

## User involvement in research: building on experience and developing standards

Four interlinked expert seminars/focus groups, organised by a Steering Committee linked to the 1997 Toronto Group, discussed user involvement in research. Participants were a mix of academics, service users, user-researchers, people with direct experience of poverty, funders and policy-makers: 147 people participated in all with approximately 20 per cent attending two or more seminars. A number of key themes were discussed (user involvement in conventional research; peer review; involving people from black and minority ethnic communities in research; participatory approaches). Summary conclusions were carried forward to subsequent meetings. The series drew out the following points:

- Power imbalances between users and researchers or users and funders still meant that involvement was not mainstream practice or that practice was often still quite poor.
- There was a consensus that ideas of 'quality' in research were crucial but that some academic definitions of quality needed to be critically reviewed. It was felt they could reflect academics' own perspectives or perceived priorities rather than accurately reflecting people's real experiences.
- Good examples of involving people in conventional research demonstrated possible approaches. These pointed to standards on resources, addressing power relationships and pursuing outcomes as a result of the research.
- Peer review (at both the proposal and reporting stage) was a central process. There were a number of examples of involving users, and these pointed to standards on supporting people to take part and getting feedback on the developing practice.
- Black and minority ethnic communities were particularly excluded from involvement in research, despite the volume of research about their lives. Participants felt it was important for research to be grounded in their experiences and to make a difference.
- 'Emancipatory' research (research driven by users themselves) is not limited to qualitative approaches. Participants highlighted the fact that user researchers also have the same responsibilities to involve users and to ensure that research is not simply an end in itself.



## Background

Until comparatively recently, the idea of *involving* service users or other people with the direct experience of social exclusion in a meaningful way in research would have been seen as the preserve of a very few committed researchers or funders. The idea of users *controlling* research was even more limited. However, in recent years the idea of user involvement in research has gained greater currency. There are a growing number of user-researchers. Increasingly, funders say that they expect proposers to address user involvement. Mainstream researchers are more likely to include user involvement in their proposals. This has brought fears as well as hopes.

There are concerns that: mainstream researchers are undermining real involvement by tokenistic practice; user researchers are being marginalised in the competition for research funding; and some funders need to develop their own practices and standards to produce meaningful involvement.

There is a consensus that one should pursue ideas of 'quality' in research, but there is confusion and disagreement about what 'quality' means.

Given that funders are increasingly requiring proposers to demonstrate user involvement, there is a pressing need to uncover the issues, to demonstrate examples which illuminate good practice, and to develop principles of (or at least pointers to) quality standards.

A group of researchers, service users, user researchers and practitioners met at a conference in Toronto in 1997, concerned to promote and develop empowering practice of involving users in research. Following a national seminar in 2000 (sharing the experiences of users of health and social care services in research) members of the Toronto Group took forward a linked series of four seminars (in 2004). These seminars were intended to look at the key issues facing users in research and in developing ideas of quality (in research and in involvement).

Four themes were identified as crucial in the current context of research – involvement in conventional (mainstream) research; user involvement in peer review; the involvement of people from black and minority ethnic communities; and the lessons from 'participatory' approaches (where users participate in research projects) and 'emancipatory' approaches (where users drive research projects). It was felt that a focus on these four themes would illuminate wider principles and issues.

There were discussions around ideas of poor and good practice on involvement, drawing on people's own experiences (as mainstream researchers involving people or as service users being involved in research). Problems were highlighted, but there was also a drawing together of examples of good practice in each of the four themes. These examples were used to illuminate positive approaches and to draw a consensus on general pointers to good practice (or practices to avoid).

## Conventional (mainstream) research

Conventional research is usually concerned with generating reliable, replicable knowledge, being scientific and rigorous, maintaining objectivity, retaining distance from its subject matter, being neutral, impartial and avoiding value-based judgements. However, it is also important to recognise the social and political context of research, the perspectives and fallibility of researchers themselves, the competing types and perspectives of knowledge, and ethical issues. In this context, conventional research can be a contested area for user involvement. However, seminar participants identified areas of progress and it was seen as important to discuss and disseminate these.

The seminars confirmed the view that user involvement in traditional or mainstream research is still not widespread. A key reason for this was felt to be the unequal power relationships that existed between academic researchers and research participants. This often meant that the aims or methods employed in research projects did not capture or reflect the lived experience of those it was notionally intended to benefit. Funders were also seen to have a responsibility here, but it was felt there were still too few examples of funders taking ideas of involvement seriously. There were, however, enclaves of good practice developing that pointed towards standards of involving people. These included:

- Users are involved from start to finish, and there is a commitment to act on the results of the research.
- Funders are equally committed to resourcing and prioritising user involvement.
- Training and support are available for users *and* researchers.
- A commitment to make the research accessible to those whose lives it reflects. The project does not simply end when the research is complete – there is a commitment to action as a result of the research.
- Researchers are committed to sharing power and control with service users.

## Peer review

Peer review involves sending a research proposal or research report to people who have expertise in the area, but who are not directly connected with it, for comment or review. This was seen as important, because (at the start) it determined who got funding and (at the end) it helped to validate the meaning and robustness of the findings of the research.

Researchers who had studied the effectiveness of peer review had concluded that it was an imperfect way to judge the quality or importance of a piece of research – but that it is probably the best way we have at present.

Again, power relationships between users and funders (or users and researchers) were felt to be important. Users can feel isolated, or feel they are the token user on a committee. There is little training for taking part, and this can lead to users feeling exposed or unskilled for the task at hand. Users often feel they are only expected to comment on ‘user involvement’ in the proposal, and not on the overall aims and purpose of the work.

Users commented that there were some good examples of involvement in peer review and felt that they could now point to areas where progress could be made. They said that it was important that:

- Funders look at their overall processes of involvement, about numbers, roles, training and support for users.
- The funding organisation is committed to listening to the views of service users (and other reviewers) – to receive feedback about their peer review processes and to give feedback on the results of the review.
- Practice needed to be more inclusive for a number of groups. There are people who are particularly excluded from involvement in peer review (for example, people with learning difficulties, people with sensory impairments).
- Service users are encouraged and supported to comment on any aspect of the proposal or report, and not just about user involvement.

## People from black and minority ethnic communities

Research about Britain’s black and minority ethnic communities has been undertaken for many years. In most of this research people have been the ‘objects’ of research rather than potential participants in the research process. Increasingly, however, the voices of people from black and minority ethnic communities have begun to be heard – both as researchers and as research participants.

Some communities are still under-represented in much of the research that has taken place – for example, Chinese communities and newly arrived communities. By contrast, other communities have been over-researched and have become frustrated at the lack of change that has happened as a result of this research. This latter point has meant that, for researchers, the process of building trust is very intensive and takes a long time. Communities will measure success by the impact of the research. They have also said that it is important to get feedback about what has happened as a result of the project.

A number of pointers to good practice emerged from some of the positive experiences of involvement. Good outcomes were felt to be more likely when:

- Researchers build relationships with people from the communities they hoped to research.
- People from black and minority ethnic communities are involved as partners throughout the research process.
- The research addresses questions that communities agree are important to their lives.
- People from black and minority ethnic communities are themselves researchers or co-researchers.
- Specific attention is paid to practical arrangements such as interpretation, translation, appropriate venues and refreshments.
- There is a commitment from everyone to use the research to bring about change, and to feedback what has happened.

## Emancipatory approaches

The origins of ‘emancipatory’ research lie in the American black civil rights movement. ‘Empowerment’ is an inherently political concept in which notions of power and inequalities of power are central. Most research is perceived to be unbiased, objective and neutral. However, disabled people, mental health service users and others have said that often these perceptions are simply grounded unquestioningly in the views of those who have power – and reinforce those views.

Emancipatory research is controlled by users from the beginning of the process. This poses challenges, because it does not simply mean that a researcher is a user. To date, most emancipatory research has focused on qualitative methods. However, this type of research is not about methods, it is about who has control. Any research method could potentially be adopted by a user-led group and used for emancipatory research.

Some mainstream funders are beginning to make the involvement of service users in research a requirement for funding. Researchers may therefore seek only to 'tick the boxes'. If emancipatory research is funded within traditional research organisations it is often taken forward without any exploration of the tensions and contradictions inherent in this. Ethics committees also often fail to understand the approaches or importance of emancipatory and user-controlled research.

Participants discussed the above issues, as well as looking at a number of approaches to emancipatory research. A consensus emerged between the seminar participants that:

- Definitions of emancipatory research and user involvement in research need to be debated and shared more widely.
- There is a need to evaluate best practice in emancipatory research.
- More funding is needed for emancipatory approaches. A proportion of funding being set aside for more emancipatory approaches would help to address some of the power imbalances.
- Emancipatory research needs to be judged by the same standards on involvement and purpose. The outcomes of the research in strengthening the community involved in the research are crucial.
- User-researchers have the same responsibilities to involve service users as conventional researchers, and emancipatory research cannot be an end in itself. For it to be valued by users it needs to lead to changes.

## About the project

The project team was funded to deliver four linked seminars about the central current themes of user involvement in research. Joint funding was provided by the JRF, Involve, REU and Centre for Citizen Participation at Brunel University. The series was co-ordinated by Rachel Purtell (Folk.us) and Barry Hobbs, and the project was administered by SCIE. Bec Hanley compiled the final report. These three worked with a Steering Group of Peter Beresford (Brunel), Tracey Bignall (REU), Don Brand (SCIE), Alex O'Neil (JRF), Carey Ostrer (SURE), Roger Steel (INVOLVE) Julia Warrener (Kneesworth Hospital) and Toby Williamson (MHF).

A total of 147 people took part in the seminar; approximately one-fifth attending two or more meetings. The seminars took place between January and June 2004 in London, Birmingham, Manchester and York. The Steering Group attended each seminar and ensured that, in addition to the specific themes for each seminar, the findings and issues from one seminar were shared with the speaker presentations and discussions at subsequent seminars.

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## For further information

The full report, **Research as empowerment? Report of a series of seminars organised by the Toronto Group** by Bec Hanley for the Toronto Seminar Group, is published by the Joseph Rowntree Foundation (ISBN 1 85935 317 7, price £13.95). You can also download this report free from [www.jrf.org.uk](http://www.jrf.org.uk) (ISBN 1 85935 318 5).

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