Guidance for Good Practice

Service User Involvement in the UK Mental Health Research Network

UK Mental Health Research Network

SERVICE USER RESEARCH GROUP ENGLAND

CONTENTS

This document and how to use it

These guidelines were produced with the aim of providing guidance to researchers and service users who wish to develop collaborative research projects and programmes involving service users within the UK Mental Health Research Network. The document is in two main parts:

I Literature Review

The literature review provides much of the evidence for the guidance, covering a range of issues from the benefits of involving service users in research through accessible language, training and support to payments and resources. This section is particularly useful if you need to gather evidence for supporting the involvement of service users in research. Many of the papers referenced are based on the experience of conducting real projects, are practical in nature and have provided much of the evidence for the development of the guidance.

II Guidance for Good Practice

The guidance contains practical pointers and suggestions for how to involve service users in research. They broadly follow the research cycle in eight sub-sections:

1. Underlying principles
2. Capacity building
3. Identifying priorities
4. Commissioning research
5. Ethical Approval and Research Ethics Committees
6. Undertaking research
7. Dissemination and Implementation
8. User controlled research

Examples are given throughout of ways in which some organisations have addressed the issues. Three case studies are included which result from site visits (to Direct Impact in Wakefield, SURESearch at the University of Birmingham and SURE at the Institute of Psychiatry in London.)

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- We expect these guidelines to be used in different ways by different people, depending on the level of experience and knowledge of this approach to research.

- The Executive Summary is a good place to start as it provides an outline of the main contents. However, it does only give key guidance, and does not explore the detail behind them.

- Trusts and research organisations who are just beginning to think about involving service users in their research might find it useful to start by considering underlying principles and capacity building (sections 2.1 and 2.2).

- Service users wishing to work with a Trust or research organisation might find section 2.1 (underlying principles) and section 2.6 (undertaking research) useful in identifying good practice and issues that they need to think about before embarking on a research project.

- People who are already engaged in collaborative research (both service users and researchers) might find sections 2.6 and 2.7 (undertaking research and dissemination & implementation) useful in reviewing and revising any policies or practical issues they have found difficult, as well as in planning for future projects. Section 2.6 covers the range of service user involvement from consultation through to employment, with advice and information on such areas as payment, budgeting, support and training.

- Section 2.4 (commissioning research) is aimed primarily at commissioning bodies and funders of research, and section 2.5 (ethical approval and research ethics committees) at RECs. However both may prove useful to researchers and service users who are wishing to communicate their needs to either of these bodies.

- Service users and researchers who are interested in creating opportunities for user-controlled research should find section 2.8 useful in identifying some of the supporting evidence and helpful contacts. Section 2.8 is also valuable for those wishing to support the further development of user controlled research.

The key guidance arising from the research and consultation process is highlighted at the end of each of the eight sub-sections.

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Executive Summary

The service user arm of the UK MHRN, the Service User Research Group England (SURGE), was awarded to a partnership between the Mental Health Foundation, Shaping Our Lives, the Centre for Citizen Participation at Brunel University, the NIMHE Experts by Experience group, and the Survivor Researcher Network. The guidance summarised here is one part of the work of SURGE which will also be supporting people throughout the UK MHRN to involve service users in research and to connect with each other where similar goals or needs can be identified.

This guidance is for researchers and service users who wish to develop collaborative research projects and programmes involving service users within the UK Mental Health Research Network. The aim is to assist in the development of user involvement in research and user-controlled research throughout the UK MHRN. The guidance is based on an extensive review of the literature, contributions from SURGE partners and visits to case sites. The document has two sections:

I Literature Review

The literature review provides much of the evidence for the guidance, covering a range of issues from the benefits of involving service users in research through accessible language, training and support to payments and resources.

II Guidance for Good Practice

The guidance broadly follows the research cycle from underlying principles through capacity building and undertaking research to dissemination and implementation, with the addition of a section on user-controlled research.

This summary has been produced to provide a brief digest of key principles and guidance for the development of Good practice in Service User involvement. It is designed for use alongside the Full Guidance document, which explores and expands upon these key areas in greater depth and offers more detailed practical suggestions, examples and case studies.

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Summary of Key Guidance

Key to main areas of responsibility:

M = UK MHRN H = Hubs R = Researchers SU = Service users

2.1 Underlying Principles [R; SU]

It is important for all researchers and service users participating in a research project to take time to consider the principles underlying their work. SURGE recommends the following principles as essential to good collaboration:

- Clarity and transparency: Researchers need to be clear about why they are seeking user involvement, and service users about why they are taking part. Clarity is needed from the start about the nature and aims of a project and the roles and responsibilities of all parties. It can help for role descriptions or contracts to be put in writing so that everyone knows what is expected of them.
- Respect: It is important that everyone taking part in a research project respect each other and respect each other's right to express their own views.
- Diversity: Researchers need to ensure that they take account of the diversity of the population they serve when seeking to build capacity amongst local service users. It is important that the diversity of service users to be involved in a research project should reflect the nature of the research project itself.
- Flexibility: Flexibility needs to be built into research projects from the start: flexibility in relation to timescales and resources as well as working practices and expectations of service users whose mental health may affect their attendance and ability to work from time to time.
- Accessibility: Researchers need to use plain language and avoid jargon where possible (or explain it clearly). Accessible formats for the presentation of all materials may be necessary: it is good practice to establish any access needs at the start of a project.

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2.2 Capacity Building [H; R; M]

Building capacity amongst local service users is a challenge for many research departments and researchers who wish to involve service users in their research. However, researchers or research organisations need to consider capacity building amongst research staff as well as service users if user involvement in research is to become a successful enterprise.

- Explore the local community and identify local service user groups; the mental health voluntary sector can often help in signposting this information. It is useful to identify any existing experience within the Trust of carrying out collaborative research, in order that this experience and any associated contacts, can be built on.
- It is important to build up collaborative relationships over time in order to build up trust as well as expertise. Attempting to recruit service user participants at the last minute when a research bid needs to be submitted can be damaging to both parties. Remaining in contact with service users and researchers who have completed collaborative projects can also help in this process;
- Ensure that a budget to develop collaborative relationships can be identified: money to pay people's expenses and for preliminary training and support can be vital;
- Contact others for advice on what works – including those identified in this guidance and the INVOLVE Support Unit;
- Be prepared to offer and receive relevant training that will help to build everyone's capacity for successful collaborative research;
- Keep a record of people within your organisation who have relevant experience and expertise in this field so that this can be built on.

2.3 Identifying Research Priorities [M; H]

Service users and user groups are likely to have different priorities for research to those identified by researchers, Trusts or Government policy. The most successful involvement of service users in research is likely to take place where there is some convergence of agreement in priorities, i.e. where a research project is of intrinsic interest to service users as well as to researchers.

- Consult with local service users and user groups about their priorities for research and seek to find some areas of common interest with current Trust or MHRN research priorities;
- Inform service users about your priorities and research currently being carried out within your department/Trust and across the MHRN;

- Research Interest Groups, which are beginning to be established within the context of the Mental Health Research Network, need to ensure that they are consulting with and including service users in the development of research topics.

2.6 Undertaking Research **[H; R; SU]**

There are no easy answers as to how to carry out collaborative research smoothly and successfully. There are, however, a number of key issues that can help and the following guidance comprises a long list of these. However, the two that stand out are adequate support and supervision, and appropriate training for everyone involved. Along with the underlying principles outline in 2.1 above, these would go a long way towards enabling a successful outcome.

It is suggested that any collaborative research project be categorised as follows:

Degree of service user involvement		Please tick
Consultation		
Collaboration	Researcher initiated	
	Jointly initiated	
	Service user initiated	
Control		

- Consulting with service users
  - Always involve more than one service user in a consultation, and ensure that adequate and accessible information is provided;
  - Payment of fees and travel expenses should be made available on the day of the consultation;
  - Consult with people with integrity: be clear about how you will be taking their views on board;
- Planning and starting a project
  - Service users should be involved from the start of a project;
  - Resources should be planned in advance to take into account the time and money required to involve people fully;
  - Plan for flexibility, support, training and periods of absence;

  - Researchers need to communicate well in advance with
    - Finance department
    - Human Resources department
    - Occupational Health

    about their intention to involve or employ mental health service users in research – in order to facilitate the process and pre-empt any difficulties that may arise;
- <u>Supporting and maintaining a project</u>
  - Adequate support for service users is vital: practical, emotional and research related support;
  - Training in relevant knowledge and skills is vital for both service users and researchers;
  - Be prepared to be flexible and to negotiate about the research process with sensitivity and respect;
- <u>Employment of service user researchers</u>
  - Serious consideration needs to be given to the role of the employed service user and the ways in which their views are to be contributed to the research process.

Suggested checklist for funding/budget planning

- Payment of fees and travel & care expenses to user-researchers;
- Fees for research participants;
- Enough funding to include more service user interviewers, consultants or researchers than the project needs, to cover for periods of absence;
- Support for service users (may be an additional support worker or alternative);
- External supervision;
- Physical resources, such as space and communication technology to enable service users to take an equal part in the project;
- Training for service users and for staff (as appropriate);
- Time/venue/refreshments to meet with each other for mutual/peer support;
- Dissemination and feedback to participants: in different formats relevant to your project (e.g. language, accessible written and oral presentations);
- Insurance – liability.

Adapted from Faulkner A. (2004) "The Ethics of Survivor Research"

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2.7 Dissemination and Implementation [H; R; SU]

For many service users, there is little to be gained from taking part in research if the results are not going to be publicised and used in some way. Many service users are motivated to take part in research out of the desire to change and improve mental health services. This may present a challenge to researchers who do not have the power to implement the results of their research, but it is an issue that needs to be addressed in some way.

- Dissemination to service user audiences in accessible formats must form part of any dissemination strategy;
- Implementation is a priority for many service users: if possible, it should be built in from the start of a project through adequate budgeting and through the involvement of local stakeholders; however, if implementation is not likely, then this needs to be clearly communicated to the service users involved;
- Ensure that service users are informed about any publications that take place as a result of the research in which they have been involved;
- Endings need to be given due consideration: find a way to mark the ending of a project and a way to enable service users and researchers to reflect upon their experience and the learning they have gained through collaborating;

2.8 User-Controlled Research [M; H]

User-controlled research has an important role to play in exploring topics of specific concern to service users; challenging the validity of traditional knowledge standpoints and the meaning and status of sources of ‘evidence’ in an ostensibly evidence-based NHS.

- The promotion and encouragement of user-controlled research is part of the range of research adopted and supported by the MHRN;
- Any evaluation of the involvement of service users in research needs to take account of the full range of different approaches to user involvement in research, including user-controlled research.

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Glossary of Terms

Acronyms

COREC	Central Office for Research Ethics Committees (see REC below)
INVOLVE	(*formerly Consumers in NHS Research)* Standing Advisory Group on Consumer Involvement in the NHS R&D Programme. The Involve Support Unit provides advice and information on public involvement in research. There is a website and they produce a range of useful publications. www.invo.org.uk
UK MHRN	UK Mental Health Research Network
NHS R&D	National Health Service Research and Development
NIMHE	National Institute of Mental Health, England
REC	Research Ethics Committee. Local RECs have the responsibility of giving approval for research projects to go ahead. They are concerned with good practice in relation to the treatment of patients and clients in research as well as with high quality standards in research.
SURE	Service User Research Enterprise: research unit based at the Institute of Psychiatry, London
SURGE	Service User Research Group, England: part of the Mental Health Research Network – SURGE produced these guidelines.
SUREsearch	Service Users in Research and Education: group of service users involved in research and education co-ordinated from the University of Birmingham by Professor Ann Davis and Colin Gell.

Research terms and NHS terminology[1]

Action Research

Research designed to explore a practical situation or service, with the aim of implementing findings as they are discovered and bringing about positive

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[1] With thanks to INVOLVE publication: 'Getting involved in research: a Guide for Consumers' Royle et al, 2001.

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change. Typically the research will follow a cycle of investigation – findings – action (implementation) – investigation – findings and so on.

Advisory Group

A group of people brought together to offer advice on a project. They will each be chosen on the basis that they have some experience or expertise to bring to the project, and will meet on a regular basis during the life of the project.

Collaborative research

In this case: an active partnership between researchers and service users to carry out a research project. Collaborative research can also refer to any partnership to carry out research, such as that between researchers and health service practitioners.

Commissioning research

This is the process of selecting someone to underake a particular research project. It will typically involve advertising the research topic, selecting a shortlist of the best proposals from those submitted, and reaching a decision about which one to fund. The final decision may be informed by peer review, i.e. engaging other independent researchers and experts to read and comment on the shortlisted proposals.

Consumer

The term 'consumer' refers to anyone who is a consumer of the service, including patients, carers, long-term users of services, organisations that represent consumers' interests and members of the public who are the potential recipients of health promotion programmes. The intention is to distinguish between consumers and health or research *professionals*.

Dissemination

The process of ensuring that the results or findings of a research project reach a wide and relevant audience. This might involve giving talks at conferences, speaking on the radio, writing articles in newsletters or journals and giving talks at events arranged for people for whom the project is relevant.

Empowerment

Empowerment is what happens when someone gains a greater voice in situations where they have little power or say over what happens to them; or when someone gains greater control over their life through learning the skills or finding the opportunities in which to express themselves.

Epistemology

The theory or science of the method or grounds of knowledge.

Ethics (see also RECs above)

In research terms, ethics are the principles underlying the practice of reseach that will ensure, as a minimum, that no harm or abuse will be done to research participants. Examples include informed consent and maintaining confidentiality. Ethics can also include other values held dear to researchers and service users, such as the importance of respect, clarity and transparency, diversity and accessibility.

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Evaluation

An evaluation seeks to assess how well a service or project is doing against its aims and objectives, and against some specified standards or level of quality. It is likely to use both qualitative and quantitative methods and to gain the views of service users, staff and other ‘stakeholders’ of the service.

Focus group

A focus group - or group discussion - is a small group of people brought together to discuss and respond to research questions. It is a good method to use when a researcher needs to gain people’s views about a service or ideas about a new or ideal service.

Hub

Research ‘hub’ is a relatively new term, coined in relation to the Mental Health Research Network. Rather like a hub in the centre of a wheel, the idea is that the hub brings together networks of people and organisations who will undertake research in different partnerships. The MHRN has a number of ‘hubs’ associated with it, most of which are regional and so will bring together regional networks of people and organisations. SURGE is a non-regional hub which seeks to co-ordinate a network of people and organisations interested in service user involvement in research.

Implementation

The process of acting on the findings of research to bring about positive change.

Informed consent

Ethically, a researcher needs to gain ‘informed consent’ from a research participant before they can proceed to include them in the research. It means that the participant must be fully informed and understand about the research and what involvement will entail before they agree to take part.

Methodology

A system of methods or ways of going about undertaking research.

NHS Research and Development

The Department of Health funds research through two main programmes. The NHS R&D programme aims to identify NHS needs for research and to commission research to meet those needs (£89m in 2002-2003). The policy research programme undertakes development and evaluation in public health, health services and social care in order to ensure that policy is based on reliable evidence of needs. All of the research is directly commissioned (around £30m pa). See: http://www.dh.gov.uk for further information.

Outcome/outcome measure

An outcome may be the result or effect of a treatment on a patient, e.g. a change in the level of depression caused by the use of anti-depressant medication. The outcome measure is what is used to measure the effect of the treatment on the patient. In this case, a questionnaire may be used before and after the use of the medication to assess whether it has brought about any change.

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Qualitative research

This is research that endeavours to gain understanding about personal experience and the meanings behind actions or beliefs. It is usually obtained through in-depth interview and seeks themes and issues rather than facts and figures. As it is produces rich and detailed information, there will be few participants and analysis may not be applicable to the general population.

Quantitative research

This is research that aims to understand the world through measurement, facts and figures: data that can be readily analysed through statistical methods and widely generalisable.

Research Governance

Research Governance refers to the process by which broad principles are set for good and ethical practice in research; it seeks to promote high quality scientific and ethical standards, encourage innovative research, and prevent poor performance and adverse incidents. The Research Governance Framework for health and social care was published in April 2001.

'Service user' and 'Survivor'

These terms can be used rather differently by different people. The term 'service user' is usually used where the people to be involved in a project are using or have used services, i.e. they are or have been patients or clients. Very often, in the context of research, this means they have used the service being explored within the research project.

The term 'survivor' is often intended as a more broad term to include people who have experienced mental or emotional distress, whether or not they have used mental health services. However, 'survivor' is also used politically to refer to people who have survived mental health services and/or treatments; in this sense it is shorthand for 'psychiatric system survivor'.

Stakeholders

These are people or organisations who have a recognisable 'stake' or interest in the service or project in question.

User controlled / user-led research

This is research where service users lead or control the research: design, undertake and disseminate the results of a research project. There may be a distinction between the two: user controlled research may be more comprehensively under the control of service users, whereas user-led research may be funded from within an organisation where some control is retained but is led by service users. There is a project currently funded by Involve to scope this area, and to arrive at agreed definitions.

Introduction

The UK Mental Health Research Network was set up in 2004 building on a network that was set up by NIMHE. It is co-ordinated by the Institute of Psychiatry, Kings College London and the Universtiy of Manchester. The network supports clinical trials and other high quality research which is aimed to improve the standard of health and social care.

There are eight research hubs which have clinical, academic and service user components. The clinical component consists of primary, secondary and social care and the academic component is a mix of high quality multi-disciplinary researchers from universities and research consortia.

The MHRN put out to tender the contract to provide the service user arm of this network, with the aim of supporting user involvement in research throughout the mental health research network. The Service User Research Group England (SURGE) was awarded to a partnership between the Mental Health Foundation, Shaping Our Lives, the Centre for Citizen Participation at Brunel University, the NIMHE Experts by Experience group, and the Survivor Researcher Network. Contact details for the partnership and its constituent partners may be found in Appendix A.

The impetus to involve service users in research has come from a number of sources, not the least of which are service users and user groups who have campaigned both for involvement and for independence in conducting their/our own research (see below). This has been paralleled by a growth of interest in public involvement in research.

In 1996 the Department of Health established the Standing Advisory Group on Consumer Involvement in the NHS R&D Programme, Involve (formerly Consumers in NHS Research). The aim of Involve is to ensure that consumer involvement in R&D within NHS, public health and social care fields improves the way that research is prioritised, commissioned, undertaken and disseminated. Their objectives are:

- To develop strategic alliances with key groups in order to promote greater consumer involvement in health research

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- To empower consumers to become more involved in research and development in the NHS
- To monitor and evaluate the effects of consumer involvement in NHS, Public Health and Social Care research & development

More recently this policy initiative has been embodied in the form of Department of Health guidance in the Research Governance Framework for Health and Social Care (April 2001). The Framework includes two areas of relevance to service users (and carers):

- A call for the active involvement of service users and carers at every stage of all research; and
- A move towards greater openness about research undertaken by organisations and particularly their findings.

The Research Governance Framework

"2.2.6 Participants or their representatives should be involved wherever possible in the design, conduct, analysis and reporting of research. Social care research has a long tradition of the involvement of participants in research. [Involve] has established the principle that major advisory bodies in NHS R&D programmes should normally have at least two consumer representatives."

from **Box B Standards in a Quality Organisation Undertaking Research: Ethics**

"Research is pursued with the active involvement of service users and carers including, where appropriate, those from hard to reach groups such as the homeless."

The impact of these developments has been to introduce into a range of public funding streams requirements on researchers to demonstrate in funding applications how consumers will be involved in their research projects, as well as to put user (and carer) involvement on the agenda of NHS R&D frameworks.

Note on carer involvement: The policy initiatives referred to above include the requirement to consider the involvement of carers as well as service users in research. SURGE and the current document are concerned with the involvement of mental health service users in research. However, good practice in user and carer involvement often includes negotiation of similar issues. Service users and carers share the experience of being low paid volunteers among groups of professionals, talking about personal and emotional experiences with people delivering services. However it is important also to acknowledge their different perspectives and need to be supported by people who understand and share that perspective.

At the time of writing, the UK MHRN has advertised a tender for a small scoping exercise to establish how the UK MHRN can support carer involvement in its research projects.

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I Literature Review

This review primarily considers user involvement in *mental health* research, although some reference is made to other disciplines. It should be acknowledged that other organisations have produced guidelines for user (or consumer) involvement in research. Involve, for example, has produced two booklets, one intended for researchers and one for consumers (Hanley et al, 2003; Royle et al, 2001). In these documents the authors take the reader through the stages of research, at each stage presenting options for consultation, collaboration and control. Folk.Us (based at the University of Exeter) has also produced a report on lay involvement in health research including recommendations (Baxter et al, 2001) and a brief report of the research with guidance aimed at service users (Thorne et al, 2001). These reports are recommended to the reader of the guidance presented here.

The literature on the involvement of mental health service users in research is not extensive, and is supplemented by reference to literature concerning user-led or survivor research as well as the (often unpublished) direct experience of people and projects. Some papers are written by academic (non-user) researchers for the benefit of other researchers, some are written by service users for the benefit of service users and some are more clearly collaborative in perspective. Several significant themes emerge from the literature, of which the following predominate:

1.1 Benefits of involvement
1.2 Early involvement
1.3 Power and negotiation
1.4 Clarity and transparency
1.5 Flexibility
1.6 Accessible language
1.7 Support
1.8 Training
1.9 Payments
1.10 Resources

1.1 Benefits of involvement

The benefits of user involvement may be benefits for the service users, for the researchers or overall benefits for the research itself. Rewards and incentives for service users are discussed elsewhere so this section focuses on the benefits for the research – the potential for user involvement to improve the research process and/or the outcomes. For the most part we are discussing perceived and reported benefits, as there is little evaluative research into the outcomes of involving service users in research. At the time of writing, Involve has commissioned research to evaluate the effects of consumer involvement in the London Primary Care Studies programme, eleven projects funded by the former London regional office.

Several papers suggest that the user perspective itself brings benefits with it: by offering insight into what it feels like to experience mental health problems, to use mental health services or to receive certain treatments, service users can help ensure that the content of the research is more relevant to clinical practice and the results more relevant to service users. This view is expressed in Hanley et al (2003), Trivedi and Wykes (2002), Allam et al (2004), Goodare and Lockwood (1999) and Rose (2003a). Rose points out the particular value of taking up a research position within an academic institution:

> *'I think it can complement and sometimes challenge mainstream mental health research… This perspective should not compromise research rigour, and there may be a danger of being over-involved. But I do not see this in our team any more than I see it in other professionals who are committed to their discipline.'*
> Rose (2003a)

In concrete terms this means that service users can make positive contributions to the design of research questions and questionnaires and the use of outcome measures. Allam et al (2004) discuss the benefits of involving service users and carers in the design of relevant questions. Trivedi and Wykes (2002) detail the considerable negotiation needed to determine the outcome measures used in the research, a study of the effects of medication education sessions on local inpatients. Two chosen measures were of insight and compliance, both of which the user researchers challenged in favour of measures of patient empowerment. A compromise was reached whereby both types of measures were used.

Wykes (2003) develops the argument a stage further in an editorial for the Journal of Mental Health. She examines the following three areas where user involvement may change clinical research for the better:

1. Improving scientific quality (the research questions may change for the better)
2. Changing the outcome measures (outcome measures become more related to the ones that are important to service users)
3. Amending the method of research (perhaps augmenting the RCT approach to include the views of service users)

Ramon (2000) contends that user involvement in the research process leads to the 'generation of new and more in-depth knowledge in the field of mental health'. She also comments on some potential benefits to researchers (a better understanding of the lives of service users and lay perceptions of research) as well as those of service users, and mentions one of the findings of evaluation research: 'more truthful information from the research participants than would otherwise have been possible'.

This last issue is mentioned by Allam et al (2004) for whom it was one of the main reasons for adopting a collaborative approach to the research, despite finding few references to support it.

> *'People who have been interviewed by service users have said that they feel able to speak more freely to others who are using services rather than those providing it; they have less fear of being judged, and therefore response rates have been found to be higher in user led research.'*

Both Rose (2001) and Faulkner & Layzell (2000) refer to this phenomenon, and Rose examines it in relation to previous authors (Clark et al, 1999; Polowycz et al, 1993) both of whom found a positive difference in the responses made to client as opposed to professional interviewers.

Allam et al (2004) detail the collaborative process throughout, exploring the involvement of users and carers in the development of questions and interview schedules through analysis and interpretation to dissemination. The section on analysis and interpretation is of particular interest. The authors suggest that the systematic differences in the interpretation of responses between the service users and carers (and potentially professionals) provide strong justification for involving service users and carers in the research process:

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1.1

> *‘The validity of the findings must be improved by working together and coming to a joint agreement about the meaning of the data.’*

Another potential contribution mentioned by some is that of facilitating access to other service users to participate in research, particularly people who belong to marginalised groups (Hanley et al, 2003; Fleischmann and Wigmore, 2000).

Several papers discuss the benefits of service user involvement for the dissemination stage of research (e.g. Telford et al, 2002). This, it seems is one area where service users come into their own for often they are more familiar with accessible routes to reaching service users and user groups as well as local stakeholders, than are the academic researchers whose preferred medium tends to be peer-reviewed journals. Hanley et al (2003) report that voluntary organisations may assist in dissemination by carrying summaries of research in user-friendly language in their newsletters and magazines. This has certainly been the route for such projects as the Mental Health Foundation’s Strategies for Living project and the Sainsbury Centre’s User Focussed Monitoring projects.

1.2 Early involvement

Several papers (Faulkner and Morris, 2003; Thorne et al, 2001; Faulkner, 2004) point to the value and importance of involving service users at an early stage in the research process. This is primarily to ensure that service users can be involved in early discussions about the research, and is particularly well expressed by Thorne et al (2001):

> *'Everyone should be involved as early as possible in the research process so that the direction of the research is clear, everyone knows what they are doing and there is commitment to the project.'*

Elsewhere, it is pointed out that if this does not happen, then many of the decisions about the research may already have been made without the involvement of service users which reduces their potential to influence a project. In reality, proposals often have to be developed quickly in response to research tenders leaving little time to involve service users at this early stage. Equally there may be no funding available to involve service users prior to the start of a live project.

This issue indicates the importance of building up relationships over time with service users, so that some groundwork can be done in preparation for such time-limited funding rounds. In their key principles for user involvement in research, Faulkner and Morris (2003) advocate building up 'relationships of trust and respect over time between researchers and local service users'. Telford et al (2002) similarly suggest, in their recommendations for NHS Trusts, that Trusts identify local expertise through the registration of past or current initiatives involving users and staff/researchers with experience in this area. Rose (2003) emphasises the importance of building capacity for the future; offering training and opportunities to enable service users to achieve relevant qualifications if they want to, or to be trained as interviewers and facilitators of focus groups. All of these proposals seek to avoid the tokenism of inviting one or two service users onto a research advisory group at the last minute, when a research project has already been established, designed and funded.

1.3 Power and Negotiation

The majority of the papers acknowledge that collaborative research brings with it a need for researchers to share power and to negotiate openly with service users. Faulkner and Morris (2003) for example, state in their principles that researchers need to:

> *'Be prepared to discuss and negotiate on the substance of the project (e.g. the underlying principles, models and methods). This is essential if service users are to be able to make a difference to the research.'*

Similarly, the Folk.Us team (Thorne et al, 2001) conclude that working in partnership usually involves a shift in power from professionals to lay people 'which some professionals may find hard to deal with at first'.

Trivedi and Wykes (2002) report that negotiation between researchers and service users may be one of the most challenging aspects of user involvement for the clinical researchers concerned. However, they too point out that

> *'[Service users'] views, values and opinions need to be taken seriously if they are really to influence research.'*

They advocate formalising the partnership with an explicit agreement about how they will work together, including issues such as how service users will be involved, payment and acknowledgement of service users' contributions. In further examining this experience, Wykes (2003) suggests that this process of negotiation, although searching and uneasy at times, is an indication of a successful collaboration: if it did not exist, she suggests, it 'may mean that a blurring of roles and expertise had occurred and that the creative tension had been lost'.

Several authors note that the power shift may be difficult to achieve or challenging for professional researchers, and may represent a fundamental shift in roles. Macran et al (1999), writing on psychotherapy research, state that perhaps the greatest difficulty facing these professionals will be the:

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> *'Relinquishing of professional power and adopting a new model of both the therapeutic and research contracts'.*

Ramon (2000) recommends that power needs to be addressed by all those involved in both co-inquiry and participative action research. Interestingly, she also addresses the power gained by service users in becoming researchers and how this may influence the relationships they develop with the service users they interview. However in the conclusions she emphasises the value of on-going negotiation in working out a shared perspective on the research:

1.3

> *'This entails exchanging ideas and perspectives, negotiating power relations, give and take on both sides, including at times giving up some cherished ideas and perspectives, recognition of the value of both partners' contributions by each, a lot of informal and at times formal support, sharing the uncertainty that any research project brings with it … and ensuring that there are intrinsic rewards that enable participants to continue.'* (Ramon, 2000)

Carrick et al (2001) write a great deal on the complexities of power and empowerment. In their research, they were able to be flexible about the methodology and about presenting findings to a user group for validation, but were clear about areas where they retained power. Perhaps a key issue here is the fact that the researchers were clear about what could and could not be negotiated.

Several papers talk of a process of negotiation regarding the methods used (Carrick et al, 2001; Ramon, 2000; Trivedi and Wykes, 2002; Macran et al, 1999) and primarily reflect upon the benefits of this process both for the research and for the research partnership, whilst acknowledging the extra time and resources involved. A couple of papers discuss negotiating the outcomes and outcome measures used in the research (Trivedi and Wykes, 2002) and/or the questions asked during the course of the research (Allam et al, 2004).

In a report reflecting on the experiences of researchers and service users involved in a collaborative research project, Faulkner (2004) writes that several of the service users involved felt that they had no say over the way in which the project was conducted, that academics still held the power. To some extent this seemed to be a result of service users being involved after the initial proposal and funding had been agreed, but there was also a sense in which user researchers felt powerless. The report points to the need for greater clarity at the start of a project about roles and responsibilities, as well as greater flexibility in negotiating the research process.

There is some evidence that the power differentials in mental health research have an additional layer of complexity. Both Beresford (2002) and Rose (2003) write of the paradox concerning the supposed 'irrationality' of those diagnosed with a mental illness engaged in the fundamentally rational process of research. Rose describes this as the most 'corrosive' aspect of the power differentials present:

> *'It is as if some collaborators are regarding user researchers through a double lens – once as a researcher and secondly as somebody's patient'.* (Rose, 2003)

Similarly Macran et al (1999) suggest that one of the reasons that clients' perspectives have been neglected in psychotherapy research is that they are thought to be unable to make reliable judgements about their psychotherapy because of their 'impaired state'. A stark example of this is reported in Faulkner (2004) where service users were required by the local Trust to go through an Occupational Health interview. This was experienced by several of the team as damaging and stigmatising, because inappropriate questions were asked of people about their life history in relation to mental health and illness. A complaint was made but the issue was not fully resolved during the life of the project.

A discussion about power leads us inevitably to a consideration of empowerment. There are a number of authors who relate (genuine) user involvement in research to the empowerment of service users. Indeed, it is proposed that the greater the involvement or influence over the research the greater the potential for empowerment.

> *"Whilst it is not suggested here that only research which offers service users the fullest amount of control is adequate or acceptable, there does seem to be a relationship between the extent of service users' involvement in research and its capacity to serve an empowering function."* (Beresford and Evans, 1999)

This paper raises a couple of important issues: a belief – held perhaps by service users and user groups – that user-controlled research is held up to be the 'gold standard' of user involvement in research, and empowerment as a primary goal of research. User-led or user controlled research has its roots in emancipatory research and has the empowerment of service users at the heart of it. Collaborative research can also be seen to make this claim, but the degree to which the collaboration is truly 'joint' will come into play here. Carrick et al (2001), in reflecting on the fact that an aim of collaborative research is emancipation, suggests that it is a desirable but secondary goal for her – secondary to the desire for 'discovery, confirmation and communication of worthwhile information'. Nevertheless she, like Ramon (2000), was able to be flexible about research methodology in response to the views of her research participants implying a significant delegation of power.

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Several of the subsequent themes are interrelated with the issue of power and negotiation: the importance of early involvement and clarity/transparency have implications for the sharing of power; equally the use of accessible language opens up the field of negotiation for those less likely to share in the language of research; and the ability to be flexible implies the ability to share power.

1.3

1.4 Clarity and transparency

As stated above, several papers refer to principles of clarity and transparency in relation to a willingness to share power with service users through the process of negotiation (Trivedi and Wykes, 2002; Carrick, 2002; Thorne et al, 2001; Faulkner, 2004). Both Faulkner (*in press)* and Thorne et al (2001), in writing on general principles, advocate clarity – about why service users are to be involved in a project, and about their roles and responsibilities from the start:

> *'It is very important that people's roles and responsibilities and the aims of the project are clear right from the beginning.'* (Thorne et al, 2001)

For some authors the issue of clarity and transparency is extended to incorporate values of honesty and trust in collaborative partnerships (Allam et al, 2004; Ramon 2000, Carrick 2001; Thorne et al. 2001). However, clarity and transparency are more tangible and perhaps easier to advocate or promote than trust, which takes time to develop and is dependent on building up relationships.

Practical examples of explicit agreements (such as that developed by Trivedi and Wykes) to clarify the partnership arrangements can assist in the development of trust. Certainly the absence of such clarity early on can provoke a lack of trust, as illustrated in Faulkner (2004); one recommendation to emerge from this experience was as follows:

> *'That arrangements for the management and supervision of a project are made clear to all from the start, particularly in the case of a collaborative project and with particular reference to the support needed for service users and project co-ordinator(s)'*

The issue of support is taken up later. The process of negotiation itself can establish and develop a relationship of trust (Allam et al, 2004; Ramon, 2000; Trivedi and Wykes, 2002) which can be built on subsequently in future projects. For Ramon, this process was a way of working out a shared perspective on the research, as noted above. Allam et al (2004) note, from the service users' and carers' perspective, an increasing trust and confidence in the researchers built up over time alongside an understanding of their role and approach. Trivedi and Wykes (2002) write of the 'often challenging and not always comfortable' meetings between researchers and service user but conclude that they served an important purpose:

> *'in allowing a mutually respectful relationship to build up between clinical researcher and user, which eventually enabled them to agree to look again at the project and consider working on it together in partnership research.'*

1.5 Flexibility

A flexible approach towards research involving service users is advocated by a number of authors (Allam et al, 2004; Trivedi and Wykes, 2002; Carrick, 2001; Ramon, 2000). Several raise the issue of resources (both time and money) as requiring flexibility, both within projects and organisations and outwith them – in the form of deadlines and other limits laid down by commissioners and funders.

Practical guidelines also advocate the need for flexibility in relation to time and resources, as well as mentioning the need for a flexible approach to availability or attendance to reflect people's fluctuating mental health needs. (See Faulkner, 2004; Thorne et al, 2001; Ramon, 2000).

Two projects explore the need to take a flexible approach to methodology and methods as mentioned earlier (Carrick, 2001; Ramon, 2000). It may be that this reflects a truly joint collaboration where the views of service users as researchers are taken seriously and acted upon. It may also be that the nature or funding of these research projects were such that they could allow for some flexibility in methods. Frequently research is obliged to follow the pathway laid down in an agreed proposal, particularly if approval has been granted by a Research Ethics Committee (REC). However, this is where the importance of a flexible approach from funders and commissioners of research (and RECs) comes into play.

1.6 Accessible language

A couple of authors strongly advocate the use of accessible language, and document the resentment felt by service users who feel excluded by the use of inaccessible language and research or academic jargon. Ramon (2000) for example, records the alienation felt by some of the service user researchers in response to the language of formal research:

> *'It was necessary for the university researchers to de-jargonise terms and concepts…'*

Faulkner & Morris (2003) and Thorne et al (2001) also emphasise the importance of jargon-free language, as well as accessible formats for those with visual impairments or learning difficulties:

> *'If research is easy to understand and relevant people are more likely to be motivated to become involved'.*

Training may be a way of bridging the gap and enabling service user researchers to understand the terms and language of research; SURE (Service User Research Enterprise, Institute of Psychiatry) has taken this approach in offering a training course to local service users which covers most areas of research over a period of several weeks.

1.7 Support

Nearly all of the papers and reports based on practical experience refer to the need to provide support for service users involved in research. Allam et al (2004) conclude that support should be available at every step of the journey. Examples include ensuring that systems within the research environment do not place undue stress on service user (and carer) interviewers, and the need to provide proactive support (or de-briefing) following interviews.

Telford et al (2002) report that training and support emerged from their study as important factors to consider when involving consumers. They cite one researcher's observation that 'she needed to spend a great deal of time boosting consumers' confidence, as well as providing practical support'. Macran et al (1999) suggest that clients would need training and support in order to 'feel confident and able to express their views'. Lockey et al (2004) in exploring training for service user involvement in health and social care research also found that support was a key element of successful training.

It is notable that two sets of guidance have produced very similar recommendations on support without apparent reference to each other (Faulkner, *2004*; Thorne et al, 2001). The latter suggest that, in addition to financial support, both practical support (in terms of transport, accessible meeting places etc.) and emotional support are necessary. Faulkner (2004) similarly proposes three elements to support: alongside emotional and practical support is research-related support (or supervision). Both reports suggest that it is valuable to break down the notion of support into these separate elements in order to clarify and provide what is needed both for projects and for individuals. Ramon (2000) also suggests that support should take more than one form, also that personal continuity of such support is important and that the key person providing it needs to be trusted by the service users concerned.

The success of projects and the continued involvement of individuals can be placed at risk if the need for support is not thought through. Some of the difficulties encountered by the TRUE Project (Faulkner, 2004) can be attributed to the fact that

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one person was expected to provide all forms of support to a team of seven people and ensure that the project progressed.

Whilst the issue of payments is dealt with under a separate heading, it is worth noting here that money is a vital aspect of the support needed to secure user involvement in research. Particularly within the larger institutions and universities where bureaucracy looms large, the practical function of providing payments and ensuring that people receive money before being expected to pay for travel or other expenses, can face insurmountable barriers and be very time-consuming to resolve.

1.7

1.8 Training

As with support, most of the papers and reports included in this review had something to say about the value of providing training for service users. One report (Lockey et al, 2004) specifically examines the training available for service user involvement in health and social care research and proposes guidelines for good practice that emerge from that research. (see box overleaf)

Most authors see training as the means with which to gain the necessary skills. Townend and Braithwaite (2002) propose that training programmes need to be accessible for service users to develop research skills and should include aspects such as developing proposals, methodologies, data analysis, report writing and dissemination. Elsewhere training is discussed as a valuable incentive, providing service users with skills and confidence for the future as well as for the immediate project. Ramon (2000) for example, regards gaining new skills as one of the personal rewards to be gained from involvement. Faulkner and Morris (2003) also mention training in new skills as one of the non-financial incentives for the involvement of service users.

However, it is clear that training in research skills is not the whole story. Several authors talk of the role of training in providing people with the confidence to participate (e.g. Lockey et al, 2004; Macran et al, 1999) or with the opportunity for mutual support (Nicholls et al, 2003; Lockey et al, 2004). Allam et al (2004) recommend that training for interviewing should include a number of additional issues: active listening, reflection & exploring skills; managing one's own emotions, managing interviewees' emotions; responding to 'inappropriate' behaviour or unexpected responses from respondents.

From: **Training for service user involvement in health and social care research: a study of training provision and participants' experiences (The TRUE Project)** Lockey et al, 2004

- Training was perceived as being most useful when it had a clear aim and purpose, and was centred around specific research tasks and real research problems that drew upon the participants' experiences,
- Participants wanted to be involved in creating and developing ideas in which they could become absorbed and take ownership. Service users wanted their input to be creative and not just reacting to others' ideas, and wanted to be involved in both training and research from the start,
- A key aspect of successful training was exchange and sharing between people, both trainers and participants. This was mutually supportive, sometimes using ice-breaking exercises, small group work and role-play,
- Training helped affirm the strength and value of service users' experiences and understanding of health conditions and services,
- Confidence to contribute developed in a 'safe' environment. This is one where others show that they value what a participant is saying and that if they wish to challenge it, then that is done in a constructive and helpful way,
- Considerable time and space was needed to allow all participants to make a full contribution. Project timescales and funding should reflect this.
- Training had enormous value to participants' personal development and confidence. Almost without exception, training led to actual involvement in research and a desire to do more.
- Language was a significant challenge for those providing training. Effective training 'demystified' research, providing a base from which stakeholders can understand one another's language and purpose.
- Payment was a sensitive issue. Although training commonly was seen as a mutual 'exchange' of skills and knowledge, typically participants were not paid for attending training, whilst trainers and employed researchers were paid.
- A further finding from this study was that 'training for service user involvement in research was not readily available. Only a handful of organisations provided open access training on a regular basis. Training was diverse in style and content, and often was developed for a particular service user group or project.'

One of the projects with the most experience of providing training to service user researchers is the Mental Health Foundation's Strategies for Living programme (reported in Nicholls et al, 2003 and Nicholls V, 2001). The training reported in the later publication included the following core sessions:

- Introduction to research
- Ethical issues
- Questionnaire design
- Interviewing skills
- Focus groups
- Analysis
- Writing up
- Endings

They designed the programme to run alongside the research projects so that sessions occurred at appropriate times, and introduced a number of additional sessions in such issues as assertiveness and group dynamics. They emphasised the need to ensure some flexibility in responding to people's different needs in the training, and regarded the training sessions as having an important role in enabling the researchers to get together and share experiences:

> *'Researchers often shared worries and problems at the sessions and were able to offer each other advice and encouragement… One researcher said: 'I always come away from training sessions feeling inspired and positive about my research project."*

Both the Strategies for Living project and the User Focused Monitoring project (Sainsbury Centre for Mental Health) emphasise that training needs to be adequate and thorough if it is to maintain high standards of research. This is supported by Townend & Braithwaite (2002) who envisage a future where service users will be seen as capable of undertaking research that is at least as rigorous as that undertaken without them.

Faulkner (2004) addresses some of the ethical issues surrounding the provision of training, and emphasises the need for flexible and accessible training, as well as the importance of ensuring that the timing of training is appropriate to the needs of the project and the trainees. Many people consulted for this report favoured a step by step approach as followed by Nicholls et al (above).

Several papers address the potentially more controversial issue of the need to provide complementary training for the researchers and clinical academics involved in carrying out the research. For example, Townend & Braithwaite (2002) suggest that training be provided in 'how to work effectively in collaboration with service user researchers' and Trivedi and Wykes (2002) mention that training involving both service users and clinical academics will 'help to break down the barriers on either side'. In a similar vein, Macran et al (1999) suggest that researchers and therapists will need training in the skills to conduct co-operative inquiry and Rose (2003a) suggests that the capacity of the academics needs to be built alongside that of service users learning to be researchers:

> *'They need to learn what user involvement in research can and should amount to and be persuaded that collaborative research will increase quality and provide a* necessary *complement to mainstream research.'*

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1.9 Payment

Many of the papers included in this review recognised the need to pay people appropriately for their contribution to the research process, whether or not they had managed to do so themselves. Ramon (2000), for example, records the fact that the pay for service users 'was insufficient as a realistic recompense for the work undertaken'. Similarly, Allam et al (2004) found that in reality the payments they had allowed for 'only represented a small fraction of the time that service users and carers invested in the research'. They conclude:

> *'Researchers need to ensure that service users and carers are paid realistically.'*

Faulkner (2004) found that most survivor researchers were in favour of realistic payment for involvement at whatever level. Whilst reflecting on the importance of choice, she also goes on to point out:

> *'the issue of payment does bring into play the relationship between rewards and responsibilities; if you are being paid a proper rate for the work then the work/employer can have more formal expectations of you, possibly even a formal contract. This may be a good thing in some circumstances and not in others.'*

1.9

Payment of a realistic nature goes some way towards balancing the power differential between researchers and service users and acknowledging the real contribution being made to the project. There are, however, barriers to realistic payment. People who are in receipt of benefits will face a number of limitations on the payments they can receive. There are now a number of publications that address these issues and give guidance to both employers and service users on what is acceptable legally. Researchers planning to involve service users need to inform themselves about these issues (see II The Guidance for further information and resources).

Payment also needs to take into account travel and subsistence expenses as well as the need to pay for child or other care. Some people paid service users for the period of time spent in training, whilst others did not; this is an issue of contention addressed by Lockey et al (2004) in their review of training for consumer involvement in health and social care research.

1.10 Resources

Leading on from the above, most of the papers refer to the need for adequate or additional resources in order to successfully involve service users in research. Whilst this may often entail extra financial resources, and therefore careful consideration of the budgetary implications of involving service users, it is important to note that the most precious resource for many authors was time. Although time itself invariably has financial implications, this is not always the case; flexibility in the approach to deadlines can also be helpful (see 1.5 above).

> *"If user-researchers are to be closely involved then a time commitment needs to be given to this process in the research proposal and this must be costed into the project's finances."* Trivedi and Wykes (2002)

The financial resource implications of involving service users include payments of fees and expenses (e.g. travel, care, subsistence) to service user researchers as well as the availability of adequate training and support. Guidelines, such as Faulkner & Morris (2003); Thorne et al (2001); Hanley et al (2003), all advocate the need for adequate time and money to enable the successful involvement of service users in research to take place. Research papers too reflect on their experience of needing more of both:

1.10

> *"We all found that working collaboratively was much more time-consuming than expected: the training took longer than anticipated…; organizing interviews was a very lengthy and frustrating process…; interviews took at least half a day each including travelling in a rural area, preparation and winding down with the interviewee; analysis and coding took up several days of researchers' own time. We had budgeted for a payment per hour long interview, in reality this only represented a small fraction of the time that service users and carers invested in the research."* Allam et al (2004)

Physical resources associated with access to computer and office equipment, stationery and administration were also mentioned by some as inadequate or ill-prepared for (Faulkner, 2004).

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II Guidance for Good Practice

This Guidance is based on the literature review and on further consultation with service users and researchers engaged in collaborative research. In addition three site visits were made: to SURE at the Institute of Psychiatry in South London, Direct Impact in Wakefield (South West Yorkshire Mental Health NHS Trust) and SURESearch at the University of Birmingham. These site visits form the basis of the case studies used in the text.

Suggestions are made about good practice for collaborative research and in some instances, more definite guidelines are proposed. The focus of these guidelines is research to be undertaken across the Mental Health Research Network. The guidance follows the structure given below:

2.1. Underlying principles
2.2. Capacity building
2.3. Identifying priorities
2.4. Commissioning research
2.5. Ethical Approval and Research Ethics Committees
2.6. Undertaking research:
  - Consulting with service users
  - Planning and starting a project
  - Supporting and maintaining a project
  - Employment of service user researchers
2.7. Dissemination and Implementation
2.8. User controlled research

2.1 Underlying Principles

Clarity and transparency:

- Researchers need to be clear about why they are seeking user involvement and service users about why they wish to become involved in a project. It would be useful for both to put their reasons down in writing and/or to discuss them at the start of a project.
- Clarity is needed from the start about the nature and aims of a project, and about the roles and responsibilities of all parties.
- In particular, it is essential that it is made clear to service users if there are any limits to their involvement – for example, limits to what aspects of a project they can influence or participate in.
- Researchers need to be clear about the incentives to involvement they are making available (e.g. payment, training) and the support and supervision to be provided.
- Both researchers and service users would benefit from a frank discussion about their expectations of the research project, what they hope they will gain from it and so on.
- It may be helpful to establish a contract outlining rights and responsibilities on each side (for example, Trivedi and Wykes, 2002).

Diversity

- It is important that the diversity of service users to be involved in a research project should reflect the nature of research project itself.
- When looking at capacity building, researchers need to ensure that they take into account the diversity of the population which they serve and include people from minority ethnic communities as well as people with different mental illness diagnoses, taking into account issues relating to gender, sexuality and physical disabilities.

➢ Like their professional counterparts, service users have a diversity of views and will not all feel the same way about an issue or research project. This diversity of views also needs to be taken into account when considering involvement in a project or group.

Example: Shaping Our Lives (SOL)

Shaping Our Lives is a national independent user controlled organisation. In a ground-breaking project exploring user-defined outcomes and outcome measures, Shaping Our Lives engaged with nine groups of service users:

- Three generic groups for users of social services
- Two groups of disabled people
- Two groups of people with learning difficulties
- One group of survivors/people with mental health problems
- One centre for integrated living

The findings of the research included that service users believed outcomes should be approached from a qualitative standpoint that fully recognises the individual and subjective nature of outcomes for people. Many of the issues raised were related to the actual process of service provision, which the authors relate to the fact that in many cases services are not delivering a discernible outcome for people.

The way in which Shaping Our Lives works is to bring together a range of different service users in all their work. The degree of commonality 'makes working together in this way extremely valuable'. A follow-up project looked at the application in practice of on-going work about what service users meant by 'user defined outcomes'. This piece of work included older people, mental health service users, Black groups and disabled people.

For further information see:

* Turner, M. (1998) *Shaping Our Lives Project Report*. London: National Institute for Social work

* Shaping Our Lives, Black User Group (West London), Ethnic Disabled Group Emerged (Manchester), Footprints and Waltham Forest Black Mental Health Service User Group (North London), and Service Users' Action Forum (Wakefield), (2003), *Shaping Our Lives – From outset to outcome: What people think of the social care services they use*, York, Joseph Rowntree Foundation/York Publishing Services. www.shapingourlives.org.uk

Respect:

- ➢ It is important that all those participating in a research project respect each other and, in particular, respect each other's right to express their views.

Flexibility:

- ➢ Flexibility needs to be built into research projects involving service users from the start; this has implications for funders and commissioners of research to allow greater flexibility in timescales and resources;
- ➢ Researchers need to be aware of the need for flexibility in relation to time and resources also; as well as in relation to the level of involvement, since some service users may experience on-going distress and be unable to attend at all times.
- ➢ Flexibility in relation to the nature of the project itself is also needed if genuine involvement - and hence negotiation about the project - is to be permitted.

Accessibility

- ➢ It is important for researchers to use plain language and avoid unnecessary jargon (or explain it clearly where it is necessary to use it);
- ➢ Accessible formats for the presentation of research materials may be necessary for research collaborators as well as participants; it would be good practice to establish any particular access needs at the start of a project.

Summary of Key Guidance: Underlying Principles

It is important for all researchers and service users participating in a research project to consider the principles underlying their work. SURGE recommends the following principles as essential to good collaboration:

- Clarity and transparency
- Diversity
- Respect
- Flexibility
- Accessibility

2.2 Capacity building

Building capacity among service users is a challenge for many research departments who wish to involve service users in their research. However, researchers and Trusts – particularly Trust R&D Departments - need to think about capacity building amongst their own staff as well as among local service users, if user involvement in research is to become a successful and useful enterprise.

An early stage is for researchers to explore the local community and find out what service user groups exist locally. The voluntary sector can often help in signposting this information. Taking the time to identify experience of collaborative research within the Trust may reveal other researchers with experience and/or relevant contacts to share. It is suggested that the organisation keep a register of research projects where service users have been involved in order to build on this experience locally. Advice and information can also be sought outside the Trust with others who have carried out similar work, for example the examples given here and the organisation INVOLVE.

Example 1: **Service User Research Enterprise (SURE)**

SURE at the Institute of Psychiatry has convened a group of local service users (the CRAG – Consumer Research Advisory Group) to meet on a regular basis and to advise those who are more actively involved in research. A training course in research skills has been run twice now, open to members of CRAG and others, with a view to involving further local service users in research projects at the Institute of Psychiatry.

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Example 2: **University of Leeds: Academic Unit of Psychiatry and Behavioural Sciences**

The Department began the process of expanding user involvement in research by holding a series of research workshops for local service users and carers, held in 2004 and funded by the ESRC. The workshops aimed to introduce participants to some research principles and to enable them to hear from people speaking about examples of collaborative and user led research. Following on from these seminars, the Department invited participants to become involved in further initiatives, such as the User and Carer Research Interest Group - a forum for discussion, support and training. In July 2004 the Department appointed three service users to work on a new research project looking at A&E services for people who self-harm.

There is no substitute for building up relationships over time with local groups or with a group convened from existing groups, of service users who are interested in research. This takes time and resources but it is vital in order to build up trust and avoid the need to recruit service user participants at the last minute, as often takes place in a short term funding round. Both of the examples given demonstrate different ways of doing this, as do Case Studies 1 (opposite) and 3 (at the end of section 2.7). In order to carry this out effectively it is necessary to identify a budget for capacity building with service users; this is important both because of the need to sustain relationships over time and to involve service users in research design prior to obtaining project funding.

Another vital issue in capacity building is the provision of appropriate training to service users in research skills and research-related subjects, and training in user involvement to researchers. It may also be possible to make other opportunities available to service users (e.g. seminars, newsletters, formal training courses).

2.2

Finally it is suggested that researchers find ways of remaining in touch with service users who have been involved in an individual project, e.g. through establishing a group that meets regularly. (This then can form the foundations of a group who may be supported and trained and involved in further projects).

Case Study 1: SURESEARCH, University of Birmingham

SURESearch was established in 2000, as a result of a meeting between service users and academics who had some experience of working together in training and research. They decided to meet regularly and the network has now grown to around 100 people, 85 of whom are mental health service users and the rest are allies. Presently SURESearch is co-ordinated by Colin Gell and Professor Ann Davis is the academic link at the University.

They have been involved in a number of research, training and education activities within the University, with the local Trust (Birmingham and Solihull Mental Health Trust) and PCTs. These include: the North Birmingham MIDAS project, teaching in local Universities (social work, nursing and mental health interdisciplinary courses) and Mind Benefits Campaign Research.

More recently SURESearch has become an active participant in the Birmingham hub of the Mental Health Research Network; they have a place on the management board.

SURESearch members value the broad agenda offered by the network; through offering a range of different activities, they can get to know people and help to identify their strengths, whilst at the same time de-mystifying research. A good example of this is the Writing Group which developed out of one of the training days. This group now has a column in the Mind magazine Openmind as its focus, with a different member contributing to it each time. SURESearch also supports members towards longer term goals: some members have been supported to enter formal education at the University and elsewhere.

Summary of Key Guidance: Capacity Building

- Build up collaborative relationships over time in order to build up trust and avoid the need to recruit service user participants at the last minute when a research bid needs to be submitted;
- Ensure that a budget to do this can be identified;
- Contact others for advice on what works – including those identified here and INVOLVE;
- Be prepared to offer and receive relevant training that will help to build everyone’s capacity for successful collaborative research;
- Keep a record of people within your organisation who have relevant experience and expertise in this field so that this can be built on.

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2.3 Identifying priorities for research

Service users and user groups are likely to have different priorities for research to those identified by researchers, Trusts or Government policy. The most successful involvement of service users in research is likely to take place where there is some convergence and agreement on priorities: in short, where a research project or tender is also an issue of concern to service users. It is significant that where consultations have taken place, service users and user groups tend to paint a rather different picture of the topics in need of research. They tend to prioritise issues relating to social welfare and daily living, abuse and discrimination, self management and alternatives to mainstream treatments and services. We return to this subject again in section 8 User-controlled research.

Example: South London and Maudsley NHS Trust

A consultation meeting was arranged with service users and members of local service user groups to ask what they considered mental health research priorities should be. The meeting was widely advertised across the four Boroughs served by the Trust and 40 service users attended. Participants were asked to identify topics that future research in the Trust should pursue, to arrange these into thematic areas and then to vote for the themes to establish a rank order. A total of 14 areas were identified and ranked as follows:

1. User involvement in all stages of the research process
2. Discrimination and abuse
3. Social/welfare issues
4. Arts as therapies
5. Users' choice
6. Positive alternatives such as complementary therapies
7. Advocacy

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8. Physical environment (e.g. inpatient wards)
9. Positive approaches in mental illness
10. New treatments
11. Addictions research
12. Provision of information to service users
13. Psychological therapies
14. Research on myths and misconceptions

The Trust acknowledged that priorities of service users were not the same as those of professionals and funding bodies. Subsequent to this consultation, the Trust and the Institute of Psychiatry supported the formation of the Service User Research Enterprise (SURE). Further consultations have taken place through the Consumer Research Advisory Group (CRAG). *Reported in Thornicroft et al (2002) Journal of Mental Health 11, 1, 1-5*

Summary of Key Guidance: Identifying Priorities

- Consult with local service users and user groups about their priorities for research and seek to find some areas of common interest with the current research priorities of your department/Trust;
- Inform service users about your priorities and research currently being carried out in your department/Trust;
- Research Interest Groups, which are beginning to be established within the context of the Mental Health Research Network, need to ensure that they are consulting with and including service users in the development of research topics.

2.3

2.4 Commissioning research

Where a funding body is asking for service user involvement in research proposals coming to it, it is vital that the funding body itself is able to demonstrate good practice; how otherwise is it to judge the value or strength of the user involvement claimed in the proposals?. INVOLVE held a workshop on commissioning in 2003[2], to which consumers, researchers and commissioners were invited. The workshop addressed three key themes: how to involve members of the public on commissioning boards or advisory groups, as peer reviewers and in grant applications. The common themes to emerge across the groups were: the need to reduce jargon, define terms and make language more accessible; payment and the financial implications of involving members of the public in research; the need for support for everyone involved in the process and the value of building relationships; and the need to 'close the loop' by informing members of the public of the outcomes of the research.

We would additionally recommend:

- At least two service users to sit on the decision making forums of research funders;
- That research funders offer advice and guidance on user involvement to researchers and service users planning to put a proposal to the funding body;
- Service users to act as (paid) reviewers on all research proposals where user involvement is a requirement;
- Funders meet with shortlisted applicants and their proposed service user partners to ensure that the proposed collaboration is genuine.
- Some flexibility in the management of resources. The Joseph Rowntree Foundation, for example, have a separate and significant budget which they use to disseminate the findings of work supported by the Foundation to relevant audiences.

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[2] Royle, J. (2003) Report of commissioning workshop. INVOLVE.

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Example: **National Programme on Forensic Mental Health R&D**

This research funding programme has instituted the following:

1. Developed a user involvement induction pack, service user peer review forms and research glossary;
2. Service users are members of the advisory committee;
3. A service user peer review panel (payment made for work);
4. Commissioned an expert paper on User Involvement in Forensic Mental Health;
5. Commissioned 3 projects specifically around user involvement, one of which is user led;
6. Continue to ensure user involvement in research through the application procedures and report monitoring.
7. The Programme is currently looking at involving forensic service users in reviewing proposals.

Summary of Key Recommendations to Commissioners and Funders of Research

- Commissioners need to ensure that all literature regarding research funding is accessible to the involvement of people not familiar with research jargon;
- Commissioners need to take account of the financial implications of involving service users in commissioning processes;
- Any decision-making commissioning body should involve at least two service users;
- Where funding is to be given on the understanding that user involvement in the research is to take place, funders should meet with shortlisted applicants and their proposed service user partners to ensure that the proposed collaboration is genuine;
- Flexibility in the funding and commissioning procedures should be introduced in order that researchers can respond appropriately to the needs of the service users involved.

2.5 Ethical Approval and Research Ethics Committees (RECs)

Research which takes place within the NHS has to be approved by an NHS Research Ethics Committee, but there is currently no clear system of ethical review for social care research. The Department of Health (May 2004) produced an implementation plan for research governance in social care research[3]. The Government's Research Governance Framework states that the dignity, rights, safety and well-being of participants must be the primary consideration in any research study. These are the main concerns of RECs, which address issues of *beneficence* (that the research is for the common good) and *non-maleficence* (that research should do no harm).

In the Department of Health consultation for developing research ethics for social care, it was argued that the current system of RECs was designed to protect vulnerable people, rather than to hear their voices and support a greater role for service users in research. The consultation came up with a number of recommendations, including that there should be:

- A user led reference group for COREC (the Central Office for Research Ethics Committees),
- A register of social care ethical researchers managed by a user led organisation,
- Peer review of research proposals by service users,
- If users are to be involved on RECS or other committees then they need training and support to make the most of their roles.

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[3] Department of Health (2004). Research Governance Framework for Health and Social Care: Implementation Plan for Social Care.

CONTENTS

The consultation carried out for *The Ethics of Survivor Research* (Faulkner, 2004) resulted in the following suggestions:

- that the process of application should be simplified and made more 'user-friendly'
- full feedback should be given to applicants,
- that there should be a complaints procedure and/or appeals procedure in place for those not satisfied with decisions.
- that RECs become more familiar with different types of research, including qualitative research and user-led research.

2.5

CONTENTS

2.6 Undertaking Research

It may be useful for service users and researchers alike if an individual research project is classified by the degree of service user involvement proposed. INVOLVE sub-divides consumer involvement in research into the following categories:

- **Consultation,** where consumers are consulted with no sharing of power in the decision-making;
- **Collaboration**, which involves an active on-going partnership of consumers in the research process;
- **Control**, where consumers design, undertake, and disseminate the results of a research project.

For further clarification of the nature of the research project and of the power relations involved, collaboration can be further sub-divided into:

- ➢ researcher initiated collaboration,
- ➢ true joint collaboration and
- ➢ consumer (or service user) initiated collaboration.

A simple check box could be developed for the purpose of categorising and describing projects as follows:

Degree of service user involvement		Please tick
Consultation		
Collaboration	Researcher initiated	
	Jointly initiated	
	Service user initiated	
Control		

2.6

CONTENTS

2.6.1 Consulting with service users

It is common for researchers to consult with service users and to subsequently decide how and whether to use their views. This is not an ideal route to user involvement in research but it may be an important starting point for some researchers and organisations, particularly where research priorities are being established. Consequently it is useful for us to consider some issues of good practice in relation to consultation. Consultations may be one-off with a group of service users, or may involve regular meetings or an invitation to service users to join an existing professional research group or meeting.

- Always involve more than one service users in any advisory group, consultation or meeting – whether it is a one-off meeting or group meeting regularly over a period of time.
- Where two or more service users are invited to join a meeting or advisory group, ideally they should have access to (or be members of) a larger group to provide them with support and accountability.
- Provide refreshments and allow regular breaks in any meeting.
- Ensure that service users receive adequate information about the nature of the consultation well in advance.
- Any such information should be provided in accessible language and/or appropriate formats.
- Payment should involve at least the provision of travel expenses and money should be available on the day of a meeting.
- Where service users are in the minority in a group or meeting, ensure that the Chair is well-briefed to enable the group to hear from the service user members.

2.6.2 Planning and starting a project

There are many things to think about at the planning stage, including the success of the proposal in obtaining funding and ethics committee approval, as well as adoption by the UK Mental Health Research Network. In addition, we would suggest that the following issues are thought through at an early stage in order to maximise the potential success of user involvement.

- Ideally service users should be involved from the very inception of a project if they are to have any real influence over the direction of the project and the way in which it is to be carried out.

2.6

- At the design stage, ensure that a full assessment is made of the required resources in terms of both time and money (see checklist opposite for the latter). This is a strong message from many people who have undertaken or are undertaking collaborative research!
- Flexibility should be built in from the beginning if it is to be given due consideration. Issues such as additional support, the capacity to re-schedule the timetable or scope of the research and anticipating the need for extra time at the end of the project, may need to be considered;
- Ensure that the provision of support for service users is included in the plans; if service users are involved from the start then discussions about this can take place early on. If not, then some resources need to be set aside for external and/or peer support and supervision.
- Researchers and service users need to find ways of dealing with distress if and when it arises; it may be helpful to set this up at the start of the project. For example, service users may nominate a mentor or person to contact should they become unwell at work, or suggest other strategies that enable them to retain control of the process.
- Good communication with your finance department needs to take place at an early stage. Financial systems need to be established from the start in order to ensure that the project can have cash available to pay people when they need the money.
- Similarly, communications with the Human Resources and/or Occupational Health departments need to take place in order to ensure that the involvement or employment of people with a history of mental health problems can take place without any unnecessary barriers or bureaucracy.
- It is advisable to be well informed about ways of paying service users and the barriers to paying them at an early stage. Payment should be offered to service users alongside access to advice regarding any potential effects on their receipt of benefits (see resource list opposite).
- Researchers/research managers need to assess whether service users will need to have an honorary contract and establish this if it is required. The Research Governance Implementation Plan requires that '*all researchers not employed by the NHS hold a NHS honorary contract that includes research governance procedures and responsibilities if they are to interact with individuals in a way that has a direct bearing on the quality of health care.'*

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Suggested checklist for funding/budget planning

- Payment of fees and travel & care expenses to user-researchers;
- Fees for research participants;
- Enough funding to include more service user interviewers, consultants or researchers than the project needs, to cover for periods of absence;
- Support for service users (may be an additional support worker or alternative);
- External supervision;
- Physical resources, such as space and communication technology to enable service users to take an equal part in the project;
- Training for service users and for staff (as appropriate);
- Time/venue/refreshments to meet with each other for mutual/peer support;
- Dissemination and feedback to participants: in different formats relevant to your project (e.g. language, accessible written and oral presentations);
- Insurance – liability.

Adapted from Faulkner A. (2004)
"The Ethics of Survivor Research"

Additional advice on payments to service user researchers

- "A guide to paying members of the public who are actively involved in research" Involve, October 2003 www.invo.org.uk
- Hanley, B. et al (2003) Involving the public in NHS, public health and social care research: Briefing notes for researchers (second edition). INVOLVE.
- "A Fair Day's Pay: A guide to benefits, service user involvement and payments" Mental Health Foundation, July 2003. www.mentalhealth.org.uk
- M. Turner, M. (in press) *Contributing On Equal Terms; Getting involved and the benefits system, Report to Dr Stephen Ladyman, Minister for Community*. London: Shaping Our Lives/Social Care Institute for Excellence.

2.6

2.6.3 Supporting and maintaining a project

The process of working on a project is often of more importance to service users than it is to researchers, in the sense that they may not have the same outcome-related incentives as researchers for whom the report and publications may have greater significance. Whether or not this is the case, it is vital that the process is inherently 'pleasant' or service users may withdraw from a project before the end, or may not wish to be involved in further researcher projects. The elements that can help in sustaining people's interest and enthusiasm include the following:

- Adequate support is vital. In common with other guidelines, we would recommend that support be subdivided into the following elements, in order to ensure that the issue is considered comprehensively.
    - Practical support (e.g. administration, finance/expenses and travel arrangements, communications),
    - Research related support (e.g. regular supervision, de-briefing),
    - Emotional support (e.g. peer support, external supervision, time to talk through difficulties and issues arising).

  Providing support does not mean acting as clinician: it is vital that researchers or research supervisors do not act as clinicians to their service user researchers unless this is agreed between both parties.
- Training in relevant knowledge and/or skills is also a vital part of the process. Training may be necessary in order for service users to be able to make an equal or appropriate contribution to the research project, but it can also act as an incentive in its own right, providing skills for people that may be useful in other contexts. Training for staff, as is mentioned in the literature review, may also help in assisting research staff to understand about user involvement in research, and some of the issues facing service users coming into the workplace.
- Resolving difficulties constructively is another vital part of sustaining the process. As we saw in the literature review, there are issues of power and disempowerment to be considered and acknowledged. The way in which differences of opinion are dealt with and resolved is a major part of how this will be played out. It is essential that respect is built up on both sides and that the views of service users are taken into account in these situations.
- Flexibility needs to be an on-going consideration. If someone is unwell during the project, there need to be strategies in place to deal with this both personally and from the perspective of the project (see above), but perhaps also there may be ways of retaining someone's involvement at a lower level than was originally planned.

2.6.4 Employment of service user researchers

The employment of service users as researchers is a particular version of 'user involvement'. Employment is a key element of social inclusion; having a job may have enormously beneficial consequences for a service user or survivor. There are a couple of particular challenges, however, which merit consideration. The academic environment is hierarchical and can be highly competitive. For someone entering or re-entering employment after a period of unemployment there may be a substantial conflict between the culture of an academic institution and the less structured and more democratic nature of, for example, user groups and other related activities that service users might be more familiar with.

The hierarchical nature of the organisation and the pressure to treat employees equally within that may mean that the 'user perspective' brought to the organisation by a service user researcher might become marginalised. If the individual is employed as a research assistant, does this mean that their views are no longer respected as those of a service user? If they are treated as an equal with other research assistants then this may mean that their views are of low status within the academic hierarchy – yet they were employed *because* of their experience as a service user implying that their views or perspective are uniquely valuable. In addition, employment brings with it responsibilities as well as rights. These issues together point to the particular importance of ensuring that the individual has adequate support and supervision in their role.

- Support for a service user researcher is just as important for someone who is formally employed as it is for someone who is 'involved' in a project on a less formal basis. The provision of both personal support and research supervision should be addressed.
- Researchers looking to employ people as service user researchers need to take responsibility for communicating with Personnel or Human Resources Departments regarding their intentions and the nature of these posts.
- Managers and supervisors in clinical posts should avoid any temptation to act in the role of clinician to the service user researcher, as this is inappropriate and can be undermining. Professional and personal boundaries should be observed.
- Serious consideration needs to be given to the role of the employed service user in the project and the organisation, and to ways in which their views are able to be expressed and taken account of.

2.6

Case Study 2: Service User Research Enterprise (SURE) Health Services Research Department, Institute of Psychiatry

The Service User Research Enterprise (SURE) at the Institute of Psychiatry is perhaps the most well-established collaboration in the country between service user researchers and clinical academics. SURE works locally to the South London & Maudsley Trust as well as nationally and internationally; most employees are users or former users of mental health services as well as having research skills.

The first co-ordinator of SURE, Diana Rose, was appointed in March 2001. SURE now comprises nine staff, a growth that has come about as a result of successfully tendering for projects funded by the Department of Health and the National Health Service Executive. Associated with SURE is the Consumer Research Advisory Group (CRAG), a group of local mental health service users two of whom attend the South London and Maudsley Trust / Institute of Psychiatry R&D Steering Group. Members of this group are paid for their attendance and funding has come from the R&D steering group. They are full members of the Committee and have voting rights.

One project mentioned as an example of good practice is the Consumers' Perspectives on ECT research review which influenced the NICE guidelines on ECT practice. The methodology for this was innovative and user-focussed. A new project looking at service user experiences of the Mental Health Act is founded on good practice principles, in that it proposes to involve service users at every stage and has employed a service user researcher at each research site. SURE organises a weekly 'Clinic' inviting academics in the Institute to come for advice on how to involve service users in their research projects.

SURE places a high priority on dissemination, ensuring that the research it carries out is disseminated through service user and voluntary sector routes as well as in academic journals. There are challenges to working in an academic environment, but it seems that members of SURE are successfully rising to those challenges.

http://www.iop.kcl.ac.uk/iopweb/departments/home/default.aspx?locator=300

Summary of Key Guidance: Undertaking Research

- Consulting with service users
  - Always involve more than one service user in a consultation, and ensure that adequate and accessible information is provided;
  - Payment of fees and travel expenses should be made available on the day of the consultation;
  - Consult with people with integrity: be clear about how you will be taking their views on board;

- Planning and starting a project
  - Service users should be involved from the start of a project;
  - Resources should be planned in advance to take into accound the time and money required to involve people fully;
  - Plan for flexibility, support, training and periods of absence;
  - Researchers need to communicate well in advance with
    - Finance department
    - Human Resources department
    - Occupational Health

    about their intention to involve or employ mental health service users in research – in order to facilitate the process and pre-empt any difficulties that may arise;

- Supporting and maintaining a project
  - Adequate support for service users is vital: practical, emotional and research related support;
  - Training in relevant knowledge and skills is vital for both service users and researchers;
  - Be prepared to be flexible and to negotiate about the research process with sensitivity and respect;

- Employment of service user researchers
  - Consideration needs to be given to the role of the employed service user and the ways in which their views are to be contributed to the research process.

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2.7 Dissemination and Implementation

Dissemination

- Dissemination needs to take into account the service user audiences as well as the research and other stakeholder audiences;
- Resources, both time and money, are needed to manage the dissemination stage effectively – hence it is advisable to build these in from the start of the project;
- Accessible reports or a summary of findings can be produced to reach a wider audience of local stakeholders, service users and carers who may be interested or affected by the research findings;
- Service users may assist with ensuring that research findings reach a service user audience; for example, through newsletters, voluntary sector magazines and relevant email forums;
- In situations where there is a delay in disseminating research findings, it is good practice to stay in touch with service users who have been involved and ensure that they know what is happening;
- Other formats that may be useful in reaching different audiences are: internet publication, local meetings of service user groups and the use of other media such as radio.

Implementation

For many service users, there is little point in carrying out research without the intention of implementing the results. Some people's main motivation for becoming involved in research may well be a commitment to changing and improving mental health services. This may well present a challenge in circumstances where researchers do not have the power to implement the results of their own research. However, it is good practice to address this issue in some way.

2.7

- Involving local stakeholders from the start of a project is one way in which research can be connected with and informed by local services;
- It may be possible to identify small or intermediate elements that may be implementable.

Ending a project

Endings can be difficult for many people. There have been a number of projects where service users have been involved in, or leading, research where difficulties in finding a way to finish have been recorded (e.g. Nicholls 2000). This may be a positive sign of the way in which the project team have worked together or an unwillingness to let go of the support, activity, or people involved. If there are no possibilities for continuing in some form (e.g. as an on-going research interest group), then we would recommend that a formal ending event or day is arranged.

- Find a way to mark the ending of a project;
- Ensure people hear about the project publications if they happen after the end of a project; and ensure people are informed about any further developments;
- Enable service users to reflect on their learning and skills development, and compile a CV if appropriate;
- Enable researchers to reflect honestly and openly on the experience and to disseminate their learning to other researchers in the same organisation.

Case Study 3: Direct Impact Service User and Carer Research Group - South West Yorkshire Mental Health NHS Trust

Direct Impact was established in Wakefield in 2001, and is supported by the Trust Research and Development Manager, Dr Virginia Minogue. The group has been involved in a number of research projects locally and they have developed their own Good Practice Guidelines for involving service users and carers in audit, evaluation and research. They have a focus on the *impact* of involvement: that it should lead to the improvement and development of services.

Members value the peer support aspect of the group, the potential for involvement in research to be 'a step on the road to recovery', and the therapeutic value to the individual person. They believe that involvement from the beginning is crucial and is empowering. They feel that they are using their own awareness and insight to put the service user perspective forward and that there is a shared awareness between group members. They also mentioned the importance of training and of flexibility, and the value of support from the top in the form of the Chief Executive as well as research and development staff.

The group currently has a research proposal of its own awaiting approval from the Research Ethics Committee. The proposal is to evaluate the crisis resolution service, with the aim of exploring how the patients and carers experience the service. Two members of the group are the lead investigators and they have designed draft questionnaires and interview schedules.

Direct Impact won a Modernisation Award for their work this year, which undoubtedly gave them an enormous boost. They plan to become independent in the future.

Summary of Key Guidance: Dissemination and Implementation

- Dissemination to service user audiences in accessible formats must form part of a dissemination strategy;
- Implementation is a priority for many service users: it can be built in from the start of a project through adequate budgeting, and the involvement of local stakeholders;
- Endings need to be given due consideration: find a way to mark the ending of a project and a way to enable service users and researchers to reflect upon their experience and the learning they have gained through collaborating;

2.8 User-Controlled Research

User-controlled research has an important role to play in exploring topics of concern to service users, and challenging the validity of conventional knowledge standpoints, the nature of the relationship between knowledge and direct experience, and the meaning and status of sources of 'evidence'.

> *"…the focus of user-controlled research is with who originates and makes decisions about research and evaluation. Its general contention is that such control rarely lies with the (disadvantaged and oppressed) groups which are most liable to become research subjects."* Beresford (2002)

But user-controlled research provides a space for the development of fundamentally different research methodologies and epistemologies[4], redressing the balance from the professionally controlled research agenda. Furthermore, it is predominantly within user-controlled research that we see exploration of some of the subjects that service users and user groups have identified as priorities: for example, poverty and welfare benefits (Shaping Our Lives; the Mental Health Foundation), user-defined outcomes (Shaping Our Lives) and alternatives to mainstream treatments (the Mental Health Foundation). INVOLVE has recently (in 2004) funded a project aiming to explore definitions and understandings of user-controlled research and identify good practice. The project is being carried out by Shaping Our Lives (one of the SURGE partners) and the report will be published by INVOLVE in 2005.

Example: the Strategies for Living programme, Mental Health Foundation

In the first phase of the Strategies for Living programme, a major qualitative research project was carried out into people's strategies for living with mental distress (Faulkner and Layzell, 2000). In addition, the programme funded six small research projects carried out by service users, investigating the giving and receiving of massage, auricular acupuncture, membership of user groups and empowerment, alternative strategies, attendance at mosque for Moslem men and users' views of drop-ins.

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[4] *Epistemology:* theory or science of the method or grounds of knowledge

The second phase funded a total of 16 projects around the UK and published a report of the experience (Nicholls et al, 2003). This report describes the realities of supporting user-led research. It includes the achievements and challenges of this process in relation to issues of: power; roles and relationships; ethics; resources; and training. The report also outlines the lessons learned from these experiences, using examples and stories to illustrate points, and includes tips and recommendations. The following reports are among those produced by the supported research projects:

- The Healthy Benefits Research project
- Dancing for Living
- Working on Up (about the barriers to accessing and retaining paid work)
- Hospital Leave for Patients Detained under Section 37/41
- Life's Labours Lost (the impact of losing employment)
- Rainbow Nation (experiences of Black women in Bradford)
- Self-Help Groups for People who Self-Harm
- Improving Acute Psychiatric Hospital Services According to Inpatient Experiences

For more information about these reports see the Mental Health Foundation website: www.mentalhealth.org.uk

Summary of Key Guidance: User-Controlled Research

- The promotion and encouragement of user-controlled research is part of the range of research adopted and supported by the Mental Health Research Network;

Research funders and commissioners may wish to consider the allocation of funding rounds for user-controlled research, in order to support its development. Any evaluation of the involvement of service users in research needs to take account of the full range of different approaches to user involvement in research, including user-controlled research.

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CONTENTS

Appendix A: SURGE Partners

Mental Health Foundation
Sea Containers House
20 Upper Ground
London SE1 9QB
0207 803 1116
www.mentalhealth.org.uk

Shaping Our Lives
Unit 57, Eurolink Centre
49 Effra Road
Brixton
London, SW2 1BZ
020 7095 1159
www.shapingourlives.org.uk

Centre for Citizen Participation
Brunel University
Twickenham Campus
300 St Margaret's Road
Twickenham
Middlesex TW1 1PT

NIMHE Experts by
Experience (EbyE) Group
London Development Centre
Kings Fund
11-13 Cavendish Square
London W1G 0AN
0207 307 2450
www.nimhe.org.uk

Survivor Researcher Network
c/o Mental Health Foundation
Sea Containers House
20 Upper Ground
London SE1 9QB
0207 803 1155

Useful Contacts

SURE (Service User Research Enterprise)
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Institute of Psychiatry
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020 7848 5104

SURESearch
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Department of Social Policy and Social Work,
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Promoting public involvement in NHS, public health and social care research
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