can access both discourses, can speak two languages, have a double identity. This double identity is clearest when we use both our own experience and our research expertise when trying to carry out user-focused research. In this way, we can argue that the knowledge produced by users is more complete than that produced by mainstream researchers. Of course, relations of power and control mean that struggle will be necessary before this is necessary and it is likely to take quite some time.

The translation between the discourse of professionals and that of users is not an easy one. We must take the best of 'science' but always inflect it with our own and others' knowledge of experiencing psychiatric services. This is particularly important for a collaborative research unit such as SURE. We work alongside clinical academics and although this can be difficult it means that our work is influenced by more than one stream of thought and hopefully then produces more complete pictures of treatments, services and people's lives.

Conclusion

This paper has described some positive examples of collaborative research between users and professionals without minimising the difficulties. I have also argued that, now user-research has reached a certain stage of development, we need to go beyond method in the sense of techniques and start to think about methodologies and theory. We also need to be aware of the many different ways in which power relations are active in the field I have been describing.

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