

The role of service user research in generating knowledge-based health and social care: from conflict to contribution

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English This article draws on the first-known review of user-controlled research, to explore the potential contribution of service user knowledge and service user research to the development of evidence-based policy and practice in health and social care. It locates this discussion in the context of competing research ideologies and the broader history of user involvement and user-controlled research. The concept of 'valid' knowledge remains contested and the article suggests, drawing on the views of service users, that their research and experiential knowledge is likely to have a helpful and particular role to play in the generation of useful knowledge as part of a wider spectrum of research approaches and knowledge production, and that the position of such research should be safeguarded to enable this to happen.

Français Cet article se base sur la première revue répertoriée de la recherche contrôlée par l'utilisateur, en vue d'explorer la contribution potentielle des connaissances des utilisateurs de service au développement de la politique basée sur les preuves et la pratique dans les soins de santé et l'aide sociale. Il place la discussion dans le contexte des idéologies de recherche rivales et l'histoire dans son sens plus large de l'implication des utilisateurs et de la recherche contrôlée par les utilisateurs. Le concept de connaissances « valables » reste contesté et l'article soutient, en se basant sur les opinions des utilisateurs de service, que leur recherche et leurs connaissances acquises par l'expérience ont de fortes chances d'avoir un rôle utile et particulier à jouer dans la génération de connaissances utiles en tant que partie d'un éventail plus large d'approches de recherche et de production de connaissances. Il affirme que la position de ces recherches doit être sauvegardée pour que cela puisse se produire.

Español Este artículo se basa en el primer examen conocido de investigación de usuario controlado para explorar la contribución potencial del conocimiento del usuario del servicio y la investigación del usuario del servicio para el desarrollo de la política basada en la evidencia y en la práctica en la salud y la asistencia social. Esta discusión se sitúa en el contexto de ideologías competitivas de investigación y en la historia más amplia de la implicación del usuario e investigación del usuario controlada. El concepto de conocimiento 'válido' permanece en disputa y el artículo sugiere, basándonos en las opiniones de los usuarios del servicio, que su investigación y conocimiento experimental es probable que tenga un papel útil y particular que desempeñar en la generación de conocimiento útil como parte de un espectro más amplio de enfoques de investigación y conocimiento de producción, y que la posición de tal investigación debería ser protegida para permitir que esto suceda.

Key words

user involvement • user-controlled research • knowledge • evidence-based practice

Introduction

The focus of this discussion is the contribution service users can make to the development of evidence-based policy and practice. This is addressed as part of the broader focus of an Economic and Social Research Council (ESRC)-supported seminar series concerned with the generation of 'valid knowledge' or 'evidence' to understand 'what works' in health and social care. There is as yet no consensus about the role service users can play in knowledge formation and different approaches have been developed. The purpose of this article is to gain a clearer idea of the contribution service users can make, based on current evidence.

At the time of writing, at least two initiatives have been developed (by the Social Care Institute for Excellence and Involve) to find out more about the outcomes and benefits of service user involvement in health and social care policy, practice and research. These seem to follow from a strong sense that as yet, while interest in such involvement has greatly increased, there is little evidence of its value or efficacy. Sarah Carr's 2004 report, which raised the issue of whether user involvement makes a difference to social care services, reinforced mounting interest in this topic, not least because it found that little attempt had up until that time been made even to ask the question, let alone answer it (Carr, 2004).

At the same time, interest in outcomes from user involvement – in research and elsewhere – highlights a broader issue, which perhaps lies at the heart of much of the interest in this question. It suggests that careful enquiry will enable us to find exactly what difference (particularly what improvements, if any) such involvement can and has made. It is as if there is an expectation that such enquiry will enable the production of a set of neutral findings about which there can be consensus, so that we can all 'know' what gains and losses result from user involvement in research. But a preliminary point needs to be made here. It is in the very nature of user involvement that such a result is unlikely. This is not to say that we should not be searching for the most helpful and rigorous approaches to user involvement in research to maximise its usefulness. That is certainly a necessary and worthwhile task. However, user involvement in research is unlikely to be amenable to the production of neutral and agreed findings. By its very nature the issues it raises are philosophical, moral and methodological, rather than narrowly technical and objective.

It is this basic point, that discussion about user involvement in research (as elsewhere) is essentially value-based, that necessarily underpins any consideration of its role. This issue cannot be ignored. It needs to be taken into account. Doing so reveals opportunities for the critical consideration of such research and provides a starting point for exploring the contribution of user involvement in research to the generation of valid knowledge and evidence.

In looking at the part that service user research can play in knowledge formation, this article explores the philosophical, methodological and epistemological issues involved and draws particularly on a recent review of user-controlled research commissioned by Involve, the body established by the UK government to advance public, patient and user involvement in health, public health and social care research. This review provides a data source for understanding what service users see as the characteristics, strengths and weaknesses of such user-led research. The article examines these to help

assess the contribution such research may have to offer in knowledge formation, as well as some of the challenges that will need to be addressed for this to be possible.

A question of validity

A key issue is what counts as validity in knowledge and evidence. According to the dictionary, 'valid', in the present context, means 'sound, defensible, well-grounded' (Fowler and Fowler, 1964). But the question is, of course, in whose estimation? We know that the concept of validity in research and what is seen to count as valid, is a complex and heavily contested one with a long history. This background can only be briefly reported here. Crucially, it seems to relate to two overlapping areas of potential disagreement. These are concerned with:

- research approach and methodology – particularly related to traditional quantitative and qualitative approaches;
- standpoint and identity – associated with the differing perspectives of 'scientific researchers' and service users.

Research approaches

Dominant research discourse, particularly in medical and health research, continues to be tied to quantitative research approaches based on randomised controlled trials and traditional systematic reviews. These emphasise positivist values of 'neutrality', 'distance' and 'objectivity'. It is this discourse that has historically been associated with the development of 'scientific' research and which is still particularly linked with the production of 'high-quality' research associated with qualities of reliability, replicability and validity.

The roots of such modern research are generally traced to the 18th-century western European Enlightenment. The Enlightenment's approach was one based on belief in the primacy of 'reason' – thus it came to be known as the Age of Reason. Its philosophy rested on belief in the human capacity to think, to reflect, to deduce and to reason. It was the age that saw the burgeoning of modern western science with its preoccupation with experiment, testing, measurement, comparison and demonstrability. This was associated with a desire to challenge the existing dominance of 'unreason', associated with metaphysical and theologically based understandings and knowledge formation. Modern research traditions can be seen as having their origins in this concern to develop knowledge based on what can be discovered through human powers of reason, coupled with the development of rigorous 'scientific' approaches to understanding, causation, measurement and hypothesis testing. This has given us modern definitions of research like Kerlinger's: the systematic, controlled, empirical and critical investigation of hypothetical prepositions about presumed relations among natural phenomena (Kerlinger, 1970, p 8).

It is also a key inspiration for positivist research, that is, research as Hollis has described it, 'which applies scientific method to human affairs conceived as belonging to a natural order open to subjective enquiry' (Hollis, 1999, p 41). While significant

progress has been made in achieving acceptability for qualitative research approaches, these still occupy a subordinate position in terms of the value attached to them in dominant research discourse and in dominant perceptions of what counts as means of generating high-quality data to provide an evidence base.

Different understandings of validity tend to be held by proponents of these two main research approaches. Those who favour qualitative research approaches are frequently critical of the positivist value base of traditional quantitative research, while, for example, quantitative researchers in the medical field are cautious about the emphasis on subjectivity and values in qualitative research.

Standpoints

Service users have tended to take a different view from traditional mainstream (positivist) researchers regarding the validity of research findings as an evidence base for policy and practice. There is now a history of over 30 years of such discussion from service users, their organisations and service user researchers. This was initially developed by disabled people and first came to wider attention over the evaluation of the Leonard Cheshire Le Court residential home by a team of 'independent' researchers from the Tavistock Institute. Disabled residents in the home felt that their own views about their ability to live independently outside an institution were ignored and devalued. They therefore invited in researchers, in the belief that the findings of impartial 'experts' would confirm disabled people's views about the institutionalising and discriminatory nature of life in residential services and add credibility and validity to their accounts.

In the event, the researchers rejected residents' wishes for more independence and autonomy as 'unrealistic', seeing their situation as an inevitable consequence of their disability (Miller and Gwynne, 1972, p 15). It was because the researchers saw disabled people as essentially 'parasitic' that Paul Hunt, one of the leaders at Le Court and subsequently of the British disabled people's movement (Beresford, 2005), dismissed such researchers in turn as 'parasites' themselves (Hunt, 1981, p 43). Miller and Gwynne discussed at length their efforts to conduct 'balanced', 'detached' and 'scientific' research. Hunt, however, highlighted the study's bias, arguing that it was entrenched in an individualistic/medical perspective of disability, which understood disabled people and their impairment to be the barrier to inclusion, rather than acknowledging broader social, political, economic and other barriers.

For Hunt and other disabled people involved with him, there was no neutral position for disability researchers. They saw research and researchers as historically aligned with the service system and its ideology, and felt that this was essentially damaging and disempowering to disabled people themselves. While this has not necessarily been the stance of all service user research since, it certainly represents one of its significant starting points. Such research has been characterised by a wariness, if not a suspicion, of the ideology underpinning mainstream research approaches. Service user research can also be seen as part of a broader research approach, which challenges positivist research and is particularly associated with feminist scholars.

Valuing experiential knowledge

Hunt and other disabled residents placed value on their own experiential knowledge, and this has been a feature of disabled people's and service users' research ever since. Experiential knowledge, that is to say knowledge based on first-hand experience (of disability and other oppressions), has been seen by its advocates as a form of knowledge that has value like other forms of knowledge. The fact that it is based on subjective understanding is not seen to invalidate it. While some critics have suggested that disabled people and other service users have sought to privilege their 'knowledge claims' over others, it is more accurate to say that they have sought to gain some credibility and legitimacy for them, alongside other sources of knowledge (and evidence) (Glasby and Beresford, 2005).

Service user contributions to knowledge

Thus we can see that there are competing views about the validity of research-based evidence relating both to different roles and perspectives and to different research approaches. We cannot assume that there will be agreement about what counts as valid evidence among researchers, practitioners, the public or service users. That being so, the aim of this discussion is to explore the contribution that service users think they can make to the generation of knowledge, without assuming that there will necessarily be any consensus about this among other stakeholders.

Service users have long made a contribution to knowledge in health and social care. Their views have been sought as a data source by health and social care researchers. Historically, it has been the latter who have collected, collated and analysed these views, rather than service users themselves. Thus understandings of service user views have tended to be mediated by the interpretations of non-service users, particularly those of researchers and policy makers, and it has been service users' knowledge, rather than service users themselves, that has been drawn into formal research.

More recently, with emerging interest in 'public, patient and service user' involvement in research and evaluation, service users themselves have been engaged in research – both in the research process and in research structures. Individuals and their organisations have become involved in research projects in at least three ways, through:

- (1) *Involvement in conventional research projects.* The participation of service users to a greater or lesser degree, in all or some aspects of the research process, is the commonest expression of user involvement in research. Such involvement may essentially be an 'add-on' to existing research methods and methodology, but it may nonetheless be – and be experienced as – a helpful and truly participative experience by service users. Equally, it is the form of involvement most likely to be subject to criticism as a tokenistic or 'box-ticking' exercise.
- (2) *Collaborative research.* Here, service users and their organisations are involved in undertaking research on a formal joint basis with conventional researchers and research organisations. There are a growing number of such initiatives, based primarily in non-user-led (research) organisations. While issues of power

inequalities may remain because of overall inequalities in status, power and resources between conventional researchers and service users, this approach has led to a significant and growing number of successful collaborations that have been valued by both groups of stakeholders.

- (3) *User research*. This is also known as survivor research, user-controlled research, user-led research and emancipatory disability research. These terms are used both synonymously and to denote overlapping, sometimes similar, research approaches, developed in some cases by different groups of service users. Here the emphasis has been on service users initiating the research and controlling it themselves. This does not necessarily preclude the involvement of non-service users in the research process, but it is likely to mean that they will come under the control of service users, service user researchers and service user organisations.

This article focuses on the third of these ways in which service users have come to be involved in research and evaluation – user or user-controlled research. This is not because it is seen as preferable to the other two types of involvement. It is chosen because the indications are that service users see it as able to make a particularly helpful contribution to the development of knowledge (Turner and Beresford, 2005), and it thus has particular value as a case study. In addition, a review of user-controlled research, focusing on its ‘meanings and potential’, was recently commissioned by Involve, the National Health Service (NHS) research and development organisation with responsibility for supporting public, patient and service user involvement in health, public health and social care research and evaluation. This was published late in 2005 and provides a helpful evidence base for this discussion. The author of this article was involved in producing the review, which was based both on a thorough literature review and on the direct views of a wide range of service users and service user researchers, gathered through a survey, individual interviews and group discussions (Turner and Beresford, 2005).

The review sought to conform to current understandings of a user-controlled approach to research and evaluation in a number of ways. Such a review had long been called for by service users, user researchers and their organisations and was thus consistent with their priorities. The project was managed by Shaping Our Lives, a national, independent, user-controlled organisation and network. It was undertaken by service users, with the involvement of an ‘electronic’ steering group made up of service users, as well as an advisory group including service users. It was also committed to the emancipatory goals of research as a means of advancing personal empowerment and broader social change. An emphasis was placed on including diverse service user perspectives, and individual interviews and group discussions were held in addition to the review of existing literature and other sources, to maximise user involvement in the project (Turner and Beresford, 2005).

Clearly, this review cannot offer a definitive response to the issue under consideration, since it represents a snapshot tied to a particular time and does not include the perspectives of all interested stakeholders. However, the expectation, as has been made clear, is that there is unlikely to be consensus among different stakeholders. The review does, however, provide a detailed and in-depth discussion that has been

carefully produced, so that its own strengths and weaknesses as a data source are open to examination. As such, the review and this discussion of its findings, may offer a starting point for further consideration and additional enquiry.

Service users who participated in the review seemed to feel that their research had a particular contribution to make and brought with it particular benefits. Those whose views were sought referred to some of the benefits that they associated with user-controlled research when they talked about its definition, values, principles and good practice. They also referred to benefits in general discussion of user-controlled research. As one service user put it, 'It has identified new theories, new paradigms and new ideas which give explanation for our lives' experiences'.

Participants were also asked specifically what, if any, gains they felt user-controlled research had to offer. This question both highlighted fresh issues and confirmed the importance of others that they had already referred to, including:

- the capacity to be useful;
- the identification and development of new issues;
- the ability to be more inclusive;
- personal benefits for research participants.

The capacity to be useful

Service users placed an emphasis on the usefulness of user-controlled research as one of its key contributions. They felt it was more likely to address issues of relevance to service users because it followed from them and their concerns. The control and involvement that service users had were also seen as inherent benefits in their own right. Thus:

'It provides the real experience of those using the service.' (Disabled person)

'Good research means that it comes from service users. The project I worked on with women with learning difficulties came from them – they asked for the research, they wanted to know about health information, they were saying that when they go to the GP [general practitioner] there isn't any information that they can access. It all came from them. So in a way you have to take a step back even from the first stage if there's going to be true user involvement and research that we want that's going to make a difference in our lives and is going to be implemented at the end of it.' (Disabled person)

'User-led research can enable intervention to become effective and economically efficient. I did a study of wheelchair users and interviewed 143 consumers. Every single one of them said that there were bits of their lives that they could do if they had the right wheelchair but nobody ever asked them what they wanted to do, so they never had the right wheelchair. So they couldn't get all round their homes, they couldn't get to work, they couldn't do their gardens, they couldn't look after their kids, they couldn't do their shopping. They'd been given wheelchairs that fitted the

medical criteria and clinical judgement but nobody actually asked the consumer what they wanted to do and where they wanted to go. You can't give somebody a proper wheelchair without knowing these things, you've got to get all these details from the user. It's exactly the same in every other area of health and social care. If you don't find out what priorities an individual has but choose for clinical, medical or service priorities, then you are missing the target. The money is there to help the user but if the service provider decides that it is not going to listen to the user and their priorities and follow the service's priorities instead, then they are missing the target and wasting their ammunition.' (Disabled person)

'If the questions have been set by someone who has been in the situation, they are totally different from questions that have been put forward by any other group because we have had the experience.' (Mental health service user/survivor)

'You are more likely to come up with what people need and want. You are more likely to ask the right questions.' (Older person)

The identification and development of new issues

One mental service user/survivor highlighted how user-controlled research had already opened up new areas for development. She said: 'You get a fresh perspective' and pointed to the whole field of alternative approaches, including spirituality and spiritual healing, in which user-controlled research has encouraged new interest and developments. Other participants pointed to how the NHS has been adopting alternative and complementary approaches to health in the light of evidence provided by service users. Some suggested that any user involvement in research could offer its own helpful insights but that user-controlled research could go beyond this and offer more:

'User-controlled research is working from the inside and going out whereas most research is people looking at something from the outside and going in, so the perspective is very different in user-led research because it starts from the inside.' (Mental health service user/survivor)

'[It is] better informed if done well; more relevant to the reality of living as a disabled person; more likely to challenge established perceptions and inform social change.' (Disabled person)

The ability to be more inclusive

Participants also referred to the capacity of user-controlled projects to have a more inclusive approach to research that encouraged more diverse involvement. They also saw the benefit in terms of research being a form of collective advocacy:

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'User research is a way of advocating on a wider scale. I can go along to a meeting and talk about my problems and they can just say it was my individual experience. But if I go and research it thoroughly and come up with some findings, then they have to listen. So it becomes a kind of service user representative.' (Mental health service user/survivor)

One participant made the point that the benefits of user-controlled research are also felt by service providers:

'There is a difficulty [for service providers] in finding the right research method to ensure that people who use services are able to express their needs properly. How the questions are put is very important. Users may be afraid of losing their support if they answer adversely. Service providers need another method to make sure that they get users' real ideas out.' (Disabled person)

Personal benefits for research participants

Service users were anxious to point out that the benefits from user-controlled research should not just be seen in terms of improved research. They emphasised that user-controlled research was a positive experience for participants – as all research should be. For example:

'A lot of user-controlled research has a struggle to make things better for people's lives. But it can have a particular benefit in that it is a much more positive experience for people to be involved in. It's a positive experience for people to have other service users with skills doing it with them on the basis that they have a sense that [the researcher] will have a belief in what they say and understand them.' (Mental health service user/survivor)

'Being involved with projects can give people self-confidence. Giving people an opportunity to be properly involved is a very positive experience.' (Disabled person)

'It is empowering for participants and researchers.' (Service user)

Service users saw empowerment not only as a principle of user-controlled research but also as one of its benefits:

'I think that that should be an aim of research, that the research process should be built in such a way that it allows people to be reflective.' (Disabled person)

The importance of process

One of the major issues that has emerged in work on user-defined outcomes, as well as other research undertaken by Shaping Our Lives (which jointly carried out this review for Involve), is that good outcomes tend to come from good processes

(Turner, 1997, 1998). It may be helpful to relate this to research itself. Clearly, if research is meant to serve a positive purpose, its process needs to be empowering rather than potentially disempowering. Not only did some service users make clear this connection, but they also saw user-controlled research as having a particular capacity to deliver empowerment.

It might be argued that some of the particular strengths that service users saw in user or user-controlled research were not particularly concerned with making a contribution to knowledge. However, it might also be argued that a capacity to support inclusion, to encourage people's participation in research, to identify relevant new research areas and to generate useful research – the qualities highlighted by service users – would all have a positive part to play, even if only indirectly, in developing knowledge.

The commitment to making change

It was not only service users who laid particular stress on the commitment of user-controlled research to making change. The literature about user-controlled and related research reflects the same emphasis. This is not to say that other research approaches have not also been linked with making change. However, what distinguishes user-controlled research is its identification with a strong commitment to, and capacity to make, change in line with what service users want.

This links with the example of disability research discussed earlier, the Tavistock Institute evaluation of the Leonard Cheshire Le Court residential home. Not only did this experience lead to distrust of mainstream research among some disabled people, it also led them to pioneer a different approach – emancipatory disability research – which they hoped might be more supportive of their rights and needs than traditional medicalised research. Emancipatory research has not only played a significant role in making possible change in the lives of disabled people, it has also provided a body of evidence to show that the findings and conclusions of the Tavistock Institute researchers about the inability of disabled people to live independently were incorrect. Such research can therefore be seen to have generated knowledge that can be shown to have wider validity – beyond the disabled people's movement.

Within the context of disability, emancipatory research has played an important part in making the case for the development of direct payments policy and practice, which has offered a new way for disabled people to secure appropriate support to live their lives on more equal terms with non-disabled people (for example, Zarb, 1997; Hasler et al, 1998). The work of disabled researchers like Morris and Barnes has also been identified as providing a basis for the introduction of anti-discrimination legislation (Morris, 1993; Barnes and Mercer, 1997).

In discussions about user-controlled research, service users highlight its ethical, practical, philosophical and methodological advantages over other research approaches (Vernon, 1997; Lindow, 1999; OpenMind, 2002; Beresford, 2003; Faulkner, 2004). They also argue that user-controlled research is able to transmit the views and experience of service users with the least likelihood of distortion and inaccuracy, because of

the understanding that comes from shared experience (Rose, 2001, 2003; Beresford, 2003; UFM Network, 2003).

Discussion and conclusion

In the context of competing research philosophies and approaches, this article has sought to illuminate the potential contribution of that form of user involvement research that identifies itself as user-controlled research. The evidence it draws on suggests that such research has a definite contribution to make, but it is also clear that this contribution cannot be considered in isolation from traditional research values. These may influence broader judgements about its extent and nature, and may have a direct – often negative – impact on such judgements.

It is, however, reasonable to conclude from the Involve review that such research, from the perspective of service users, user researchers and their organisations, has a valid and particular contribution to make to the generation of knowledge. It can not only help in the development of new knowledge, but can also make possible the creation of knowledge in areas that might otherwise be overlooked and engage a wider range of user perspectives and analysis than might otherwise be the case. Thus, as service users see it, user-controlled research can fill gaps that may be left by other research approaches. This would seem to justify its inclusion in the broader spectrum of research approaches, to be used to address appropriate research tasks on the basis of ‘horses for courses’.

However, there are still at least two outstanding areas that demand further consideration. We still need to know more about what stakeholders other than service users – for example, mainstream researchers, research commissioners and research users – think about the contribution of such research. More work also needs to be done to see what, if any, contributions user involvement in research more generally (through user involvement research and collaborative research) may have to offer.

Researchers coming from a narrow positivist view may reject user-controlled research and question its validity because of the value that it places on subjectivity and experiential knowledge, and its rejection of the supposedly scientific values of objectivity, neutrality and distance. However, it is difficult to see how the positive views of service users and service user researchers about its potential contribution can be dismissed out of hand, especially if the broader aim of research discourse is to be rigorous, impartial and inclusive of diverse perspectives. Just as it would be mistaken to overstate the claim for user-controlled research, it would be biased to reject it out of hand.

However, positivist research values may offer more than philosophical objections to user-controlled research. Their continuing dominance in fields like health and medical research means that they also create objective obstacles to its use. This was clear from the Involve review in which service users identified issues that led many to see an insecure and marginal future for user-controlled research. These included the continued dominance of medicalised research, the perception of user research as inherently biased and the ongoing difficulties that it faces in securing funding (Turner and Beresford, 2005, pp 65–80). Many interviewees believed it to be at a significant

disadvantage in relation to other forms of research and felt that there needed to be structural and attitudinal changes for this situation to change (Turner and Beresford, 2005, pp 130–40).

Two recent examples provide telling reinforcement of the concerns raised by service users. Both relate to efforts to take forward discussion of public involvement and engagement in research. In the first, the journal *Nature* ran a leader in 2004 raising the idea of involving ‘the public’ in deciding how government research funds should be spent (*Nature*, 2004). This received a critical response from a largely scientific readership. The second example followed the Social Research Association’s December 2005 annual conference, where the subject of discussion was ‘Necessity or nuisance? The role of non-researchers in research’. *The Times Higher Education Supplement* reported the conference under the negative headline ‘Research by public could be “unreliable”’ (McCall, 2005), resulting in an exchange of correspondence attacking and defending user involvement in research.

However, concerns about public, patient and user involvement in research are at least now receiving an airing. This could be a first step towards more thoughtful discussion and evaluation of such research, which may in due course enable us in our different stakeholder roles to develop a fuller understanding of its role and potential as a source of knowledge for improving policy and practice in health and social care. Meanwhile, hopefully, more attention will be paid to ensuring adequate and secure funding to undertake and develop user-controlled research in order to safeguard its future.

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