Research as empowerment?
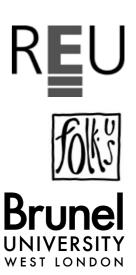
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Research as empowerment?

Report of a series of seminars organised by the Toronto Group

Bec Hanley for the Toronto Seminar Group

JOSEPH ROWNTREE FOUNDATION

INVOLVE
Promoting public involvement in NHS, public health and social care research

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Contents

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Summary

There is growing interest in evidence-based policy and practice in health and social care. Alongside this is an increasing interest in extending the involvement of service users in research.

This is a report of a series of seminars, which was organised by the Toronto Group to further explore these issues. The seminars took place at different locations around England and brought together a range of different stakeholders. They covered four topics:

- involving service users in traditional or mainstream research

- involving service users in peer review

- involving people from black and minority ethnic communities in research

- emancipatory research.

We hope that this report will be relevant to anyone with an interest in service user involvement in research.

Involving service users in traditional or mainstream research

Traditional or mainstream research is the type of research that is most often published in peer-reviewed journals. Randomised controlled trials have been seen as the gold standard for this research.

Service user involvement in traditional or mainstream research is still not widespread. One of the fundamental barriers to the empowerment of service users in mainstream research remains the unequal relationship between the researcher and research participants. The way that research is funded also has important implications for empowerment and participation in research. A further barrier to involvement relates to the methods used in health and social care research. For example, randomised controlled trials do not lend themselves as easily to user involvement as other more qualitative research methods. Expectations of the research may be a barrier – service users and researchers may have different ideas about the purpose of the research – is it to bring about change, or to gain more knowledge? There are also pressures of time. Little support is available in terms of training and mentoring for service users who become involved in research, or for researchers who wish to work in partnership with service users.

Finally, there has been little evaluation of the effectiveness of user involvement in research – so the evidence base for involving service users as partners in research is very poor.

Some issues relating to the empowerment of service users in mainstream research need further consideration by researchers and service users. A key question that remains unresolved is whether all health and social care research should be participatory, and whether user-led research is necessarily more empowering for other service users.

Good practice in the involvement of service users in traditional or mainstream research might include the following components.

- Service users are involved from the beginning to the end of the project and there is a commitment to acting on the results of the research.

- The project funders are committed to the involvement of service users and ensure that the project is adequately resourced.

- Appropriate training and support are available for service users and researchers.

- There is a shared commitment to making the research available and accessible to a variety of people, including those whose voices are not often heard.

- The researchers are committed to sharing power and control with service users.

Involving service users in peer review

Peer review involves sending a research proposal or research report to people who are not directly connected with it for comment and review. There is no single process for peer review within research and there are no templates for service user involvement in peer review. However, service users can offer a unique and complementary perspective.

The challenges service users face when they become involved in peer review are similar to those they face when getting involved at other stages of the research process. Many centre around power. There are also practical issues. If involvement processes and relationships are not already established, there may be a tension between the amount of time it can take to involve service users in peer review and pressures to commission research quickly. Service users may be expected to be 'representative' without being resourced or encouraged to seek the views of other

service users. Funding can also be a barrier to involvement, as can issues about capacity. Many service users would welcome training about research and peer review, so that they can participate more fully.

Good practice in the involvement of service users in peer review might include the following.

- The commissioning organisation is committed to service user involvement and has made time to set up appropriate processes.

- Service user reviewers are clear about their role.

- Service users are encouraged to comment on any aspect of the proposal or report, and not just on how users are involved.

Involving people from black and minority ethnic communities in research

Research about Britain's black and minority ethnic communities has been undertaken for many years. However, most of this research saw people from these communities as the 'objects' of research, rather than as potential participants in the research process.

Increasingly, the voices of people from black and minority ethnic communities have begun to be heard in research – both as researchers and as research participants. However, a number of barriers remain. Some communities are still under-represented in much of the research that is taking place – for example, Chinese communities and newly arrived communities. In contrast, other communities have been over-researched and have become frustrated about the lack of change that has happened as a consequence of this research.

Practical arrangements, which are important in all participatory research, are particularly important in research that actively involves people from black or minority ethnic communities. Research involving people from black and minority ethnic communities is often under-resourced and tends not to be funded as part of mainstream research programmes.

Researchers may not address the questions that people from black and minority ethnic communities see as a priority. Research involving people from black and minority ethnic communities is often open to the charge that it is not 'representative', that it fails to reflect the views of a wide enough variety of a particular community or communities.

Good practice in the involvement of people from black and minority ethnic communities in research might include the following.

- Researchers are committed to building relationships with people from the communities they hope to research, and to involving people from black and minority ethnic communities as partners throughout the research process.

- Researchers seek to involve communities that have been under-represented and/or groups within communities that may have been under-represented.

- The research addresses questions that people from black and minority ethnic communities have identified as important.

- People from black and minority ethnic communities are themselves the researchers, or co-researchers.

- Specific attention is paid to practical arrangements.

Emancipatory research

A number of researchers have written about what emancipatory research is, and what it means for researchers and those who are researched. Our seminar focused on a number of key questions:

- Who controls research?

- Are some research methods more emancipatory than others?

- How can we focus more on people's experience?

- What happens to research after it is complete?

One of the key barriers to the development of emancipatory research is what is currently seen as 'evidence'. This means that, to date, very few emancipatory research projects have been funded and even fewer have received large amounts of funding. Service users and ex-service users who undertake research find it hard to be taken seriously as researchers. Research undertaken by service users is rarely published in peer-reviewed journals and therefore does not gain recognition from other parts of the research community, or from those who judge the quality of research.

Research as empowerment?

Even when emancipatory research is funded, ethics committees may be resistant to approving that it can take place, as they often do not understand the importance of emancipatory and user-controlled research. There is also a danger that, as more service users become researchers, emancipatory research can exclude the very people it was meant to support as it becomes more professionalised.

Good practice in relation to emancipatory research might include the following.

- The research is controlled by and accountable to service users from the outset, with service users identifying and prioritising the research question.

- The project is funded adequately.

- The timescales are realistic, to allow enough time for the research to be completed in an inclusive way.

- The research seeks to reflect the experiences, concerns and priorities of service users – bringing individual experiences together to draw conclusions and make recommendations.

- The project seeks to support the empowerment of those involved in it and, where possible, the empowerment of the broader community being studied.

- Those involved are able to access a network of people involved in emancipatory research to share experience and develop practice.

Participants at our seminar on emancipatory research

1 Introduction

There is growing political and policy interest in evidence-based policy and practice in health and social care. This interest has been reflected in the establishment of the National Institute for Clinical Excellence (NICE), the Social Care Institute for Excellence (SCIE) and, more recently, the National Institute for Mental Health (NIMHE).

Alongside this has been a greatly increased interest in extending user involvement in research, and in new research approaches that highlight more inclusive and equal research relationships. This development has led to the establishment of INVOLVE (formerly Consumers in NHS Research) and the extension of its remit to cover public health and social care research funded by the Department of Health. A growing number of statutory and independent research funders now ask for evidence of service user involvement in research funding proposals. There are also groupings of service user researchers and a growing body of material both discussing user involvement in research and providing findings from studies that actively involve service users.

At the same time, the current emphasis on evidence-based policy and practice has encouraged debate about the status of both traditional 'scientific' research approaches and participatory research. Knowledge about more participatory research approaches is not widely shared; discussion of such research remains at an early stage and ideas of 'evidence' and 'empowerment' in relation to research require closer, more inclusive and systematic consideration.

This report sets out to summarise the discussions that took place at a series of four seminars to further explore the developments outlined above. Our aim in publishing this report is to stimulate further discussion and debate about research as empowerment. We have not presented a verbatim account of what happened at each seminar. Instead, we have tried to identify some pointers towards good practice and to highlight some issues that need further discussion and action. We hope that this report will be relevant to anyone who is interested in user involvement in research and not just to those who attended the seminars.

This report focuses on four key areas:

• involving service users in traditional or mainstream research

• involving service users in peer review

• involving people from black and minority ethnic communities in research

• emancipatory research.

In the following chapter, we summarise what participants at the seminars thought good practice would look like in each of these areas. We then highlight a number of recommendations to improve practice. In the final four chapters of this report we give more information about the discussions that took place at each of the seminars and offer some examples of service user involvement in research.

Participants at our first seminar held in London

2 Some pointers towards good practice

Much of the discussions at the seminars centred around what good practice in different aspects of participatory research might look like.

What might good practice in the involvement of service users in traditional and mainstream research look like?

- Service users are involved from the beginning of the project, when the research question is decided, to the end of the project, when there is discussion about how the results can be acted upon.

- The project funders are committed to the involvement of service users and ensure that the project is adequately resourced, so that everyone involved can be offered payment for their time and expertise, and that service users can be involved from the outset to the conclusion of the project.

- There is a shared understanding about the purpose of the research.

- Appropriate training and support are available for service users and researchers.

- There is a shared commitment to making the research available and accessible to a variety of people.

- The project does not end when the research is complete – there is a commitment to action as a result of the research.

- The researchers are committed to sharing power and control with service users who are involved in the project.

What might good practice in the involvement of service users in peer review look like?

- The funding organisation is committed to service user involvement and has made time to set up appropriate processes.

- Service user involvement is adequately resourced, with payment offered to reviewers.

- Service users are offered training in peer review.

- The funding organisation is committed to listening to the views of service users and to giving them feedback about what happens as a result of their input.

- Both the papers provided for review and an explanation of the peer review process are available in plain English and in accessible formats.

- There is a commitment to listening to the views of a range of service users, including those whose voices are not often heard.

- Service user reviewers are clear about their role. If funding organisations are seeking a more 'representative' view, they encourage and resource service users to seek the views of their peers.

- Service users are encouraged to comment on any aspect of the proposal or report, and not just on how users are involved.

- There is a clear process by which service users and other reviewers can feed back any concerns or complaints about the peer review process.

What might good practice in involving people from black and minority ethnic communities in research look like?

- Researchers seek to involve communities that have been under-represented and/ or groups within communities that may have been under-represented – these may be young people, older people, people who have newly arrived in the UK or people who speak different languages.

- Researchers are committed to building relationships with people from the communities they hope the research will benefit.

- People from black and minority ethnic communities are involved as partners throughout the research process.

- The research addresses questions that people from black and minority ethnic communities have identified as important.

- People from black and minority ethnic communities are themselves the researchers, or co-researchers.

- Specific attention is paid to practical arrangements, such as interpreting, translation, culturally sensitive venues and refreshments.

- There is adequate funding available to support these practical arrangements, and to ensure that people from black and minority ethnic communities are involved from the outset through to the completion of the project.

- All involved are committed to making change as a result of the research and to feeding back results of research in accessible ways.

What might good practice in emancipatory research look like?

- The research is controlled by service users from the outset, with service users identifying and prioritising the research question.

- The project is funded adequately, to ensure that all those taking part can be paid for their time and expertise, and that service users can be involved from the outset through to the conclusion of the project and the dissemination of results.

- There are strong links to user organisations and, if possible, the project is based in a user-controlled organisation.

- The project is accountable to service users and the ownership of the project is clear.

- The timescales are realistic, to allow enough time for the research to be completed in an inclusive way.

- The research seeks to reflect the experiences, concerns and priorities of service users – bringing individual experiences together to draw conclusions and make recommendations.

- Those involved in the project work hard to ensure that power relationships between researchers (whether service users or not) and service users are more equal.

- Any tensions or conflicts of interest are acknowledged and explored.

- The researchers use the most appropriate research methods to address the question.

- Whichever method is chosen, the research is carried out in a rigorous way with particular attention to ethical issues.

- The project seeks to support the empowerment of those involved in it and, where possible, the empowerment of the broader community being studied.

- Those involved work hard to involve those groups that may be marginalised within the particular community being studied.

- The project is accessible to service users – the language is accessible and appropriate, the results are reported in a variety of ways and are easy to find.

- Support and training are available to service users and researchers involved in the project.

- There is a shared commitment to acting on the results of the project.

- Those involved are able to access a network of people involved in emancipatory research to share experience and develop practice.

Participants at the seminar on peer review

3 Recommendations

Participants at the seminars made a number of recommendations. These are reproduced below.

1 Empowering service users within mainstream and traditional research

1.1 *A series of guidelines and principles about user involvement in research and user-controlled research should be developed for ethics committees, research funders and researchers*. These guidelines should not be prescriptive. They should include:

- practical ideas

- examples of good practice

- how to build relationships with service users before a research project begins

- budgeting for involvement, especially before research begins

- an emphasis that users should not be involved in a tokenistic way, or in ways that might harm them

- advice about developing an access policy, to ensure that a wide range of service users can get involved in research

- research funders should ensure that issues of diversity are being addressed.

1.2 *The sharing of information and networking among and between service users who are interested in research and researchers who wish to work in participatory ways should be encouraged*. This might be done via a website, such as the electronic library that is part of the Social Care Institute for Excellence (SCIE). Such a website should include examples of participatory research and information about resources available.

1.3 *Organisations that have an interest in or commitment to user involvement in research should receive more recognition*.

1.4 *Empowering research should be recognised as 'good' research by funding bodies and by the Research Assessment Exercise (RAE)*. This could begin to be achieved by:

- involving people who use services and researchers who work with them as peer reviewers

- encouraging research advisory bodies to adopt a participatory approach to the research agenda

- service users gaining more understanding of how people are appointed to research advisory bodies and beginning to influence this process

- offering support to service users who are currently members of research advisory bodies

- the production of a paper on participatory research for research funding bodies.

1.5 *Service user groups should be encouraged to build their knowledge of research*, so that they can apply for their own research funding and make judgements about whether research they are asked to be involved in is valuable to them.

1.6 *Training about participatory research and dissemination of participatory research should be developed in parallel*. Professionals and users need training about participatory research, and information about participatory research needs to be disseminated to professionals and service users.

1.7 *The institutional conservatism of health and social care organisations should be challenged*.

2   Involving service users in peer review

2.1 *Service users should be involved in all aspects of commissioning if peer review is to be meaningful*. Service users should be involved in reviewing all aspects of a proposal or report if they wish – their comments should not be limited to the extent of user involvement. Feedback to user reviewers should be an integral part of the process.

2.2 *There is a need for transparency in the peer review process*. The process should be clearly described in plain English. Both the papers provided for review and an explanation of the peer review process should be available in plain English and in accessible formats. The role of service users must be easily understood. There should be a clear process by which service users and other reviewers can feed back any concerns or complaints about the peer review process.

2.3 *There is a need for capacity building and training for commissioners, researchers and service users*. Commissioners and researchers need help to understand why and how to involve service users meaningfully. There is a need to extend opportunities for service users to get actively involved in research.

2.4 *Budgets to support service user involvement in research should be explicit and accounted for.* This will ensure that these funds are genuinely spent on user involvement and not diverted to other areas.

2.5 *There should be incentives to encourage research funders to take user involvement in peer review seriously.*

2.6 *When reviewing a proposal or report, the most important criterion should be whether the research is relevant to and will benefit service users.* This means that reviewing of reports is just as important as reviewing of proposals, and that a reconsideration of what is meant by 'good science' is needed.

2.7 *This is a debate that should be continued.* There is a need to influence organisations that have power over peer review processes, for example the Research Assessment Exercise (RAE) and research funders. In order to do this, a good practice guide should be developed, with examples of where peer review has worked well.

2.8 *User involvement needs to be an integral part of the whole research process, not just peer review.*

3 Involving people from black and minority ethnic communities in research

3.1 *Research about and with people from black and minority ethnic communities should be based on the priorities of these communities.*

3.2 *People from black and minority ethnic communities should be actively involved from the outset* – before the research question is set – and then continue to be involved throughout the research process.

3.3 *Research results need to be disseminated more widely, in accessible forms, to people from black and minority ethnic communities.* Research language must be made accessible and relevant to people from black and minority ethnic communities who participate in research.

3.4 *People from black and minority ethnic communities need to benefit from research* – research funders should consider allocating funding to implement research findings, so that something practical is seen to happen as a result of research.

3.5 *Sufficient resources should be made available to actively involve people from black and minority ethnic communities in research.* This involvement needs to move beyond tokenism. Funding is a problem in many areas of research, but research involving black and minority ethnic communities is much more at the margin of funding.

3.6 *Support and training should be made available to people from black and minority ethnic communities to develop their skills in research.* Involvement in research is a skilled activity. The contributions of service users and carers must be recognised by researchers in publications and other forms of dissemination.

3.7 *People from a range of black and minority ethnic communities should be involved in research.* There are many different black and minority ethnic communities – for example, people who were born in the UK and people who have more recently arrived here; older and younger people; newer communities as well as more established communities; people who speak different languages. This diversity should be recognised by researchers.

3.8 *A database of research projects that have actively involved people from black and minority ethnic communities should be developed*, so that experience and good practice can be shared.

3.9 *Researchers should go to where people are – culturally, spiritually and organisationally. Recruitment of people from black and minority ethnic communities to take part in research should be done sensitively*, through voluntary sector and community groups, as many people do not engage with or are very wary of statutory services.

4 Developing emancipatory research

4.1 *Definitions of emancipatory research and user involvement in research should be debated and shared more widely.* A short, accessible paper on what emancipatory research is, where it comes from and some examples of good practice should be developed and widely disseminated.

4.2 *There is a need to evaluate best practice in emancipatory research.* This evaluation should be user led.

4.3 *Service users should be actively involved in all research.* This involvement must be meaningful and purposeful, and must not be tokenistic.

4.4 *Better funding and resources for emancipatory research are needed*.

4.5 *Research funding organisations should designate a specified percentage of their funding to emancipatory research and to enabling user groups to commission research that leads to change*. Research funding organisations should also make resources available to increase capacity among user groups to become more active in research.

4.6 *Emancipatory research should be as inclusive as possible*, recognising its roots in the black civil rights movement, feminist research, research led by disabled people and mental health service users. One way to do this might be to have a network of people interested in emancipatory research. Perhaps INVOLVE could support an email discussion group on this.

4.7 *There is a need to explore ways to support service users who are actively involved in research*, including ways to keep them safe, especially when things go wrong.

4.8 *Guidelines for ethics committees on user involvement in research should be developed*. These guidelines should include advice about supporting user-controlled research.

4 Background to the seminars

What is the Toronto Group?

The Research as Empowerment – Toronto Group was set up following the fourth International Empowerment Conference, which took place in Toronto in 1997. The Toronto Group aims to promote and share social care research that empowers social care users who take part in research, and social care users more generally.

Members of the Toronto Group are service users, service user researchers, researchers, practitioners, educators and managers, who participate on equal terms. The Group meets to debate and discuss issues about the involvement of service users in social care research. It has no permanent funding, paid staff or fixed base. If you would like to find out more about the Group, please contact Roger Steel at INVOLVE, email rsteel@invo.org.uk, telephone 023 8065 1088.

In November 2000, the Toronto Group held a national seminar, supported by the Joseph Rowntree Foundation. The seminar brought together a wide range of participants, including users of health and social care services. The aims were to share experience, explore some of barriers to undertaking more empowering and inclusive research, and identify ways to overcome them. Participants at this seminar identified and prioritised a number of issues for further discussion and reflection. These formed the basis of a series of seminars held in 2004, which are the focus of this report.

The Research as Empowerment seminar series

This series of seminars was organised by the Toronto Group to share, synthesise and add to the pool of knowledge that exists about developing more empowering research, making possible more inclusive approaches to the development of the knowledge base of health and social care policy and practice.

The seminars took place at different locations around England and brought together a range of different stakeholders. Those who attended the seminars included service users, service user researchers, researchers, practitioners, policy makers, trainers, research commissioners and funders.

The seminar series was core funded by the Joseph Rowntree Foundation, with additional funding from INVOLVE (formerly Consumers in NHS Research) and the Race Equality Unit.

Four topics were addressed in the seminars.

- *Mainstream and traditional research approaches: do they include and empower the people that count?* This seminar was held in London on 24 February 2004.

- *Does peer review present obstacles and barriers to service users involved in research?* This seminar was held in Birmingham on 24 March 2004.

- *Research and black and minority ethnic communities: is it a different experience?* This seminar was held in Manchester on 28 April 2004.

- *Emancipatory research: putting it to the test!* This seminar was held in York on 26 May 2004.

We have drawn extensively from speakers' papers in the remaining chapters of this report. We have also included examples of projects that illustrate some of these aspects of good practice in boxed *examples of involvement*, and quotes from service users and other seminar participants that describe their *experiences of involvement*.

The following chapters in this report all follow a slightly different format, to reflect the different ways in which each of the seminars was structured.

Participants at our third seminar, held in Manchester

5 Empowering service users within mainstream and traditional research

Introduction

Empowerment has its modern origins in the American black civil rights movement. The concept of empowerment within the context of health and social care research has often been diluted and/or poorly defined, but its roots in the second half of the twentieth century can be traced to liberatory and emancipatory politics.

What do we mean by traditional or mainstream research?

Traditional or mainstream research is the type of research that is most often published in peer-reviewed journals. It 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.

Randomised controlled trials have been seen as the gold standard for this type of research.

However, this description of traditional research fails to recognise:

- the social and political context of research

- the fallibility of researchers

- the range of knowledge being generated

- issues of ethics.

Despite considerable discussion and development, emancipatory research (see Chapter 8) and participatory research continue to be seen as the poor relations to traditional or mainstream research.

What do we mean by empowerment?

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Here is one definition, put together by Peter Beresford, a service user and professor of social policy:

> Empowerment has been an explicit and key concern of the disabled people's and social care service users' movement. It has been taken to mean challenging service users' exclusion and disempowerment. Two aspects to empowerment are regularly identified: personal and political empowerment. Personal empowerment is concerned with strengthening the individual's position, through capacity and confidence building, skills and assertiveness training, to be able to gain more power. Political empowerment is concerned with seeking to make broader change that will increase the objective power (political, cultural, social and economic) available to people. A particular appeal of the idea of empowerment is the way it can address and unite these two concerns: individual and social transformation.

> Empowerment is an inherently political idea in which issues of power, the ownership of power, inequalities of power and the acquisition and redistribution of power are central. Some commentators in the disabled people's movement have emphasised empowerment as an expression of their own self-organisation and collective action (through the development of user-controlled organisations). They see the key route to both personal and political empowerment as through a collective process, based on working and struggling together. Others, for example, in the mental health service users/survivors movement, place more emphasis on the role of self-help and mutual aid and support in enabling people's empowerment. There are both objective and subjective components to empowerment. It is concerned with increasing the actual power that people have and their personal capacity to use it.

> Many service users are emphatic that people can only empower themselves; others (particularly professionals and service system workers) can't empower them. Such workers can support people's empowerment or stop obstructing it. They cannot engender it.

> The emancipatory and user-controlled research developed by the disabled people's and service users' movements and their researchers identifies empowerment as a major goal for research.

Empowering service users in mainstream research

Some of the main drivers for the growth in user involvement in health services research have been the policies and practices promoted by the Department of Health. These have included the establishment of INVOLVE in 1996, with the aim of ensuring that service user involvement in R&D within the NHS improves the way that research is prioritised, commissioned, undertaken and disseminated. The remit of INVOLVE was expanded in 2001 to cover social care and public health research funded by the Department of Health. Policy impetus came through the publication of the Research Governance Framework, which calls for the active involvement of service users and carers at every stage of research supported by the Department of Health.

However, user involvement in research is still patchy, and there remain a number of barriers to the involvement of service users in mainstream and traditional research.

What are the barriers to empowering service users within mainstream and traditional research?

One of the fundamental barriers to the empowerment of service users in mainstream research remains the unequal relationship between the researcher and research participants. Involvement and empowerment can be limited by the beliefs, attitude and behaviour of researchers. For some researchers, the prospect of involving service users as partners in research is frightening, as it challenges traditional notions about who is the expert and who the recipient of this expertise – and who has power and who does not. There is often a tension for academic researchers between a commitment to user involvement and the requirements of peer review and the Research Assessment Exercise, which determines the amount of research funding a university receives from the Government.

> **Experiences of involvement**
>
> Ayesha Vernon, independent researcher and service user
>
> Lots of research projects these days have service users as members of advisory groups. But, if you look at the membership of these groups, which is often a mix of service users, practitioners and researchers, the involvement tends to be tokenistic, because of the power dynamics involved. If users don't have confidence and knowledge of the research process, they are going to express views tentatively and defer to the researchers.
>

In one research project I carried out, I had intended that the research would be a partnership with service users. They were going to be involved in the proposal, in doing the research, in writing the report and so on. I worked with two groups of disabled people from the Asian community, as that's what my research project was about. But what I failed to take into account was that the organisations I was planning to involve didn't have any knowledge of the research process, so they continually told me that I should do whatever I thought was best when I asked them for their views.

Despite my best intentions, this project was less than ideal in terms of service user involvement. For my next project, I looked at mental health service system use in Leeds. Here, we trained 12 mental health service users to be researchers alongside us. We devised the training in partnership with these users, and then we worked alongside these users to do interviews and analysis. The feedback from these people was much more productive. People found it built their confidence. There was meaningful user involvement.

Funders must put money into capacity building – offering training to service users about the whole research process, so that users have confidence and knowledge. Otherwise involvement will continue to be tokenistic.

Research is a competitive activity and it can be hard to share power. It is difficult to be receptive to suggested research changes, though easy to take credit for other people's good ideas. Some academics consider that research will be tainted by seeking to make it relevant to users. Issues of power therefore need to be addressed if participatory research is to be truly participatory. In some projects, a failure to address these power relations means that user involvement becomes tokenistic and often meaningless.

At a more practical level, the way research is funded has important implications for empowerment and participation in research. The organisations that pay for research may themselves act as a barrier to the active involvement of service users. It is very difficult to imagine the pharmaceutical industry, which funds the vast proportion of health research, involving service users in setting the research agenda.

Even in the public and voluntary sector, there may be little if any emphasis placed on involving the people who are the 'subjects' of research, and service users are still rarely involved in setting the research agenda.

Whichever agency is funding research, it is usually not possible to obtain costs for preparing research bids and, because of this, service users are often excluded at the very stage where they could have most influence – in setting the research question and in deciding how it will be addressed.

Funding makes possible the employment of service users, payment for their time, the development of user-derived outcomes, training and mentoring, consultation of wider groups of service users, time to respond to changes to the study recommended by service users and the opportunity to share the research findings widely.

In many instances, service users are not paid for their involvement in research. Some service users and voluntary organisations now refuse to take part in research if they are not paid. More research funders are beginning to accept that payment to service users is a legitimate use of research funds, so this situation is changing, slowly. However, when payment is offered, other barriers may need to be overcome. Some service users live on benefits and receiving payment may jeopardise their longer-term livelihood.

Participants discuss barriers to involvement in mainstream research

Experiences of involvement

Ann Mooney, mental health service user and member of the Service User Research Forum

We work very hard, fighting to improve the way mental health service users are cared for in hospital and out in the community. I believe we put a lot into the meetings we attend. We don't just go with our own views, we go round to local mental health hospitals talking with service users and telling them what we're doing. They respond with their own views and we take them back to our meetings. This makes them know that we can all make a difference.

You cannot get what we know from a book. I know professionals spend many years working hard to obtain the knowledge that makes them what they are. But most service users have been to hell and back to obtain our knowledge. I wish I was given the chance to study, rather than the path I went down.

My belief is that, if you're asking service users to come and give input, then some payment should be offered, as their experiences are invaluable. But, if it's to help them improve their knowledge, I don't believe you should pay, but some help with out-of-pocket expenses could be offered. Some service users work and take time off for meetings, most are on benefits. All service users should be reminded that they are responsible for declaring any earnings received and it's also your *[the professional's]* responsibility to check on current legislation in full and give a copy to anyone receiving payment.

A doctor said to me 'I thought you did this kind of work because you care'. So I asked him did he do his kind of work because he cared about us? He said, 'Yes', so I asked him should he be paid then. He said yes, because he had studied for many years to give as much as he gives. I told him all the reasons from my childhood, why I had first-hand knowledge that made me able to give the care I give. But I'd rather have gone to university than to gain knowledge the way I was forced to.

Often funding for a research project runs out before analysis and writing up have been completed. Without the funds to involve service users at this stage, they may become disengaged – at a time when their involvement could be particularly useful, as often research is seen as the means to an end, rather than an end in itself for many service users.

A further barrier to involvement relates to the methods used in health and social care research. For example, randomised controlled trials do not lend themselves as easily to user involvement as other more qualitative research methods. Conversely, within the academic community, user-controlled research is often considered biased and lacking in rigour.

Expectations of the research may also be a barrier – service users and researchers may have different ideas about the purpose of the research – is it to bring about change, or to gain more knowledge? Many service users prioritise the former, whereas the latter is still predominant.

There is a danger that, in their eagerness to involve service users, researchers may present their project as having more potential for change than in fact it has. In the past this has meant that some communities have refused to participate further in research until they can see change happening as a result of previous research.

There are also pressures of time, often imposed by research funders or by the institutions employing the researchers. This can add to the pressure on researchers for a 'quick fix'. They may then fail to involve any service users meaningfully, or to involve only those who are easy to identify.

Little support is available in terms of training and mentoring for service users who become involved in research, or for researchers who wish to work in partnership with service users.

Finally, there has been little evaluation of the effectiveness of user involvement in research – so the evidence base for involving service users as partners in research is very poor.

> ### Experiences of involvement
>
> Alison Faulkner, independent survivor consultant
>
> Turning the tables and carrying out research that we believe is relevant and important to us as people living with the experience of mental distress can be a powerful experience. I became a researcher at about the same time as I became a service user – about 20 years ago. But for many people it is something that happens in a different order: learning research skills can be a powerful way of learning more about your own and others' experiences and about ways of dealing with or managing them.
>
> *continued*

The subjects we choose to research have a different emphasis to those chosen by clinical academic researchers, because we are driven by different motives. We are more likely to be influenced by the range of things that affect our lives in material ways; clinical academics are more likely to be influenced by issues that will attract academic, political or financial attention. (This may be an unfair generalisation!) The priorities that we put forward are different; they reflect a more holistic approach to mental illness and distress, and are more inclined to emphasise the social living issues (reflecting a social model of disability) than medical and clinical issues (reflecting a medical model). There are also some significant areas of agreement, such as 'stigma' and discrimination, acute care and crisis intervention, and employment.

User involvement in research is not just about making the interviews more user-friendly to the research participants (although this is an area where evidence does support the advantage of involving service users); it is also about questioning some of the philosophical foundations for the research itself. It is not enough to invite a user to sit on an advisory group. Researchers need to acknowledge the change in ethos that this represents and to understand that we, as service users, have access to some specialist knowledge and views that may be valuable in the conduct of the research. Quality, ethics and rigour are not the exclusive domain of clinical academic researchers. Evidence is not the exclusive domain of randomised controlled trials.

Overall I am enthusiastic and optimistic. The work of INVOLVE supports the growth and development of real user involvement in NHS, social care and public health research. I am able to work independently as a result of these developments. But I still attend meetings where people pay lip service to user involvement in research, are patronising about our expertise and dismissive about our abilities to undertake our own research. So, things have changed enormously – but they still have a long way to go.

Some issues for further consideration

Some issues relating to the empowerment of service users in mainstream research need further consideration by researchers and service users. A key question that remains unresolved is whether all health and social care research should be participatory, and whether user-led research is necessarily more empowering for other service users.

Research as empowerment?

Traditional and mainstream research methods such as randomised controlled trials have been seen by many as disempowering, but others feel that this is not necessarily the case. For example, a user-controlled organisation might choose to commission a randomised controlled trial, if they felt this was the most appropriate method to use.

A further question is whether traditional research has a missing dimension if it does not actively involve service users. Service users can be involved in all the different types of research. But, when research methods that may be seen as less flexible, such as randomised controlled trials, are used, it may be the case that additional skills and expertise are needed to ensure that service users are not marginalised. Appropriate relationships between researchers and service users are particularly important here. In these cases, involvement at an early stage, for example in defining the question, the aims of the research and the outcome measures, will be crucial.

How do we stop academic research being privileged at the expense of service user research?
(Seminar participant)

Examples of involvement

The Economic and Social Research Council (ESRC) Growing Older Programme

The ESRC Growing Older (GO) Programme, which was launched in 1999, set out to encourage participative approaches to ageing research.

There are 24 separate research projects, which have investigated different aspects of quality of life in old age. The projects are large and small and span most social sciences disciplines. Together they cover most of the issues that are central to an understanding of quality in later life and how it may be extended. The Programme is unusual (for scientific research) in having an explicit objective to try to contribute to policy and practice in the field of ageing.

Why did it also seek to encourage participation in the field of ageing? In part it was a reflection of the general transition in social science research away from a rigid separation between researcher and research. This was pioneered in disability research and is patchy across the disciplines. Partly, it was a consequence of the policy and practice orientation of the Programme. But the key factor was the conviction that all research that includes people has a duty to involve them, as far as possible, as partners.

continued

Researchers used different approaches to involve older people, including the following.

- *Discussion groups* : a research project on social exclusion in deprived urban neighbourhoods used a range of different formal and informal groups to listen to the views of older people. The project was keen to avoid using older people purely as a resource and kept in contact with the groups using newsletters, informal contacts and a final feedback session.

- *Relational research* : a research project on the role of spiritual beliefs in adjustment to bereavement used longitudinal research that involved visiting a small sample of older spouses three times in the second year of their bereavement. The close relationship formed between the researcher and the older people became therapeutic. The participants felt that taking part in the research had been personally helpful.

- *Participation* : the project on Older Women's Lives and Voices recruited ten older women and trained them to interview the individual members of the 11 discussion groups on which the research was based (see pages 35–7 for more information about this project).

These examples suggest that it is possible to involve older people as research partners in a range of very different projects.
(Alan Walker, ESRC Growing Older Programme)

Examples of involvement

Studying community regeneration in West Cornwall

Researchers prospectively following community regeneration in West Cornwall have devised a new methodological approach called a constructive enquiry. This longitudinal qualitative approach uses one-to-one interviews, focus groups, informal conversations and field-note observations of meetings with negotiated feedback sessions of the results to the participants throughout the project.

The research is in every way participative. The research brief was negotiated with the community, with their perspectives dictating how the research began. People from the community highlight the issues that they would like raised and who they would like the researcher to raise them with. Every four months the work is fed back to all the participants to inform a discussion about how best to proceed. The main themes are then analysed by a multidisciplinary group of researchers and people from the community.

It would be far too simplistic to say that the barriers to user involvement have been overcome for me by utilising a more inclusive methodology, but it does help. The methodology we are using to look at community regeneration allows you to 'see the person and listen to the story' and feel comfortable with my role and my relationships with the service users. To do this I have had to accept that standing outside of the system and observing is neither an honest nor very effective means of researching.

Sometimes it's the process that can change researchers' attitudes, rather than the outcomes of the research. In other words, when I look back at people and projects, actually working with service users has had far more impact on practice than any research outcome could have.
(Katrina Wyatt, project researcher)

Examples of involvement

What does it mean to involve consumers successfully in NHS research? A consensus study

This project aimed to develop consensus-derived principles of successful service user involvement in health research. The project came about as the direct result of the strategic direction taken by Sheffield Care Trust to carry out research in the area of service user involvement in research.

Service user involvement in research is a relatively new concept for health researchers and the researchers encountered misunderstanding about what it meant. Some of them were enthusiastic about involving service users, but did not know how to do it. There is scope for professional bodies to assist in making this health policy initiative more widely known and acted upon. Training for researchers, often provided by service users, is only just beginning on a national scale.

Service user researcher consultants were members of an advisory group. They influenced the research design and the interpretation of the findings at different stages of the research.

We learned about the process of collaborative research from the service user consultants. For example, we learned from them at the first meeting to be clear about what was expected of them and us, and they suggested ethical rules that we all agreed to observe. If less experienced service users had worked with us, we would have wanted structures and processes in place to provide support. These include the offer of training, mentoring, administrative and professional support, practical help, and access to libraries, IT systems and photocopying resources.
(Rosemary Telford, Jonathan Boote and Cindy Cooper, project researchers)

6 Involving service users in peer review

What is peer review?

Peer reviewing involves sending a research proposal or research report to people who are not directly connected with it for comment and review. Reviewers may be asked to make comments about:

- the quality of the research

- how relevant or important it is

- whether the research offers value for money

- any ethical issues

- the skills and experience of the researchers

- how the research could be improved.

A number of different stakeholders may be asked to comment on a research proposal or research report – they include service users, researchers and practitioners.

Researchers who have studied the effectiveness of peer review have concluded that it isn't a perfect way to judge the quality or importance of a piece of research – but it is probably the best way we have at present. However, it is seen as a problematic process, whether or not service users are involved.

> *Peer review is one group of people selecting a second group of people to review something written by a third group of people. How much should the three groups talk to each other and interact? It's always going to be an interesting and controversial process, and never a perfect one.*
> (Chris Caswill, chair of peer review seminar)

Involving service users in peer review – some defining factors

There is no single process for peer review within research and there are no templates for service user involvement in peer review. However, the experience of the agencies that shared their experience of involving service users in peer review (see the boxed examples overleaf) and of participants in the seminar series suggest that there are some common factors.

What service users bring to the peer review process

As peer reviewers, service users can offer a unique and complementary perspective.

- They know what it is like to be on the receiving end of research.

- They have personal knowledge and experience of a particular condition or service.

- They have an insight into the concerns of other service users.

- They may also be researchers themselves, so have research expertise.

Involvement in peer review can increase service users' confidence and expertise.

What are the barriers that prevent further service user involvement in peer review?

The challenges service users face when they become involved in peer review are similar to those they face when getting involved at other stages of the research process. Many centre around power. If people who are seen as having power in the research-commissioning process are not actively committed to listening to the view of service user reviewers, service users can feel their views are ignored and choose not to remain involved. This can also be the case if they get no feedback about what happens as a result of their involvement.

Experiences of involvement

Jennifer Taylor, Lambeth People First Research Group and Shaping Our Lives

We got asked by the Department of Health to look at an idea for research that was supposed to have been written by people with learning difficulties within People First. We looked at the writing and we thought it wasn't good. I couldn't understand it. I didn't believe it was people with learning difficulties writing it. We thought the staff had taken over.

We should be telling the staff what to do, not the staff telling us what to do. The staff should be listening to what the Government are saying – they said we'll listen to people with learning difficulties but we're not getting that at the moment. This is why a lot of people are complaining. They want things to change.

continued overleaf

> We wrote a letter to the Department of Health telling them that the research idea had been written by staff who had taken over. The Department of Health didn't take any notice of us. They wrote to us saying thank you for your letter but they still let the abuses go on.
>
> People with learning difficulties should tell the Government who should get the money to write about us, because we know what's best for us. It's our life at the end of the day.

Involvement in peer review doesn't mean that service users have any influence in the research prioritisation process – the research funded and published may still address questions that are not seen to be important to many service users. Service users can be marginalised if they are asked to comment on only the user involvement aspects of a research proposal or report.

Participants discuss barriers to involvement in peer review

Experiences of involvement

Ayesha Vernon, independent researcher and service user

About four years ago, when I was working as a full-time academic, I submitted a research project to the ESRC on disabled women's experiences of abuse. Although the referees' feedback was very positive, I did not receive funding.

I then heard from some of the referees, who said they'd like to work with me to resubmit this project. I became the junior person in the resubmission. The referees, who were now the lead researchers, submitted this new proposal to the ESRC and to the Community Fund. Again it was turned down. So now it's being submitted again.

I now feel that the people who were referees on the initial proposal and are now the lead researchers have taken over the project. My work is being used, but the power is more with them.

There are also practical issues. If involvement processes and relationships are not already established, there may be a tension between the amount of time it can take to involve service users in peer review and pressures to commission research quickly. Service users may be expected to be 'representative' without being resourced or encouraged to seek the views of other service users. Funding can also be a barrier to involvement (see Chapter 2).

There are issues about capacity. Many service users would welcome training about research so that they can participate more fully. If service users lack confidence and knowledge of the research process, they are unlikely to be able to participate fully. Often a small group of service users may be asked repeatedly to undertake peer review – there is a need for greater diversity among those who undertake peer review.

Examples of involvement

The Department of Health Policy Research Programme

The Policy Research Programme (PRP) is one of the largest research programmes run centrally by the Department of Health. The research covered is very diverse and includes a whole range of policy-related issues, ranging from cancer to social care. The Programme funds one-off research projects, ongoing research and a number of research units. There is peer review of research proposals, final reports and research units that receive long-term funding. Peer review is done by individuals, groups and committees, and reviewers are academics, policy makers, practitioners, service users and carers.

The PRP is committed to user involvement in peer review. Reviewers are asked to look at quality, value for money, policy/practice relevance, ethical conduct, skills and experience of researchers. They also look at user and carer involvement in the research process. Service users are asked to comment on any or all of these aspects of the research.

> Should user reviewers be involved in commenting on all aspects of the research, or just some of them? How well do research commissioners listen to people with a wide range of conditions and experience of a wide range of services? Are research commissioners clear with service users that peer review can be demanding, time-consuming and may not be empowering? And that research doesn't necessarily lead to change? These are key questions we need to address.
> (Carol Lupton, Policy Research Programme)

Examples of involvement

The Forensic Mental Health R&D Programme

The Forensic Mental Health Programme, which is part of the Department of Health, funds research that supports the provision of mental health services for people with mental disorders who are offenders, or at risk of offending.

The Programme involves service users in all aspects of the commissioning process. Within the peer review process, academic or scientific reviewers evaluate the technical merits of a proposal. Service user reviewers can comment on a proposal's technical merits but their added value is in the insight

continued

and awareness of service users' concerns they bring to the peer review process. They are also able to comment on whether the user involvement proposed in the research is meaningful.

A project recently funded by the Forensic Mental Health Programme looked at risk factors for anti-social personality disorder in young people. Following review, and in consultation with a service user representative from the Programme, the user involvement aspect of the project was enhanced with the establishment of a service user advisory group to feed back comments from the young people and their families to the researchers.

The Programme recently invited proposals for projects with user involvement as a priority. Proposals were subjected to peer review. Particular attention was paid to the comments of service user reviewers.

> If peer review is seen as a stand-alone procedure, service user reviewers can be left feeling as though their comments are ineffectual. Reviewers' comments should be reflected back to both the researchers and the funding body. But of equal or of more importance is that the peer review process be part of an integral user involvement strategy, which runs through the commissioning and research process.
> (Sue Spiers, Forensic Mental Health Programme)

Experiences of involvement

Brian McDonald, member of Forensic Mental Health Programme commissioning group

> I am involved in forensic mental health R&D and the attitude of the more established/eminent academics in the field was to treat the patients as data sources. Involvement in the research was rare. That is the environment into which I landed head first, with little understanding of the language, or for that matter the relevance of the research. My guide was a dictionary on social work language and in front of me was a pile of papers requiring my input. The realisation that I had the status of an equal in this primarily academic environment, where the title 'professor' is more common than 'Mr', was scary.

To remain an equal in the eyes of the rest of the group, I could accept the academic view and pretend to understand it. This would not have been wise, as not only would they spot it, they would rightly be appalled at my arrogance, and more importantly this would devalue any comment I made. Or, as I finally decided, I could ask questions on that which I failed to understand, and comment only within my area of expertise, user involvement.

This was relatively easy, for there was little user involvement in any of the papers submitted. It seemed that the sheer mechanics of involving service users in the research, when users are in secure provision would be too much to overcome. So the line 'there is no user involvement to comment on', or 'tokenistic', gave the chance to describe how it could be corrected.

In doing so it is important not to shout or blame the author of the paper, as they may have had little opportunity to understand the advantages of working with the patients and it is vital that the goodwill of those you work with is maintained.

The process of change in this committee has been described as carrot and stick. Not an original approach perhaps, but remarkably effective. To gain access to the funding process the researchers are now obliged to include a detailed description of the stakeholder input, with a budget heading that is more than just notional. The researchers' final report also requires a breakdown of how user involvement advised the work.

Allied to this there are three pieces of research where user involvement is central in the research process. One of these is user led. All are designed to ensure that users' needs are the primary force.

This is my experience of working on a committee that commissions forensic research. It is incredibly positive to be treated as a peer in this environment. It is both enabling and empowering. The way users have been integrated into the research process has occurred primarily because at director level through to the members of the committee there has been an intention to make the voice of the users have some weight. My comments have been listened to and acted on. Peer review of research has in the past been done by academics alone. The simple

device of empowering a user as a peer, giving equal value to their input, has created such a groundbreaking change in the way that research is commissioned.

So my conclusion from my own experience is that a user can, in the process of peer review, create a change in attitude *IF* the will is there to listen and act on the input given. I have been fortunate. As an example of what can happen it is massively encouraging.

Brian McDonald from the Forensic Mental Health programme, shared his experience of reviewing research proposals with other seminar participants

7 Involving people from black and minority ethnic communities in research

Introduction

Research about Britain's black and minority ethnic communities has been undertaken for many years. However, most of this research saw people from these communities as the 'objects' of research, and as a problem, rather than as potential participants in the research process.

Increasingly, the voices of people from black and minority ethnic communities have begun to be heard in research – both as researchers and as research participants. However, a number of barriers remain.

What are the barriers that prevent people from black and minority ethnic communities from becoming more involved in research?

Some of the issues faced when people from black and minority ethnic communities become involved in research are similar to any kind of participatory research – for example, there are potential conflicts of interest between paid researchers and other people involved in the project. However, there are additional barriers that can prevent the further involvement of people from black and minority ethnic communities.

Some communities are still under-represented in much of the research that is taking place – for example, Chinese communities and newly arrived communities. Some groups from within particular communities, for example disabled people or women experiencing domestic violence, may be marginalised and excluded from research. A number of factors, for example whether people were born in the UK or came here from elsewhere, may mean that there will be very different experiences within one community and that some of these are under-represented in research.

> *We need to strengthen the link between service users and carers and service providers and researchers.*
> (Seminar participant)

In contrast, some communities have been over-researched and have become frustrated about the lack of change that has happened as a consequence of this research. They may therefore decline to get involved in any further research until they can see that change has begun to happen. For researchers, this can mean that the process of building trust is very intensive and takes a long time. The move from

participation to implementation is therefore particularly important, as is feeding back what happens as a result of research to people who have participated.

> ### Experiences of involvement
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> Norma Clarke, volunteer researcher, Older Women's Lives and Voices Project
>
> When academics are doing things it's just lip service. Black people don't want lip service without construction. We need to look at how we make things better for people. If we have too many academic words that people don't understand, then it's not constructive for the people who try to get things going. You have research, then you have provision out of it. That's what I go for and what most black people go for. So when we were doing the project *[Older Women's Lives and Voices – see below]* it was nice to include things and that the academics didn't have too much say. Most people want research and then something doing.
>
> Here's a pen. You research the usefulness of the pen. Then after you're researched it you go and use the pen. That's what people want. When the Government is giving money for research, they must do it to get outcomes.

Practical arrangements, which are important in all participatory research, are also particularly important in research that actively involves people from black or minority ethnic communities. For example, it is important that venues are culturally appropriate and easily reachable. Interpretation and translation services may also be essential if people who do not speak English are to be meaningfully involved. This in turn can increase the costs of a research project and research funders may be reluctant to meet these additional costs – particularly at the dissemination and implementation stages.

This problem is exacerbated by the fact that research involving people from black and minority ethnic communities is often under-resourced and tends not to be funded as part of mainstream research programmes.

> *Research into issues important to black and minority ethnic communities is not starting from a level playing field and therefore needs additional funding and resources.*
> (Seminar participant)

Sometimes there may be a need to be more vigilant about ethical issues. Lorna Warren from the Older Women's Lives and Voices project (see boxed example later in this chapter) described how this project had involved older women as gatekeepers. Some of these women also acted as interpreters.

> *So we had to think hard about ensuring that these gatekeepers didn't dominate and that we heard everyone's voice. We kept a close eye on transcripts of interviews.*
> (Lorna Warren, project researcher, Older Women's Lives and Voices project)

Some participants at our seminar argued that there are not enough researchers who know how to work effectively with different black and minority ethnic groups, and with different generations.

Researchers may not address the questions that people from black and minority ethnic communities see as a priority. For example, researchers may focus on people's experience of using services, rather than on people's perspectives on what they consider to be important. This may mean that people's priorities are not identified and therefore not acted upon. Involving people from black and minority ethnic communities in identifying and prioritising research questions is therefore of particular importance.

> *We don't even get to see research that's about us. Research should be owned by voluntary organisations and service users, not by academics. Then we'd get the practical benefits.*
> (Seminar participant)

Research involving people from black and minority ethnic communities is often open to the charge that it is not 'representative', that it fails to reflect the views of a wide enough variety of a particular community or communities. This charge could be challenged if researchers could be open about what perspectives they tried to incorporate and who they did not, on this occasion, involve.

Examples of involvement

Older Women's Lives and Voices: participation and policy in Sheffield

This project aimed to increase knowledge and awareness of issues that affect the quality of life of older women, and their desire and ability to have a say in the services that are available to them. Older women, and particularly older women from black and minority ethnic communities, tend to have been overlooked in

continued

research. But it's difficult to understand the process of growing older without looking at what it means to be a woman, as the majority of older people in the UK are women.

So this project explored the experiences of women from a range of ethnic groups, working to connect ethnicity, gender and ageing. The researchers wanted to look at what was enhancing and not just debilitating for older women. They wanted to look at the ways women had control in their lives, not just at poverty and disadvantage.

They took a participatory approach. The project included black Caribbean, Chinese, Irish, Somali and white British women aged 50 to 94 years. In total 100 women were involved. Participants talked about growing older, using services and having a say, but led the discussions in directions that were important to them. Ten volunteers from the discussion groups then worked with the researchers to carry out life-story interviews. They were offered training. These women continue to take part in analysis and in sharing the findings of the study. A project video was also produced in English, Somali and Cantonese.

The involvement of the volunteers in analysing and disseminating the results of the research showed that research skills aren't necessarily a mysterious set of tasks that highly trained, usually white researchers can carry out. The researchers tried to ensure that everyone had a say in the language of the presentations, that everyone had a voice in conveying the findings. The volunteers spoke of an increase in confidence as a result of taking part in this research.

> As a researcher I've never had to really take on board the need to listen to other people. I'm used to taking the research data and writing it up myself. I was quite rightly challenged a number of times about what was kept in and what was left out.
> (Lorna Warren, project researcher)

Examples of involvement

Tower Hamlets Children's Fund

Tower Hamlets Children's Fund commissions services from the voluntary, community and statutory sector to provide preventative services for children and young people aged five to 13. A key principle of the Children's Fund is the active involvement of children and young people in the design, delivery and evaluation of services.

As part of the conditions of funding, the Fund needed to evaluate the impact of its services. Staff wanted to recruit an agency that could evaluate all services and that would actively involve young people. Many organisations that applied had no idea how to engage with young people, particularly how to engage with young people from black and minority ethnic communities.

Finally an evaluation agency was appointed. The Fund then recruited 16 young people aged eight to 14 who used their services. They trained them in research techniques. Each young person signed an agreement, outlining what they could expect from the Children's Fund and what the Fund expected from them. Parents also signed an agreement form.

These young evaluators then visited 36 Children's Fund projects and interviewed a selection of young people who used those services. They analysed their data in partnership with the evaluation agency and they presented the results to a variety of stakeholders, using different techniques.

Following consultation with the young people, their parents and others, it was agreed that the young evaluators would be paid for their time, using a selection of vouchers.

Saheed Ullah from the Fund identified a number of shortcomings and successes:

Shortcomings:

- We weren't able to recruit any disabled children or children with special needs – because of time and budget restrictions. As a result, no interviews were carried out with disabled children.

- This approach is very labour and research intensive, you have to be very committed.

- We didn't really engage the view of very young service users – children aged five to eight.

Successes:

- We found a model that focused on supporting young researchers, rather than focusing on a model that saw young people as objects of research.

- We've created a pool of talented, skilled and motivated young evaluators.

- Our group were representative in terms of ethnicity and gender.

- We've piloted a model that's had a very positive response from all of our stakeholders.

- We've been able to get the views of young service users in an environment that wasn't controlled by adults. The questions were formed by young evaluators and they asked the questions in an environment that was controlled by young people.

- Feedback from parents of young evaluators was very positive.

Participants at the seminar on involving people from black and minority ethnic communities in research

8 Developing emancipatory research

Emancipatory research: some defining factors

A number of researchers have written about what emancipatory research is, and what it means for researchers and those who are researched. We focused on a number of key questions.

Who controls research?

Emancipatory research is controlled by service users from the beginning of the process. Researchers who are not service users may be involved in the process, but control must be retained by disabled people.

> *We need to define what emancipatory research is. We don't want professional researchers jumping on the bandwagon pretending they are service users and that they do emancipatory research. It's no good just changing the words and not the attitude and the practice.*
> (Seminar participant)

Are some research methods more emancipatory than others?

To date, most emancipatory research has focused on qualitative methods. However, this type of research is not about methods – but about who has control. Therefore any research methodology could potentially be adopted by user-led organisations and used for user-controlled or emancipatory research.

How can we focus more on people's experience?

It is important that emancipatory research is driven by people's experiences, priorities and concerns, and draws more general conclusions based on these experiences.

> *In traditional research there seems to be no room for individual experience.*
> (Seminar participant)

What happens to research after it is complete?

Emancipatory research must lead to changes, not act as an end in itself.

> *Service users are sick of being asked the same questions over and over again … They want payback, a product from all this research, something that would benefit them.*
> (Seminar participant)

What are the barriers to the development of emancipatory research?

One of the key barriers to the development of emancipatory research is what is currently seen as 'evidence'. Most research commissioners seek to fund research that is perceived to be unbiased, objective and neutral. This has meant that existing research structures have prioritised and valued more traditional types of research over research that is seen to be emancipatory. Emancipatory research may not be seen as 'real' research because it focuses on people's experiences and making changes.

This means that, to date, very few emancipatory research projects have been funded and even fewer have received large amounts of funding.

Service users and ex-service users who undertake research find it hard to be taken seriously as researchers. If they try to undertake emancipatory research within traditional research organisations they can find this an isolating and/or negative experience. There is often a glass ceiling for many service user researchers.

> *Being an ex-service user – what they call an alcoholic – it is hard to be taken seriously by health professionals whatever my academic status and despite 16 years of abstinence.*
> (Patsy Staddon, service user and researcher)

Research undertaken by service users is rarely published in peer-reviewed journals and therefore does not gain recognition from other parts of the research community, or from those who judge the quality of research.

> *How can we look at different types of knowledge in a way that recognises them and values them?*
> (Seminar participant)

Some mainstream research 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', rather than to actively involve service users in ways that may be empowering and challenge traditional notions of where power is held. If emancipatory research is funded, it may often be funded within traditional research organisations, without any exploration of the tensions and contradictions inherent within this. This means that research that should have been emancipatory can become diluted or degraded.

Even when emancipatory research is funded, ethics committees may be resistant to approving that it can take place, as they often do not understand the importance of emancipatory and user-controlled research.

There is also a danger that, as more service users become researchers and emancipatory research becomes more professionalised, it may exclude the very people it was meant to support. There is therefore a real need for the original aims of emancipatory research as an agent for change to be kept to the fore.

> *We need to share our knowledge of emancipatory research. We need to find ways of supporting users in research and keeping them safe when things go wrong.*
> (Seminar participant)

Examples of involvement

Women's Alcohol Dependency: some sociological factors

The aim of this research is to identify the particular needs of women who experience alcohol problems, from a service-user and a feminist perspective, and to empower all involved, creating new alternatives. The project is led by Patsy Staddon, once a patient in a Bristol specialist alcohol addiction unit. The research is funded by the Avon and Wiltshire Mental Health Partnership NHS Trust and is supervised by the University of Plymouth as part of Patsy Staddon's PhD.

Patsy advertised in the local press, on radio and in other public places, and asked women who had or had had alcohol issues to contact her about their experiences and treatment. There were 60 responses, which led to 23 semi-structured interviews. The interviews usually took place in the woman's home, lasted up to two hours each and were taped.

Two-thirds of the women wanted to meet up again, in small groups of about six at a time, to discuss main themes and decide on courses of action. These focus groups took place and have already led to a self-help social and support group, which is based in Bristol but visits other parts of the area. They may also form a basis for political action, challenging current treatment and devising alternatives.

The project has a research advisory group of other women who have also had problems with alcohol use and who have also recovered using a variety of methods. The group meets up monthly to plan, devise, discuss and criticise the

continued

work. All are involved on a voluntary basis. Interviewees are encouraged to comment and criticise at all points and this material is fed back into the research.

When the research has been written up as a draft, all participants will be able to make comments and criticisms, which will be included in the final piece of work submitted to the NHS.

In the coming year, Patsy is running a further research project, Treatment Approaches, which will involve interviews with treatment staff, in which the service users' comments and concerns are raised, and staff are enabled to speak pseudonymously about their own issues and difficulties. Service users who took part in the earlier research will receive copies of this research. In this way, it is hoped that a better understanding will develop between service users and staff.

Examples of involvement

Creating independent futures – a user-led evaluation of centres for independent living and other user-led service providers

This project was commissioned by the National Council of Disabled People and the National Centre for Independent Living, and based at the Centre for Disability Studies at the University of Leeds. It was funded by the National Lottery and directed by a steering committee of disabled people and service users who have expertise in both research and independent living. It emerged from a social model understanding of disability and ran along social model principles.

The research questions were generated by an organisation of disabled people and then consulted on widely. A mixture of methods was used to ensure that the right type of knowledge was collected – large-scale surveys, focus groups and interviews. The findings were presented in accessible reports, through presentations and at a conference.

> The project conformed to expected standards of research. It was completed on time and within budget. It provided findings and conclusions that were clearly linked to the questions posed at the beginning of the project. To me this was rigorous, emancipatory research. (Hannah Morgan, project researcher)

Examples of involvement

The Citizens' Commission

In the mid-1990s, there was agreement among all major political parties that there needed to be radical welfare reform. Service users were not involved in any way in these discussions or developments. As a result, a small planning group of service users, supported by the Baring Foundation, set up the Citizens' Commission on the Future of the Welfare State.

They recruited a larger group totalling 12 welfare state service users, reflecting diversity and including a lone parent, older people, disabled people, a student, unemployed people, people on benefits, a mental health service user and a person with learning difficulties. They recruited a disabled worker and working together, with training and support, they sought the views of welfare state service users nationally through a series of discussion groups and calls for evidence.

The project worker collated the findings and the group then analysed these and organised a programme of accessible dissemination based on a 'bottom-up' approach to change. The Commission led to follow-up work involving service users in social policy discussions and initiatives.
(Source: Beresford and Turner, 1997)

Examples of involvement

Contributing on equal terms: getting involved and the benefits system

This project came about as a result of the Shaping Our Lives launch conference in 2003. The conference provided a rare opportunity for service users from all over the country to share their views and concerns. More than 250 people, mostly service users, took part in the event. It included a keynote speech from the Minister responsible for social care, Stephen Ladyman. When there was a chance for comment and questions, one person highlighted problems relating to being on benefits and 'getting involved'. When Dr Ladyman responded to this comment there was a loud roar from participants. He recognised the strong concerns expressed by service users and said:

> Can you through Shaping Our Lives prepare a paper explaining your
> experiences and the difficulties that you face and I promise that I will look

continued

into that … It will help me if I have your first-hand collated experience …
so that I know exactly what I'm talking about when I go and speak to the
Ministers.

Shaping Our Lives agreed, the Social Care Institute for Excellence agreed to
fund the research and it was carried out by Michael Turner as a piece of user-
controlled research. It served as a basis for follow-up discussion and action, with
a clear mandate from service users, as it originated from *their* concerns.

One of the characteristics frequently associated with emancipatory and
user-controlled research is that it should follow from what service users
rather than researchers want researched. It is sometimes difficult to be
clear about this. This is an example of where service users made very
clear what they wanted.
(Peter Beresford, Shaping Our Lives)

Participants discuss their experiences of emancipatory research

Reference

Beresford, P. and Turner, M. (1997) *It's Our Welfare: Report of the Citizens' Commission on the Future of the Welfare State*. London: National Institute for Social Work

Other sources of information

If you would like more information about how service users can be effectively involved in the development of the 'evidence base' for health and social care, you might like to look at these websites:

INVOLVE

INVOLVE is a national advisory group, funded by the Department of Health, which aims to promote and support active public involvment in NHS, public health and social care research.

Wessex House
Upper Market Street
Eastleigh
SO50 9FD
Telephone: 02380 651088
Email: admin@invo.org.uk
Website: www.invo.org.uk

Folk.us

Folk.us aims to facilitate and promote meaningful and effective service user, patient and carer involvement, in all types of research relating to health and social care in North and East Devon.

1st Floor, Noy Scott House
Haldon View Terrace
Wonford
Exeter
EX2 5EQ
Tel: 01392 403049
Email: folk.us@exeter.ac.uk
Website: www.projects.ex.ac.uk/folk.us/findex.htm

The Foundation for People with Learning Disabilities

The Foundation for People with Learning Disabilities works with people and their families to ensure they can use effective services, play a fuller part in communities and society, and enjoy equal rights.

Sea Containers House
20 Upper Ground
London
SE1 9QB.
Tel : 020 7803 1100
Email: fpld@fpld.org.uk
Website: www.learningdisabilities.org.uk

The Mental Health Foundation

The Mental Health Foundation aims to help people survive, recover from and prevent mental health problems.

20 Upper Ground
London
SE1 9QB.
Tel: 020 7803 1100.
Email: mhf@mhf.org.uk
Website: www.mentalhealth.org.uk

The Service User Research Group England (SURGE)

SURGE will play a key part in the delivery of mental health research which is valuable and has the confidence of mental health service users, and will support service user input to the Mental Health Research Network.
SURGE is based at the Mental Health Foundation
– see above for contact details.

Website: www.mhrn.info/surge.html

REU

Formerly the Race Equality Unit within the National Institute of Social Work, REU is a registered charity working towards better support for Britain's black and minority ethnic communities.

Unit 35 Kings Exchange
Tileyard Rd
London
N7 9AH
Tel: 0207 619 6220
Website: www.reu.org.uk

Shaping Our Lives

Shaping Our Lives is a national user network that aims to support the development of local user involvement that aims to deliver better outcomes for service users. The office is staffed Monday to Wednesday.

Email: carole@shapingourlives.org.uk
Website: www.shapingourlives.org.uk

Feedback

We welcome feedback about the issues raised in the report. We would be particularly interested to know:

• Did you find this report accessible to you?
• How could future reports be made more accessible?
• What, if any, are important issues that the seminar series and report do not raise?
• What issues raised in the report need further exploration?
• How is the information in the report likely to influence your approach to research?

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