

# **User Controlled Research**

## **Its meanings and potential**

### **Final Report**

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# Summary

## The aim and nature of this project

User controlled research has been developed by service users and their organisations as a new approach to undertaking research and evaluation. The aim of this project was to find out more about the definition, nature and operation of user controlled research. It was carried out both through a literature review and through information provided directly by a wide range of service users and service user researchers in a series of individual interviews and group discussions. The aim was to undertake the project in a way which was consistent with the understanding we so far had of user controlled research. There was a significant consistency between the findings from the two sources of information used.

## Defining user controlled research

### 1 The origins and relations of user controlled research

User controlled research has its origins in service users' dissatisfaction with traditional research, which many feel has disempowered them. It has links with 'new paradigm' research, like feminist, black and educational research. Service users tend to distinguish user controlled research from 'participatory' research (although it can also be seen as the most developed expression of 'user involvement' in research) and the two have been associated with different research philosophies. Related research approaches like 'partnership' and 'collaborative' research are also seen to have weaknesses which can disadvantage service users, notably tokenism. Service users generally see a significant difference, therefore, between user controlled research and user involvement in research.

User controlled research has much closer links with two other research approaches, emancipatory disability research and 'survivor research'. It is not always clear whether these terms demarcate different research approaches or are used interchangeably. Control by service users is explicitly at the heart of the idea of user controlled research. Emancipatory disability research is associated with the aspiration to liberate service users, but user control also tends to be seen as an inherent feature of it. This control is variously seen to lie with service users generally, service users who are the research participants and also with service users' (self) organisations. Emphasis is placed on control of research not lying with non-service users.

One other term is also used in this field, 'user led' research. Some service users use this term synonymously with user controlled research. Others feel that it is a vague and unhelpful term which can be used to suggest

ambiguously that research is being 'led' by service users, although it is by no means controlled by them.

## **2 The basis of definition**

Some service users use the terms user controlled research and research involving service users as if they meant the same thing. Most however draw a strong distinction between the two. User involvement in research tends to be compared unfavourably with user controlled research because the former is seen to embody inequalities of power which work to the disadvantage of service users.

As might be expected, control by service users is seen as the key and defining characteristic of user controlled research. Making change is commonly identified as the central purpose of user controlled research, although there is also recognition that such change may not always be achieved.

The aims of user controlled research are generally framed in terms of:

- The empowerment of service users and the improvement of their lives (both through the process and purpose of research);
- Being part of a broader process of making social and political change;
- Changed more equal relations of research production (where the people who carry out the research and are the subject of the research relate to each other on much more equal terms);
- Being based on social models of understanding and interpretation (like the social model of disability).

Key values and principles associated with user controlled research are:

- empowerment
- emancipation
- participation
- equality
- anti-discrimination

Six ways in which such research can emancipate service users have been identified. These are;

- describing of experience of disabled people/service users in the face of 'academics' abstraction/distortion of it;
- redefining disability;
- challenging traditional research methods;
- developing new, emancipatory methods;
- describing the collective experience of disabled people/service users and service user movements;
- evaluation of services run by service users.

Some writers have suggested that some groups (notably people with learning difficulties) may not be able to undertake their own user controlled research; others, including some people with learning difficulties contest this and produce their own research.

User controlled research can be based on both qualitative and quantitative research methods and is also developing its own research methods.

## **Good practice for user controlled research**

Good practice for user controlled research is seen to follow closely from adherence to the values and principles which service users associate with such research.

- Clarity; the nature, aims and objectives of user controlled research must be clearly explained to participants;
- Confidentiality and anonymity should be absolutely assured (unless otherwise desired);
- Information giving by research participants should be a positive and empowering (rather than mechanical) experience. It may also entail a two way reciprocal relationship of information exchange with the researcher;
- Equal access in terms of communication, physical and cultural access to enable the positive involvement of everyone;
- Proper payment should be made to all involved in user controlled research (if it is wanted – there needs to be flexibility). It should be made in a rapid and appropriate way;
- Appropriate feedback and reporting on the research should be ensured to participants at all its stages. They should be kept fully informed of progress and developments (unless they indicate otherwise). This is part of the process of ensuring accountability;
- Service users see democratic accountability to service users as a key requirement for good practice in user controlled research. This might be achieved by the research project itself being democratically constituted or it being located within a democratically constituted service user organisation;
- User controlled research is closely linked with making change. Follow-up action to improve the lives of service users is therefore seen as a key component of good practice in user controlled research.

## **Should the researcher be a service user?**

While service users tend to highlight the importance of user control in all aspects and stages of user controlled research, it is not always seen as essential that service users undertake all research tasks and activities. Where there does seem to be agreement is that people should be subject to the control of service users. This issue is a particular subject of discussion in relation to whether the researcher should be a service user. There is no agreement about this. Arguments for and against using service users as researchers are raised by service users themselves.

While some practical obstacles in the way of service users always taking on this role are identified, philosophical objections are also offered to researchers only being service users (for example, service user researchers may then just become another kind of 'expert', divorced from other service users). Service users tend to see all researchers and research (and not only service user researchers and research) as reflecting sectional interests.

## **The benefits of user controlled research**

Service users see user controlled research as bringing benefits through developing ideas, knowledge and understanding about service users, their lives and the services which they receive. It is not only seen in terms of the benefits it can offer service users. There are strong views that it can (and should) be helpful to other stakeholders too. But it is seen as having particular benefits to offer service users. These relate to its:

- strong commitment to and particular capacity to make change in line with what service users want;
- emphasis on supporting more equal research relationships;
- rationale of making involvement in research a more positive experience for participants.

Service users talk about the particular capacity of user controlled research to:

- Be useful, because it starts from service users' shared experience and understanding;
- Identify and develop new issues of importance to service users;
- Be more inclusive than traditional research approaches, for example, because it generates trust among potential research participants;
- Offer personal benefits to research participants (through its concern with equality and empowerment), as well as having particular contributions to make to research.



## Barriers facing user controlled research

Service users identify a wide range of barriers in the way of the development of user controlled research. These include the following:

- The continued dominance of medically based research associated with positivist values of 'scientific rigour' and 'neutrality', are seen by service users to lead to the devaluing of user controlled research, with its emphasis on subjectivity, personal experience and allegiance to disadvantaged groups;
- There are concerns that while 'user involvement' in research and user controlled research may currently be more acceptable, fashions may change, leaving both insecure and without long term credibility;
- A key barrier is felt to be mainstream research assumptions that user controlled research is subject to bias. Service users stress its transparency and capacity to be rigorous, as well as the value of it taking sides with disempowered groups. They refer to the inherent bias that can affect all research (and particular biases like that created by the powerful role of the pharmaceutical companies in medical/psychiatric research). The tendency to devalue user controlled research as biased is identified by some service users as a form of discrimination in itself;
- Service users emphasise the capacity of user controlled research importance to be inclusive and address diversity, but also identify obstacles there can be in the way of this and the need to avoid false claims of being 'representative';
- There is a strongly held view that user controlled research faces particular difficulties in securing funding and does not compete for it on equal terms. The problems this creates are further magnified by the additional resource issues that the participatory and inclusive values of user controlled research generates;
- Service users are a large and diverse group. They do not necessarily have shared experience, understandings or agendas. This can undermine solidarity, give rise to discrimination and create its own inequalities and hierarchies which can limit the potential and effectiveness of user controlled research;
- User controlled research can generate particular difficulties, pain and stress for service user researchers who share similar experience to those of research participants. This needs to be addressed with sensitivity and support;
- The shortage of suitable good quality training is still restricting the supply of potential user researchers, while familiarity with and

experience of user controlled research among mainstream researchers, research organisations and funders is delaying the acceptance and extension of user controlled research. There are unmet needs for education and training among all participants: service users, service user researchers, non-service user researchers and research related organisations. At the same time, some service user researchers, particularly researchers with learning difficulties are being excluded from research opportunities by arbitrary requirements for them to have conventional academic qualifications to which they have had less access.

## **The future**

There are a wide range of concerns about the future of user controlled research. Service users highlight many fears that they have. User controlled research is seen as having a particular contribution to make and this gives some people hope for the future. Others see user controlled research as at a disadvantage in relation to other forms of research and feel that there will need to be structural and attitudinal changes for this situation to change.

Service users identified four key areas of activity for taking user controlled research forward. These are through:

- Improving its relationship with research funders;
- The national co-ordination of user controlled research;
- Strengthening the position of user controlled research;
- Linking user controlled research with user involvement generally.

## **Conclusions**

User controlled research has made much progress but still faces major barriers and problems. There has been a much greater focus in research on user involvement in research, although service users have highlighted its significant limitations. In addition most funding has been devoted to supporting user involvement in research and proportionately very little to take forward user controlled research.

There is now a significant body of user controlled research, both small and large scale, based on qualitative and quantitative research methods and it can be seen to constitute a coherent and feasible research approach. While there are many areas of agreement, there are also some issues where significant differences of opinion exist. The report offers a series of recommendations to take forward user controlled research and understanding of it.

## Recommendations

The findings from this project have implications for all the key stakeholders involved in research and the development of new approaches to research, including user controlled research. This includes research organisations and mainstream researchers, funders, commissioners, service users, user organisations, user researchers and those involved in research governance and ethics procedures. An effective strategy for supporting the development of user controlled research will need to address all of these.

### Sharing knowledge about user controlled research

- There is still considerable misunderstanding and misapprehension about user controlled research. Existing knowledge about user controlled research, including the findings from this project, needs to be widely disseminated to service users, mainstream researchers and research organisations, members of ethics committees and to research funders;
- Additional guidance on both the principles of and good practice for user controlled research needs to be produced to enable it to develop on equal terms with other research approaches. The findings from this project offer additional material to be used in future guidance and training resources;
- It is important to develop *accessible* materials about user controlled research. From undertaking the literature review it became apparent that some of the writings on this subject can be as difficult to understand as literature on traditional research. If user controlled research is to engage a wide range of service users and be widely developed by service user organisations, then information about it needs to be produced that is accessible as possible;
- Information and guidance need to be developed, particularly for research funders on how to support user researchers and user controlled research as part of their overall funding strategy and responsibilities;

### Recognising the resource implications of user controlled research

- User controlled research has particular resource implications. Ensuring equal access, enabling diverse involvement and supporting service users to carry out their own research on equal terms, all have resource implications. User controlled research, for these reasons tends to take longer and gives rise to additional costs. Both of these issues need to be recognised by research funders and research organisations;

## **Training to support user controlled research**

- More training (particularly user led training) about user controlled research needs to be developed for all key stakeholders, including mainstream researchers, service users, research organisations and research funders;
- There is no agreement among service users over whether researchers in user controlled research should themselves be service users. There are different philosophical viewpoints about this. But service users also highlight practical obstacles restricting the availability of suitably skilled user researchers. These need to be addressed;
- More training opportunities are needed for service user researchers, including further opportunities for research training. Unnecessary requirements to possess formal academic qualifications which can act as a barrier excluding service users with appropriate skills and experience, particularly service users with learning difficulties, should not be used to debar them from research employment opportunities. At the same time there need to be more opportunities for service users who wish to, to undertake undergraduate and postgraduate research training and PhDs with funding provided. Such training opportunities should be monitored;

## **Including black and minority communities**

- This project has unfortunately not provided much information about user controlled research in relation to black and minority ethnic communities. Further exploration of user controlled research from the perspective of black and minority ethnic service users is needed so that appropriate support can be offered to take forward this aspect of user controlled research;

## **Safeguarding the future of user controlled research**

- Service users feel very insecure about the future of user controlled research. Practical steps need to be taken to challenge this sense of insecurity and to safeguard user controlled research for the future and to make sure that it has the potential to make its full contribution;
- Both statutory and non-statutory research funders increasingly require evidence of user involvement from research projects seeking funding. In addition, the allocation of research funding should be monitored to record the scale and proportion allocated to user controlled research and emerging trends. In relative terms this proportion remains tiny and a key proposal of the first social care service user workshop convened by INVOLVE was that it should be increased significantly;

- More funding should be made available to support larger user controlled research projects, including ones employing quantitative, comparative and longitudinal studies;
- A significant proportion of what is identified as user controlled research is currently being undertaken by non user controlled organisations. This is particularly true of large research projects. This development needs to be monitored. More support is needed for user controlled research to be undertaken on equal terms by user controlled as well as other organisations;
- A coherent programme of evaluation of user controlled research projects needs to be established in order to maximise its contribution;
- Variations of research methods and methodology are already developing as a result of the introduction of user controlled research. These should be explored and collated in order to disseminate the learning they are providing.

# 1 Introduction

## 1.1 Setting the scene

There is now starting to be a growing awareness of user controlled research in the wider research community. This does not necessarily mean that researchers know much about it or that they see it yet as an acceptable part of the research landscape. But it does mean that questions are beginning to be asked about it and a point has been reached where greater understanding and clarification are likely to be helpful. The aim of this project and report is to make a start on this task; to help both researchers and non-researchers; service users and non-service users, gain a better grasp of how user controlled research is defined, what it can offer and what its strengths and weaknesses may be.

Research has been a key issue in the history of service user movements. It was actually one of the catalysts for the development of the UK disabled people's movement. A group of disabled people were spurred into further activism that led to the creation of the disable people's movement when their complaints about the Leonard Cheshire residential home that they were living in, were rejected by a project set up to research their situation. (Barnes and Mercer, 1997) Hunt, one of the disabled people involved, felt that the research did not address the problems of institutionalization that they experienced and saw the research as biased against disabled people in its concepts, methods, analysis, recommendations and conclusions. He believed that its commitment to 'scientific objectivity' led to its devaluing of a key source of evidence – the disabled people involved (Hunt, 1966, 1972, 1981; Barnes and Mercer, 1997; Gibbs, 1999, Miller and Gwynne, 1972).

Disabled people's critiques of mainstream research led to their development of emancipatory disability research. In turn other groups of service users developed their own 'survivor', 'service user' and 'user controlled' approaches to research.

Much has happened since these early days in the 1970s and 1980s. Such research from disabled people and other groups of health and social care service users, has begun to impact on mainstream research developments, debates and organisations. A significant and growing body of research and related literature have emerged. There has also been a parallel development – calls and requirements for 'public, patient and service user involvement' in research. This has gathered great momentum in recent years (Kemsall and Littlechild, 2000; Hanley et al, 2003). However, service users still frequently express the view that their research – the research which they seek to initiate and undertake – is still marginalised. They highlight the difficulties they face securing funding and the problems of credibility they encounter. On the other hand, as yet there seems to be limited understanding of such research on the part of traditional research institutions, structures and funders. There seems to be a lack of clarity about what it is, its methodological soundness and what if any its merits may be.

The aim of this report is to try and encourage a better understanding of such 'user controlled research' and to clarify what it is, what it looks like and what it can offer. The report is concerned with the meaning and nature of 'user controlled research'. Its starting point was a call from INVOLVE, the governmental organisation committed to advancing public, patient and service user involvement in research (formerly Consumers in NHS Research), to undertake a small scale review to explore the issue of: *User controlled research – what is it and how is it done?* The aims of this review were to:

- Establish definitions of user controlled research;
- Set out criteria for good practice in the conduct of user controlled research;
- Identify areas of good practice in completed projects, highlighting why they represent good practice;
- Examine the barriers to the acceptance of user controlled research;
- Examine the role of 'sectional interests' in influencing research practice;

This focus grew out of a wider uncertainty about what exactly constituted user controlled research and a sense that until there was a clearer understanding of what it meant and how it was defined, progress in developing it might be limited and its particular contribution not fully understood or appreciated. This was a small scale project with a budget of £15,000.

The term user or service user controlled research has come into use only relatively recently. It is difficult to be specific about this, but it is unlikely that the term has been in use longer than 10 –15 years. Yet during this time it has made an impact and come to be used and recognised by service users, their organisations, service user researchers and a growing body of researchers interested in participatory approaches to research and evaluation. Over this period a relatively small, but significant number of research projects which would describe themselves in these terms have also been undertaken – at local and national levels. While the position it occupies may be small and not necessarily readily visible, there is no doubt that user controlled research now has a place on the research map.

However, this is not to say that there is any consensus about what it is or means. We are still at a 'finding out' stage in its development. That is why this project is timely, but also needs to be seen as being situated at an early stage in debate about user controlled research. Hopefully it will help accelerate such debate, but it needs to be stressed that so far few clear principles have been agreed about what user controlled research is and it would be wrong to see this report as providing them. The small inquiry on which it is based represents a first attempt to begin the process of explicitly exploring what user controlled research may mean to the people involved in and concerned with it.

## **1.2 The structure of the report**

We have organised this report in eight sections. The first, the Introduction, sets out the background and context of this exploration of user controlled research; what we sought to do, how we sought to do it and the problems we encountered and how we dealt with them. Sections two to six make up the greater part of the report, and set out its findings. These are organised according to the five major areas we examined, reporting both on the literature review we undertook and what service users we spoke with directly had to say about user controlled research. The five areas are:

- Defining user controlled research
- Good practice in user controlled research
- Should the researcher be a service user?
- The benefits of user controlled research
- Barriers facing user controlled research

Section seven reports how service users see the future for user controlled research and proposals they offer for improving its position in the coming years. Section eight offers our conclusions and recommendations from the project study. This is followed by a list of materials relating to user controlled research and which we used in the literature review. Finally there are two appendices; the first providing information about the service users involved in the project; the second providing the questionnaire schedule that formed the basis for individual (self-completed) interviews and group discussions.

## **1.3 What is user control?**

One issue helps highlight the continuing need for discussion and clarification in this area. Early on in its history, the disabled people's movement in the UK drew a distinction between organisation controlled by disabled people (organisations of disabled people) and organisations run by non-disabled people for disabled people (organisations for disabled people) Although there has been considerable discussion about this issue, there is not yet agreement among disability, health and social care service user organisations about what constitutes a 'user controlled' organisation. For example, is it one where 51%, 75% or 100% of the management body/board are disabled people? So far all of these have been included variously as representing 'user control'. The development of user controlled research has been underpinned by similar aspirations, but so far there have been even fewer opportunities for service users/user researchers to work through systematically what user controlled research might mean, look like and achieve.

As has been said, this hasn't discouraged the development of a significant and growing body of initiatives. Service users and service user researchers identify particular values in such research. However, if we are to take it forward systematically, develop thinking about it coherently and challenge tendencies



for it to be marginalised, we must begin to subject 'user controlled research' to rigorous review. That was the aim of the project on which this report is based.

### **Putting user controlled research in context**

So far there have only been initial attempts to relate the idea of 'user controlled' research to related research approaches like emancipatory disability research, survivor research, action-research, 'partnership' and collaborative research, user-led research, participatory and participatory action research, participatory appraisal. In some cases such terms may be being used synonymously. It will certainly be helpful to try and clarify overlaps and differences between user controlled research and these other terms and approaches. It is also likely to be useful to consider user controlled research in a range of policy and methodological settings. (Faulkner and Layzell, 2000; Mercer, 2002; Baxter and others, 2001; Winter and Munn-Giddings, 2001)

## **1.4 The project proposal**

In developing the proposal for this project, the aim was to model how it was carried out on what was known so far about the kind of values and principles associated with positive practice in undertaking user controlled research. The proposers felt that it was essential that such a scoping activity, while small scale in nature and with limited resources, should be undertaken in a credible way. This meant a way consistent with initial understandings of what 'user controlled research' should be. The team therefore sought to work with:

- clear lines of accountability;
- guidance/steer from a range of service users/user researchers;
- full recognition of race equality issues;
- recognition of the different perspectives (and their equal value) of different user groups (for example, mental health service;users/survivors, people with learning difficulties; children and young people etc);
- an emphasis on involving service users/user researchers (with different ideas and experience in this field) to seek their views directly;
- transparency in how information is gathered;
- a commitment to providing information in accessible forms;
- a commitment to dissemination and follow-up action.

The project team committed themselves to work hard to address issues of diversity in terms of:

- range of service user groups involved;
- difference according to age, 'race', gender, sexuality, class, culture, disability, distress etc.

There are known to be restrictions on the full and equal involvement of black and minority ethnic researchers in conventional research. This project sought

to take particular account of the degree to which this might be a comparable issue in the context of user controlled research and to seek any insights and examples of ways in which this has been challenged.

### **Avoiding the artificial imposition of uniformity**

In its call for bids, INVOLVE referred to an exercise to ‘understand *definitions* (in the plural) of user controlled research’. This project therefore sought to start with no assumptions about there being a ‘right’ or ‘correct’ approach to or definition of ‘user controlled’ research, but instead aimed to identify emerging principles for conceptualisation and practice. The expectation was that there is unlikely to be agreement about the definition of such research and that it may not be possible to reach an overall consensus. For example, might ‘user controlled’ mean being primarily accountable to:

- An independent user controlled organisation
- The constituency or group who are being studied (for example, older people)

Or to

- research participants themselves?

Other emerging questions, included, does the researcher have to be a service user in user controlled research? Must such research be based on a social model approach? Who has to be involved and what kind or extent of involvement is envisaged for a research project to be deemed ‘user controlled’?

We did not see this uncertainty or potential for disagreement as a problem. We thought it was important not to seek to create new orthodoxies in research. Service users are often on the unhelpful receiving end of such orthodoxies. However, we did think that it might be possible to find some basis for agreement about some core issues, principles and values that could go to make up a definition of ‘user controlled research’. There might also be a range of issues where there is not agreement. One of the aims of this work was to achieve some clarification on this matter and to draw out some general sense of the nature and purpose of user controlled research. If several answers emerged from people in response to the question ‘what is user controlled research?’ we thought it was important not to pursue one as having particular priority (for example with government and funders), but instead to support further discussion to explore such variation further.

## **1.5 The project plan**

Usually such subject reviews are carried out entirely or mainly through a literature review. A literature review was identified as one key component of the project, exploring both conventional materials and materials produced by service users, service user researchers and service user organisations.

But it was also felt that user controlled research could not be addressed adequately only by a review of related literature. The project team have a strong familiarity with relevant existing literature in this field (local, national and to some extent international) produced by service users, user researchers and others and knowledge and good networks to search for additional material. However literature search was not seen as sufficient. Relying on this mainly or solely as an information base, could have significant limitations, for example:

- Such literature cannot be assumed to provide an adequate representation of latest thinking and practice about user controlled research;
- Relying on the literature would mean that interpretation could mainly rest with the project team. This seems an unduly narrow base for understanding.

It was felt important instead to seek to develop a more inclusive approach to exploring the key aims and objectives of the review, to include:

1. A thorough literature review focusing on the topics identified by INVOLVE. Using conventional methods and also including calls for knowledge in expert locations like the Disability List (Centre for Disability Studies, Leeds University); INVOLVE and the team's own websites;
2. In addition, to involve service users/service user researchers directly both as a knowledge source and to explore their views on the issues identified within the project's aims and objectives.

### **Involving service users/user researchers in the project**

To do this, realistically within a very limited budget, a series of four discussion groups was planned. The purpose of these groups was to explore issues relating to user controlled research from the perspectives of service users, service user researchers and research participants. These groups aimed to include a wide range of perspectives, including:

- Service users with key contributions in the field of 'user controlled' and related research approaches;
- Service users who have undertaken such research;
- Service users who have participated in such research (in order to identify issues of principle and good practice from research participants' points of view);
- Service user researchers with experience of different approaches to research as well as to user involvement in/user controlled research;
- Service users from different user groups (including older people, people with learning difficulties, people with physical and sensory impairments; mental health service users, etc);
- Service users with experience of user controlled research at national and local levels;

- Service users who are geographically diverse;
- Service users who are likely to have a range of views about the nature and values of research;
- Black and minority ethnic service users with experience as above (as well as seeking to address difference more broadly);
- Service user researchers who have specifically considered the idea of user controlled research

To access service users, the plan was first to make contact with a range of service users with particular interest in user controlled research from different perspectives to seek their initial views in response to the project brief's aims and objects. This would be done using a short email self-administered flexible schedule. Some of these service users would then be invited to be members of the discussion groups, alongside additional service users with an interest and contributions to make. Some of the latter might be recruited from the initial website information trawl already referred to. These group discussions would be small and be facilitated by the project worker. In this way it was hoped, involving a relatively small number of service users, to draw in as diverse a range of participants as possible. This would include people with expertise we already knew about, some emerging from other networks as well as others who would be self-selecting. (See also Appendix 1)

In the event, the process of sending out questionnaires and getting the discussion groups together merged as we were working to get the groups completed before the summer holidays. What happened was that we advertised the project through the Shaping Our Lives newsletter and the newsletters of Greater London Action on Disability and Involve. We also let people know at meetings bringing together service user researchers and by word of mouth. Service users contacted us and we offered them the option of taking part in a group discussion or completing a questionnaire. Questionnaires were all completed electronically. The same schedule was used as a basis for group discussions and for individual self-completion, for consistency. (see Appendix 2) The questionnaire/schedule was based on issues emerging from an initial reading of literature relating to user controlled research and was revised and agreed by the electronic steering group before being sent out. This all added to the time the exercise took.

Payment was offered to service users who completed the questionnaire, but none took advantage of this offer. The group discussions were tape recorded with participants' agreement and partially transcribed, with detailed notes and verbatim quotations recorded. A diverse range of service users were involved in the project as was intended, although we had hoped that a larger number of self-completed questionnaires would have been returned. We also hoped for a higher proportion of black and minority ethnic participants (4/31). We suspect that the amount of effort we had to put into contacting service users (and their organizations) as well as the limited level of response overall reflects the restricted resources available to service users and their organisations and the competing demands on their limited time.

## **1.6 Project practicalities**

Like many research projects undertaken by service users, this one encountered difficulties. While this did not mean that it could not be completed essentially as intended, it did mean that this created major problems and anxieties for the project team. The first and major difficulty was that overall, the work took much longer to undertake than could have been expected. Yet the project team was made up of experienced service user researchers who were familiar with this issue and tried to build it into planning.

### **The literature review**

The literature review required much more time to carry out than expected. We planned to search using the terms:

- emancipatory research
- emancipatory disability research
- new paradigm research
- user controlled research
- user research
- survivor research
- social model (of disability) research
- action-research
- participatory action research
- user led research (and evaluation)
- feminist research
- educational action research

In the event, just using the terms user-controlled research and emancipatory research gave us as much as we could deal with. Online searches were carried out using the extensive archive of the Disability Research Unit at the University of Leeds, the Social Care Institute for Excellence's Caredata online database and the EBSCO electronic journals service. We also used a process of snowballing from service user sources with which we were already familiar. While the resources which we identified and used (see Bibliography), cannot be seen as definitive, they do contain a large and very wide range of relevant materials from service users, as well as associated resources.

Because the literature review took a long time to undertake, it was not completed until after the group discussions were undertaken. This meant that findings from the literature review could not be included to help focus interviews and discussions, as had originally been intended.

### **Discussion groups**

As intended, four successful group discussions were held. These were organized as planned. Much more difficulty was encountered getting individual comments and feedback, particularly from some of the busiest and best known service user researchers. Afterwards we wondered whether we should have

used a shorter simplified version of the questionnaire we were using to encourage more contributions. However we had wanted to gain more in-depth views. Perhaps a combination of both would have been a better idea. We were able to some extent to compensate for this by drawing on the published work of such user researchers, but this is definitely an area where more work would be helpful. The same was true for some of the service user organisations involved in undertaking user controlled research. Again issues of tight timescales and competing pressures of work were signalled by potential participants. Underpinning many of the difficulties were the issues raised by the very limited budget available for this project. This is a common problem for user controlled research. In *Shaping Our Lives*, we have found from experience that good levels of payment for people's involvement and expertise do encourage involvement and lower rates seem to discourage it.

This project was intended to be carried out as a collaboration *Shaping Our Lives* and *Folk.Us*. *Shaping Our Lives* is a user controlled organisation with longstanding experience of undertaking user controlled research. *Folk.Us* has a strong track record of involvement in collaborative research. The two organizations had previous experience of working together. In the event, however, because of the high level of other commitments, *Folk.Us* was unable to maintain its involvement in the work (although as part of the project, formal feedback was offered to *Folk.Us*). Instead the Project continued as a collaboration between *Shaping Our Lives* and the Centre for Citizen Participation at Brunel University, led by *Shaping Our Lives* and was jointly managed by Fran Branfield and Peter Beresford, with Michael Turner employed to undertake field work, the literature review and to undertake initial report drafting.

### **Issues of accountability**

An important issue for all research, not least user controlled research is ensuring accountability. This project sought to ensure two forms of accountability; to the funding organisation and to service users. Accountability to the funding organization was reflected in regular phone and email contact reporting progress (and sometimes difficulties maintaining it!) as well as a mid-term meeting with Sarah Buckland, Director of INVOLVE's Support Unit and Alison Faulkner, service user member of INVOLVE's Monitoring and Evaluation Sub-Group. This was a very positive meeting. Accountability to service users has long been assumed to be one of the defining criteria of user controlled research. In this project, its formal expression was the fact that the project was undertaken under the auspices of *Shaping Our Lives*, a democratically constituted user controlled organisation and regular reports on progress and developments were provided both to *Shaping Our Lives'* Management Group and National User Group. Both are made up of service users, most of whom have close links with other service user organisations.

We also sought to ensure wider accountability through establishing an electronic steering group and through a process of involvement and feedback to participating service users (see dissemination strategy later).

An early aim of the proposal was to establish a small Service User Steering Group. For reasons of economy and flexibility, this communicated mainly electronically, taking the form of an email discussion group. Its purpose was to support the project team in identifying information and literature sources and to guide the project, offering input particularly at an early stage and later on when a draft report had been produced. It included five key service users/user researchers and sought to reflect diversity. These were:

- Ayesha Vernon , disabled researcher of De Montfort University;
- Colin Barnes, disabled researcher, of the Centre for Disability Studies, Leeds University;
- Patsy Staddon, service user researcher researching with women with problems of alcohol addition, Bristol University;
- Mary Nettle, freelance mental health service user consultant and researcher;
- Simone Aspis, disabled researcher with learning difficulties.

The two key roles which this Steering Group played were first to comment on the discussion and interview schedule and second to comment on the draft report. Shaping Our Lives had previously established such virtual steering groups which worked successfully and were economical in practice – an important characteristic in this project. Participants were paid a fixed fee, with a clearly defined role and responsibility.

### **Facing problems**

This project demonstrates in its own working, yet again some of the generally recognised issues and difficulties facing user controlled research:

- Its values and process meant that it involves additional activities and tended to take longer;
- It generates additional costs that are not faced by traditional research approaches;
- It relied on the involvement of service users and service user organisations both of which tend to be overloaded, under pressure and facing financial difficulties.

This project has been constrained by limited funding and tight deadlines. We couldn't do all we set out to do. We have not achieved all that we might have hoped for. It is important for us to be honest about these limitations and to argue from them, the importance of following up the momentum which hopefully this small scale project may have generated to focus more seriously, systematically and inclusive on the nature and issues facing user controlled research. Only in this way are its limitations likely to be recognised and addressed and its usefulness and potential realised.

### **Gaps in the Project**

There are inevitably gaps in this project. While every project runs this risk, the modest scale of this one, means that it was important from the start to

recognise this likelihood. Some gaps on the other hand are perhaps unavoidable. One such is the lack of evidence from literature of any negative views of user controlled research on the part of mainstream researchers and research organisations. Service users made clear in the project that they felt there were negative often discriminatory responses to user controlled research. But these rarely surface in formal discussions and published literature. They are instead part of a hidden history of user controlled research, usually only finding expression in informal and unrecorded discussions among researchers or with service user researchers, or in the confidential and anonymised statements of peer reviewers, grant assessors and so on. Hopefully in the future it may be possible to get a more accurate and systematic picture of such opposition to user controlled research.

On the other hand, lack of time and space means that it has not been possible to report examples of user controlled research projects which illustrate good (and perhaps bad) practice. This would have been a helpful addition. Readers will however be able to access such information by following up the resource list provided.

The primary focus of this study was on the definitions and meanings that service users attach to user controlled research. One comment that we received in the review process was that the report concentrated on the *process* of user controlled research rather than addressing its '*outputs*' – that is, whether, for example, what it produces is different or if it produces different knowledge to other research approaches. There is a growing interest in what user controlled research can actually offer. In some cases, this may be because of an uncertainty about whether it does have a valid contribution to make. But there is also a constructive concern with the particular contribution it may have to make. Certainly more work is needed on identifying what user controlled research may actually offer. However, we did ask service users what they saw as the differences between user controlled and other research; its particular contribution and any particular benefits that they felt it offered and in the event, they offered much discussion relevant to what they see as the outputs of user controlled research, signalling that it had a particular, possibly unique contribution to make.

There are undoubtedly gaps in the literature identified although we have tried to make it as wide ranging and up to date as possible. Hopefully readers will alert INVOLVE to the existence of new and important material that can be added to a resource list for the future.

Finally, we were only able to speak with service users and service user researchers in our exploration of the definition of user controlled research. While we feel that these are crucial perspectives in this discussion, there is no doubt that other stakeholders are likely to have important additional insights to offer. One of the peer reviewers who read the draft report of this project expressed their regret that only service user and not 'conventional' researchers were interviewed, saying:

*What we end up with is only one side of the story.*



This is true. It would have been helpful to include such other perspectives. Unfortunately it was not possible to do so at this stage, although doing so is another important task waiting to be undertaken in the future.

## **1.7 Organising the findings**

We have organised our findings around the key issues and themes that have emerged from the project. There are five of these:

- Defining user controlled research
- Good practice in user controlled research
- Should the researcher be a service user?
- The benefits of user controlled research
- Barriers facing user controlled research

We have reported the findings both from the literature review and directly obtained from service users under each of these headings. We also have additional information from service users about how they see the future of user controlled research. The information provided by the literature review and the findings from our individual and group interviews with service users seem to be closely consistent. There do not seem to be any major inconsistencies between them. Instead they reinforce each other. There also seems to be a similar consistency between what service users say in the different group discussions and comparing the group discussions with individual interviews. This is not to say that there are no disagreements between service users, but these do seem to relate to similar issues.

## 2 The Findings: defining user controlled research

### 2.1 From the literature

#### a) Its relations with other research

Discussions of user controlled research have tended to be clear about its relation with and indebtedness to other earlier research which has had similar aims and objectives. Such 'new paradigm' research, includes feminist and Black research and the research associated with community education and liberatory educationalists like Paulo Friere (Reason and Rowan, 1981; Harding 1993 and 2004; Humphries and Truman, 1994; Baxter et al, 2001).

At the same time, some strong distinctions have been drawn between such 'user controlled' research approaches and participatory research and participatory action research paradigms. Both Swain and Zarb make comparisons between participatory research, which they see as being about involvement, and emancipatory research, which they see as being controlled by disabled people/service users (Zarb, 1997; Swain, 2001). Thus Zarb writes:

*The active participation of disabled people is therefore a necessary but not a sufficient condition for emancipatory research. Unless disabled people themselves are actively involved in determining the aims, methods and uses of the research then, clearly, it could not lay any claim to having any transformative potential. (P51)*

This is not an uncontested view, however. In their more general examination of 'lay involvement' and participatory research approaches, Baxter, Thorne and Mitchell (2001) see the key purpose of participatory research as also being about empowering people and encouraging change and improvement to empower people. There is no agreement on this issue, and part of the explanation may relate to perceived gaps in practice between the principles and philosophies associated with participatory research and its actual capacity to realise them (Cooke and Kothari, 2001). Similar issues have arisen in relation to related research strands like action-research and collaborative research, whose advocates frequently see it having an empowering and liberatory role, while its critics question its ability to deliver on these (Winter and Munn-Giddings, 2001; Ramon 2000; Williams, 1999).

Related to but also distinct from the large body of work and literature about participatory research (Cornwell and Jewkes, 1995; Whyte, 1991), has been the development of 'user' or 'consumer' involvement in research. This is a relatively recent development, emerging in the 1990s (Kemshall and Littlechild, 2000; Hanley et al, 2003). It is particularly associated in the UK with research in the fields of health and social care, but it has also developed more widely in public policy, including education, housing, regeneration and

anti-poverty policy, for example. Some discussants see user controlled research as one point in a spectrum of user involvement in research (Beresford and Evans, 1999). But there has also been a strong tendency to distinguish between user involvement in research and user controlled research. While user involvement in research is seen as a progressive development, problems of tokenism and its qualified implementation are also highlighted (Boote et al, 2002; Telford et al, 2003). Some writers have emphasised that user involvement in research and user controlled research have different origins and purposes and come from different traditions (Evans and Fisher, 1999a and 199b; OpenMind 2002).

A distinction has been drawn between what may be called managerialist/consumerist and democratic approaches to involvement in research. While the former is associated with user involvement in research; the latter is linked with emancipatory and user controlled research (Beresford, 2003). Democratic research, which he sees as originating with the disability and service user movements is concerned with personal and political change, as well as change in services. The managerialist/consumerist approach is more closely based on a market research model, originates with state and service system and is concerned with including the perspectives and data of service users within existing structures and arrangements of research, without signifying any redistribution of power and has a more narrow concern with the service system's own requirements and imperatives. Because this approach is not necessarily concerned with personal or political change and empowerment; or with supporting the development of service users' own discussions and priorities, but instead may draw them into traditional research processes and methods, it may not serve their interests and indeed potentially could conflict with them (Faulkner, 2003; Lindow, 2001; Wallcraft, 1998).

## **b) User controlled and emancipatory research**

Our starting point in this project is user controlled research. But it is important to remember that historically the starting point has been emancipatory disability research. This research approach developed by the disabled people's movement has a much longer history than 'user controlled research'. Its origins as we have seen can be traced back to the 1960s and 1970s. Its terminology has also been established much longer. In our project we found considerable similarity between people's definitions and understandings of emancipatory disability research and user controlled research. However it is important to remember that it was the former that laid down definitions and frameworks for research owned and carried out by the subjects and constituencies of such research. It also appears that much more attention has been paid in formal discussion to the definition of emancipatory research, than to either the definition of user controlled research or user controlled research's relation with other such innovative research approaches in which service users are fully involved. In their 'user led report of research into people's strategies for living with mental distress' Faulkner and Layzell (2000, Chapter 6), discussed 'user led research' in relation to emancipatory disability research. There does not seem generally to have been a particular interest in exploring their similarities and/or differences or in demarcating boundaries between

them. While this can make for confusion and uncertainty in trying to make sense of these different approaches, it may also signify that in practice, this is not seen as an important issue and that they tend to be treated as similar and overlapping.

Recurring themes in the definition of emancipatory disability research have been that it:

- Seeks to equalise the social relations of research production (so that the people who carry out the research and are the subject of the research relate to each other on much more equal terms);
- Is committed to the empowerment of disabled people;
- Is directed to achieving broader social and political change;
- rather than solely the accumulation of knowledge;
- Is based on a social model of disability developed by disabled people. (for example: DHS, 1992; Barnes and Mercer, 1997; Barnes 2003 and 2004; Mercer, 2002)

Such commentators are explicit about the political nature of emancipatory disability research (while making clear that all research is politically rooted). Thus Barnes and Mercer (1997) define emancipatory research as taking the side of oppressed people and groups rather than pretending to be neutral and objective. Criticisms of its 'bias' have frequently been levelled against emancipatory and user controlled research.

Vernon (1997), on the other hand, sees its allegiance to service users as a positive aspect of user controlled research, suggesting that to deny it is to deny disabled people's perspectives on the world. Barnes (2001) also argues that even what are seen as the hard and objective sciences include significant elements of subjectivity.

There have been discussions about the actual capacity of such research to emancipate disabled people; how much it can actually ensure that 'the researched' have power over researchers and who benefits the most from it (Oliver, 1997; Barnes, 2001 and 2003). However, its definition constantly focuses on these key concerns.

Oliver (1997) identifies six ways in which research can contribute to the emancipation of disabled people. These are:

- describing of experience of disabled people 'in the face of' academics' abstraction/distortion of it;
- redefining disability;
- challenging tradition research methods;
- developing new, emancipatory methods;
- describing the collective experience of disabled people and the disability movement;
- evaluation of services run by disabled people.

While discussions about user controlled research and emancipatory disability research frequently seem to have developed in parallel with each other, with different authors and advocates, they also seem to be developing research models which are closely interrelated and overlapping. Thus, for example, Evans and Fisher (1999b) see user control as a key element in the definition of emancipatory research, questioning how far research can be emancipatory if it is not user-controlled. Beresford and Evans (1999) make the same point, arguing that point that the extent to which a research project can be emancipatory is dependent on the level to which users are in control of the project.

### **c) The centrality of control**

Evans and Fisher (1999) point to the early engagement of users in a project, if not its initiation, as crucial to control:

*It is the difference between engaging in a self-generated activity and being invited, with whatever degree of humanity, to join an activity already underway. (p3)*

They note that transferring a project which has been initiated elsewhere to the control of users can be particularly problematic.

For some commentators, user control can be defined in terms of research being accountable to disabled people's and other service users' organisations (Barnes and Mercer, 1997; Oliver, 1997; Mercer, 2002). But there is also talk about the *effects* that users' research can have on service users' organisations.

Evans and Fisher (1999b) develop the view that research has a particular impact on the process of empowerment because of the role of research in defining the experiences and needs of service users. They describe how research became a key interest of the Wiltshire and Swindon Users' Network (WSUN), a user controlled organisation because of the (negative) involvement members had had with traditional research and their being:

*Made use of by academic researchers in order to collect our views for research which they would publish and gain credit and recognition for. (P356)*

They believe that -

*user-controlled research is part of user empowerment. (P365)*

While they acknowledge that this is difficult to assess, they see clear evidence of this in projects on which the Wiltshire and Swindon Users Network has worked. Evans and Fisher also argue that this approach has benefits to the research in terms of generating higher levels of participation, which produces better data.

Lindow (2001) makes a similar point in relation to the mental health field, saying that -

*Survivor research can be a small but key part in the move to seize freedom within an oppressive and excluding society (P145).*

#### **d) Aims and purposes**

The literature also highlights other common characteristics of user controlled and emancipatory research. Beresford and Wallcraft (1997) see change as the key purpose of emancipatory research. Looking at the mental health field, they point out that emancipatory research has started to change traditional services by challenging the ideas on which they are based. This work has highlighted the value of alternative therapies and ideas like a social model of madness and the concept of crisis as opposed to illness have emerged.

The Mental Health Foundation (2003) associates user controlled research with the same features as emancipatory research. These include, for example, its emphasis on social issues and the importance of process a process which ensures the full and equal involvement of service users in deciding what needs to be researched, designing and undertaking the research. User controlled research, like emancipatory research enables people to develop their own discussions, views and ideas, rather than get involved in other people's (Oliver and Barnes, 1998; Beresford, 2002).

Beresford and Wallcraft (1997) similarly see change as the key purpose of emancipatory and user controlled research. Looking at the mental health field, they point out that emancipatory research has started to change traditional services by challenging the ideas on which they are based. This work has highlighted the value of complementary therapies and non-medicalised ideas supported the emergence of ideas like a social model of madness and distress, in place of 'mental illness'.

While liberation and emancipation are identified as common purposes of emancipatory and user controlled research, there has been more discussion about this in relation to emancipatory research – perhaps because it is embodied in its name. Both Oliver (1997) and Zarb (1997) argue that emancipatory research cannot just be seen in terms of a set of characteristics. Each says that it is difficult to say research is emancipatory until after the event and that its capacity to 'emancipate' can only be evaluated once a project is completed and its impact has been felt.

For Oliver this means that it is difficult to lay down a specific methodology for emancipatory research. He sees the methodology as essentially being participatory or action research, though he sees these approaches as being primarily about getting disabled people into the 'research game', where emancipatory research is about changing the game itself.

Writing ten-years after Oliver's initial definition emancipatory disability research, Barnes (2001) raises the question of whether emancipatory

research should be seen as an aspiration rather than a specific methodology, though he has no doubt that it is something that researchers should be trying to achieve. A key part of what he sees as the process of emancipatory research is that it involves opening up research and creating a dialogue between disabled people and the research community.

Lindow (2001) also sees this as an important issue, but highlights problems around making academic research accessible, particularly problems relating to language. She believes that this may be a difficult issue to address as academics not always keen on popularising what they do. Beresford (2003) similarly comments on issues of language citing words like 'epistemology' and 'ontology', as being 'frightening and excluding.' (P9)

It is interesting to note on the point of language that even user-controlled research is tied to terms like 'emancipatory' which are not necessarily accessible to many service users. There is a dilemma for user-controlled research in terms asserting its validity in the face of the values and structures of academic and other forms of research and the requirements of funders, while remaining accessible and part of the disability and user movements.

Interestingly, Baxter, Thorne, and Mitchell's (2001) examination of good practice in user involvement in health and social care research identifies some of the most innovative work taking place where it does not rely on shared language between researcher and the researched and visual methods are used. They suggest that there are issues around the different vocabularies/knowledge of professionals compared with users and the implications for language.

While there is a clear preference for user-controlled research/emancipatory research in most of the writings from disabled people and other service users, there is no sense in which supporters of emancipatory research are separatist, or overly dogmatic about their methods being the right and only way to approach research on health and social care. Many of the works referred to above recognise that joint working may be valuable and necessary, although there can be difficulties in relationships.

#### **e) People with learning difficulties**

Particular issues are raised in relation to user controlled research and people with learning difficulties. These have a special significance because much research about people with learning difficulties has been undertaken based on principles of normalisation (which some people with learning difficulties find unhelpful and now reject) rather than drawing on a social model of disability.

The first group of service users to carry out their own research was disabled people. Since then other groups have developed their own research. However, there seems to be some disagreement in the literature whether people with learning difficulties are able to undertake 'user controlled research', or whether the support they need prevents this happening (Aspis, 2000). Walmsley and Johnson (2003), for example, seem to question Williams' assertion that a

group of people with learning difficulties (with her as 'supporter or co-researcher') 'learnt about research and decided they wanted to do some 'finding out of their own' (Williams, 1999). They write:

(Williams) is adamant that this is an example which shows that people with learning disabilities can appreciate what research is, can see its value and plan and carry it out.

However, another group of people with learning difficulties since then have carried out their own user controlled research project, where the role of the supporter has been very clearly set out (Hiscutt et al, 2005).

#### **f) Methods and methodologies**

User controlled research does not seem to be defined in terms of a specific range of research methods or methodologies. It has tended to be associated particularly with qualitative research methods, but it is certainly not seen to be restricted solely to these. Baxter et al (2001) observe that participatory research uses qualitative research methods. The same point has been made in relation to emancipatory research, as lending itself to the kind of subjective approach associated with qualitative research (Zarb, 1997). One reason for this is perhaps the value seen in people having the chance to 'tell their own stories' – to offer their own subjective accounts – which qualitative research is ideally suited to do. Lindow (2001) reports on user-controlled (qualitative) research in the mental health field using structured and semi-structured interviews to gather people's views, and identifies action research and critical incident analysis as other methods that are particularly useful to user controlled research.

More recently major user controlled research projects have been carried out in the fields of disability and mental health which have also employed quantitative as well as qualitative research methods. These have not only highlighted how user controlled research is able to make helpful use of such quantitative research methods, but also how it can develop these to ensure that they are consistent with the participatory and empowering values and goals of user controlled research (Barnes et al, 2000, 2001, 2002; Review Group, 2002; Rose, 2001).

While most user-controlled projects have been qualitative, user-controlled research does not have to be restricted to such methods. The restricted resources available to user controlled research and the generally higher cost of large quantitative research studies, however, may explain why such research has been less often developed in the context of user controlled research and evaluation. (Beresford 2003b).



## 2.2 What service users say

We began by asking participants in the project what user controlled research meant to them – how they defined it. This drew out many of the key characteristics that people associated with such research. These in turn highlighted a range of criteria for good practice in involving service users in *all kinds* of health and social care research -whether or not it is controlled by service users. This was an interesting and early expression of a feature of service users' comments. While they tended to draw a strong distinction between user involvement in research and user controlled research, what they saw as inherent qualities of user controlled research, they frequently also thought were requirements for 'good' user involvement in research more generally. This may explain a contradiction which crops up in some service users' comments. While most drew a strong distinction between 'user controlled' research and 'user involvement' in research, some occasionally seemed to use the two terms as if they saw them as meaning the same. Readers will occasionally see the two terms used interchangeably in this way by some participants. But as can also be seen, service users more often drew a sharp distinction between the two and in writing this report, we have abided by this differentiation.

### a) Control

It is perhaps to be expected that the issue of *control* comes out as the key characteristic of user controlled research. While this project shows how complex people's understandings of user controlled research can be; that there is much more to it than where control lies and that control itself needs to be defined in more detail, nonetheless there is clearly agreement that the issue of control lies at the heart of the matter. Participants had broadly similar ideas about what constitutes control. Crucially the distinction they draw is between service users and others having control of research. Thus there is no position of neutral ownership.

*Control is the word. It must be genuine - people must really want users to be in control. From the little bit of experience I've had, there's an awful lot of talk about users being in control but when it comes to it that doesn't happen. So for me it's about genuineness, willingness to fund, and control in the healthiest sense of the word.*

Mental health service user/survivor, Discussion group A

*They shouldn't take over and tell us not to do the research.*

Person with learning difficulties, Discussion group A

*I think that at the at least it should be (service users) setting the agenda, users should set the agenda in terms of what is researched and how it is researched. So, the agenda and the method should definitely be set by the people.*

Disabled person, Discussion group D

One person offered a definition of user controlled research based on what it *isn't*.

*User controlled research is, by definition, not provider controlled research. It is generated by and started off by user interests and user priorities. It is carried out by users who have a perspective about what other users think. It is not necessarily user-only research, for example if you need help with statistics or planning surveys or things like that, then it's perfectly OK to use researchers from universities who may or may not be able-bodied - but the initiation and the control, the interactive bit where the researchers talk to users and the writing up and the following through of the research, that is all controlled by disabled people. In my view disabled people should speak for the project - speak for ourselves and our projects and present our findings for ourselves.'*

Disabled person, Discussion group C

It wasn't only when service users were together in a group that they saw control as a key underpinning user for user controlled research. This was equally true for the wide range of responses from individuals completing questionnaires. While people offered 'softer' and 'harder' definitions, all centred round control. Who was involved in research emerged as a subsidiary issue to this. It might not only have to be service users who were involved, to be seen as user controlled research.

*Where users decide whether the research should go ahead, have some input into the methodology and process to be used and have responsibility for bringing the research to a conclusion with the findings being reported. Questionnaire 2*

*The service users decide the aim, the subject, the method, how to analyse (the results) and control the dissemination. Questionnaire 3*

*Service users choose the topic of the research, design the instruments, administer the research, do the analysis, write it up and disseminate it. Possibly with some support/advice from 'professionals. Questionnaire 4*

*It is research planned, undertaken and disseminated by service users. This might be in conjunction with others but the control rests with service users... Involvement need not necessarily mean doing it all, as long as service users stay in control it's OK. Questionnaire 5*

*It can be a variety of things - commissioning research, advising on projects, researching with professional help, or a group doing a completely 'non-professional' piece of research. Sometimes doing the whole of the project, sometimes working in tandem with professionals. Questionnaire 1*

*User controlled research as a minimum should directly involve informed disabled people in the design and delivery of the project in influential positions. Such research should follow definitions of disability that are*

*common currency within organisations of disabled people. Ideally such research should be done by researchers/organisations who have direct lived experience of disability.* Questionnaire 7

*My main criterion would be that service users set the research questions and maintain control over significant decisions that arise as the research progresses such as ethics, methodology, dissemination.* Questionnaire 8

*(It is) research which is controlled by user decision at all stages of the research project and then decision makers are part of a wider user constituency as self defined... The expertise of users' lived experience is paramount in all decision making.* Questionnaire 10

*Projects that may use researchers from all backgrounds but where service users are responsible for the design, methodology and dissemination.* Questionnaire 11

## **‘User-led’ research**

There is one additional point to address while we are considering the issue of ‘control’. User controlled (research) is a relatively straightforward term to comprehend and to define, although there is no absolute consensus about it. But another related term has also been used in this field – ‘user led’ research. This is sometimes used by service users (including in this report) and others as if synonymous with user controlled research. At other times, it seems to be used in a more generalised sense as if to mean that the research is *led* by the needs and interests of service users. Here it seems to serve more as a value or aspiration, rather than an arrangement directly concerned with the actual control of research or to whom it is accountable.

Sometimes non-service users employ this term to highlight that they seek in what they are doing to be led by what service users want. In this sense it is similar to some other terms that have come to be used in the field of user involvement like ‘user centred’ and ‘user focused’. Because of this some service users dislike and avoid the term, seeing it as vague and potentially deceptive. For this reason, we have retained the use of the term ‘user controlled research’ in this discussion, while keeping the term ‘user led’ where service users themselves have used it.

### **b) Aims and purposes**

People saw the aims and purpose of user controlled research as distinctive. They saw such research as setting out to bring about change and improve the lives of service users and the services that are needed to achieve this. There was strong agreement about this. Discussion of control flowed into discussion of aims and objectives. It was as if service users saw a commitment to improve the lives of service users and achieve change were natural consequences of research being user controlled. They took it that this is what service users would want and have a right to expect from research if it were

under their control. Thus making change can be seen as a moral imperative for user controlled research. It provides justification for it.

It could be argued that a concern with change is true of much if not all other research. Even what is called 'unapplied' or 'blue skies' research, might ultimately be seen as part of an overall package that can lead to change. However, with user controlled research, service users see change-making as the primary concern of research. This includes both change for the individual, usually framed in terms of empowerment and broader social and political change.

*The purpose of research should be to identify the gaps and to be used improve the service. I don't think research should be done just for the sake of research and just produce a beautiful document that is put on the shelf. That is why users should be involved.*

Disabled person, Discussion group A

*Research has to have the purpose of empowerment and aiming for change in line with what service users want... User controlled research offers the best hope of doing something real.*

User/survivor, Discussion group D

*Importantly, the research should have the outcome of improving the lives of disabled people in the future. It should also aim to improve the lives of the people who have taken part in the research by giving them the opportunity to build on their knowledge of the social model of disability and the other models of disability to learn more about their identity and learn through the whole process.*

Disabled person, Discussion group B

*The idea should be too make the service better for everyone.'* Mental health service user/survivor, Discussion group A

*The intervention (the research) is not valid unless it is aimed at the real world. We are living in the real world but our 'real world' is shrouded in mystery to anyone who doesn't live in it, so user controlled research aims to open those curtains so that the reality has some light thrown on it at last. We need our curtains throwing open and the light of day coming on to our real lives, the quality of our lives and our aspirations and what stops us reaching them. These things need to be exposed - if they are not exposed, then how on earth can we set out what needs to be done so that we can get a better quality of life and achieve our aspirations.*

Disabled person, Discussion group C

*The values and principles are distinct from any other research as it is about the benefit to the service user as in, whether this research going to be useful or not useful. If it is not useful, then obviously don't do it. How is it going to improve (the lives of service users) is the basic question at the heart of it.*

Disabled person, Discussion group D

*Research is done from the point of view of the user and is to the benefit of the user. Empowerment is also important.* Questionnaire 1

*It aims to produce good quality research with the aim of making a difference to services or treatments or ways of coping. It does not have academic reasons.* Questionnaire 4

*User controlled research might be seen as pushing the boundaries of what research is. It is still about 'finding out' but from a subjective stance with the intention of sustaining good services and provoking change.* Questionnaire 5

*(Research should) find out the reality of a situation; then suggest ways to make it better.* Questionnaire 8

It is important to bring out this emphasis on change as a key characteristic of user controlled research, but again it should be stressed that it can best be understood as an issue which arises from service users being in control. The logic here is simple. Why would service users want research which is not going to have a positive impact on their and their peers' situation?

This view – the making of a connection between the *location* of control and the *purpose* of research - seemed to relate to participants' experience of traditional mainstream research. When discussing the purposefulness of user controlled research, some participants contrasted this with what they saw as research of little purpose and limited value being carried out without service users and by non service users:

*They're going around in circles and wasting a lot of money and resources. When they do research it's often a waste of money because they can't use it, sometimes it's just useless.*

Disabled person, Discussion group A

*I'm sick and tired of this public and patient participation agenda. How come I'm not involved in the research? If it's not about changing my life there's no point in research.*

Mental health service user/survivor, Discussion group D

Two people went as far as to say that user involvement and control are the keys to the production of good research. It is perhaps helpful to remember that both were identified in this way. However, there were also concerns that where research was not user controlled, it could become institutionalised and preoccupied with the interests and professional concerns and advancement of researchers and research organisations and institutions. We know that research is sometimes guided by other concerns, for example, knowledge formation and development (for its own sake); the particular priorities of funders and commissioners and the politics and economics of research publishing. Furthermore there can be no question that the 'research assessment exercise' (RAE) which operates in UK universities, has had

powerful effects on research and publication. In this, utility and usefulness do not seem to be recognised as components of 'quality'. Impact seems to be measured in terms of peer review journal citations, rather than research leading to valued change in practice and policy.

*They go ahead and do research that is a waste of money. When they involve users it becomes very valuable.*

Disabled person, Discussion group A

*You get professionals and academics doing research who may have vested interests which are not the interests of the users. I see a lot of academic researchers but at the end of the day their work does not improve services one iota. I see all this money going into this research when I can see it would be better used paying carers a bit more.*

Mental health service user/survivor, Discussion group B

One participant observed that the knowledge that a project would have a potential impact had encouraged them to take part:

*I did a project and was told that the report would actually be read by the government and feed into the system that makes decisions and that definitely helped me.*

Mental health service user/survivor, Discussion group A

A similar point was made by a service user researcher about the impact of their work -

*It's an example of how I, an unemployed 'lunatic', was able to do a research project and influence government policy. For me, that's the power of user controlled research.*

Mental health service user/survivor, Discussion group B

One participant expressed broader doubts about the overall value of research:

*A lot of people are doing a lot of research. They talk a lot and they have lots of meetings but at the end of the day I think that action needs to be taken on a practical level to help people with the practicalities of day-to-day living.*

Mental health service user/survivor, Discussion group B

Thus while user controlled research may have an action element structured into it, by definition, it is still important to recognise that there may be limits to what it can achieve and its overall usefulness. Other methods than research may still need to be employed. When one participant was asked whether research can help to encourage action, they answered:

*Research can help but there are limits - you can go on doing till the cows come home, at the end of the day it's action that is needed.*

However, some participants saw user controlled research as fundamental to good service development:

*Providers are not capable of redirecting their service and making it effective by themselves. They haven't got our perspectives and our insights. They don't know what works and what doesn't, they don't know what we want. The only people who can tell them this is us. So user controlled research helps providers get themselves in line and start doing useful things so that they start to use their resources effectively and economically. They can only do that with our help.* Disabled person, Discussion group C

Service user involvement in research can make a helpful difference in that too:

*Without actually having users involved in research and putting their opinions forward, I fail to see how professionals can actually deliver a service.*

Mental health service user/survivor, Discussion group B

The doubts expressed about research as a tool in general seem to stem from the experience of research projects that have not been based on service users' view that research must relate to the 'real world,' and the view that there is an extensive amount academic research that contributes very little to the 'real world.'

Some people were especially scathing of academic research, including this person who has experience of working with universities -

*Research in a university is not about research. It's a parallel universe, it's not about research for the sake of even finding out about things, it's about chasing the money and not about doing what's worthwhile. Research is about what they think matters and their careers. It's real in one sense but it's not real in terms of the rights and needs of service users. I find it shocking.*

Service user/survivor, Discussion group D

There was also some support for university based research and there were service user researchers in each group with connections to universities. One of these responded to criticism of academic research by saying:

*I know within the school that I work in, that they work quite heavily towards making sure that the future practitioners that they are training do deliver the services that people require and there is a lot of service users involvement.*

Mental health service user/survivor, Discussion group C

To sum up, while there was strong agreement about the merits of user controlled research based on a primary commitment to change, there were very mixed feeling about other research less clearly underpinned by this objective.

### c) Values and principles

We asked people whether they thought that there are particular values and principles which underlie user controlled research. Participants clearly thought that there are. The values and principles which they identified seem to be grounded in those which guide the disabled people's and service users' movements more generally.

These values and principles include ones of:

- empowerment
- emancipation
- participation
- equality
- anti-discrimination

They were repeatedly stated. For example:

*It's about empowerment and emancipation and the values around it are that the people are authentic and are not trying to dominate each other or take advantage of each other. They help each other, value each other and listen to each other. Those should be the core values of user controlled research.*

Mental health service user/survivor, Discussion group A

*User controlled research is participative and emancipatory.*

Questionnaire 3

*It is more collaborative, that is it has more involvement and more connection between the subject of the research and the person doing it. It has less to do with seeking objectivity and more open subjectivity.*

Questionnaire 4

*(It's about) treating participants as equals, as the important partners in research. Questionnaire 8*

Service users' views about the values of user controlled research were developed further in terms of how they felt people should be involved in research and the ideology underpinning such research. Thus participants were very clear across all the groups that control has to take place from the very beginning of any project and be maintained through to its conclusion. There should be the potential for involvement in all its aspects and stages. Several (disabled) participants also made reference to user controlled research being based on a social model of disability:

*The point has to be that we are there at the very beginning before a brief is put together.*

Disabled person, Discussion group A



*Starting at the beginning, users should be involved in the planning and development of the research. It shouldn't be done by academics who have no idea about the social model of disability. Disabled people should be involved throughout the process and have the opportunity to give feedback on all parts of the research.*

Disabled person, Discussion group B

*User controlled research should be users being there right from the start to the finish. From the initiation, the planning, conducting and monitoring the research, right down to looking at the research and disseminating it. When I looked into it I found a lot of good research being done but a lot of it just isn't accessible to the common service users.*

Disabled person, Discussion group B

*Service users' involvement has to happen at all levels. You can't have user involvement and then start having meetings without service users. This does happen - they select which meetings they want users to come to. Some times it's not been properly costed - there might be six meetings but there's only enough money to have users at two of them.*

HIV/AIDS service user, Discussion group C

*Users should be involved in every aspect of the research - making up the questions, disseminating questionnaires collating the information, doing the findings, and making conclusions at the end. That for me is user controlled research.*

Mental health service user/survivor, Discussion group D

*Users are involved in the initiation, planning and eventual reporting of the research... being involved in critical aspects of the project as a whole, not just being the subjects.*

Questionnaire 2

*(It should be) based on the emancipatory research paradigm used within disability studies - eg. social model based, disabled people central not 'objects' of research, knowledge outcomes must be useable and promote/further work. It should also meet users access needs, provide training/support and be open about limitations and roles expect from users.*

Questionnaire 9

One of the questionnaire respondents put the importance of involvement at all stages of project in terms of the impact on individuals taking part in the work:

*This amounts to meaningful involvement and allows the service user some empowerment and choice in which parts of a project they can help with. It also gives people a chance to develop skills such as writing and public speaking and to develop their self-confidence.*

Questionnaire 6

Two questionnaire respondents did not see it as essential for service users to be involved all stages of a project, in terms of carrying out the work - with one commenting:

*They don't (need to be involved at every stage) – data analysis is one area that can be delegated to non service users for example. Initial desk research can be carried out by anyone with experience and an interest in the subject and there are usually well funded distribution outlets that are not user controlled.* Questionnaire 11

What service users seem to be saying is that user controlled research does not have to be research in which service users are necessarily undertaking every part of the work (although the option needs to be there), but research where service users have *control* over every stage and aspect of the work.

#### **d) User controlled and related research**

In trying to find out what user controlled research meant to service users', we also hoped to learn more about how they saw it relating to other emerging and new research approaches. There are now a range of such research approaches where issues of service user involvement and control feature. These include, for example, participatory research, collaborative research and emancipatory disability research. Do they all mean different things? Are clearly established different meanings attached to each of them? Are they just different words used to mean the same thing? Is there any agreement about these different terms?

There was some discussion about the differences between user controlled research and user involvement in research or 'user involved' research. This served as another opportunity for service users to express their doubts and reservations about user involvement in research more generally. User controlled research can be seen as one form of user involvement in research, representing its fullest expression. But service users in this project generally distinguished sharply between the two, expressing their concerns about becoming marginalised and tokenised where there is only user involvement. User involvement in research tended to be compared unfavourably with user controlled research.

*If it's just saying we've got service users involved in this research it could just be asking us what kind of sandwiches people want for lunch... control and involve are very different.*

Mental health service user/survivor, Discussion group A

*User controlled research is active and users have control over at least some aspects of a project. They may be the initiator of the project. With involvement users may be more passive and have not control.*

Questionnaire 1

*If the project is owned or run by service users there shouldn't be an issue of 'keeping' people involved, there are no 'keepers' in this way of working, other than the funders. Questionnaire 4*

*One is emancipatory the other can be genuinely participatory but is often tokenistic or is seen as short cut to getting the answered providers need. Questionnaire 9*

*Any research can involve users without it being user controlled – on advisory committees etc. Questionnaire 10*

*The latter (research involving service users) does not ensure accountability and usually constitutes tokenism. Questionnaire 11*

Discussions around the definition of user controlled research in the focus group meetings included some discussion of other forms of research and their relation to user controlled research. In one group this included a discussion around differences between user led, user focussed and other terms. Participants had comments to make about these different terms. So far it seems that while there is a sense that these terms demarcate different kinds of research, there is not yet clarity or agreement.

*To me user controlled research is a new term, I've been used to thinking of user-led research and user-focussed monitoring which I think are slightly different, might be slightly less controlled by service users. User-led research involved me in picking a topic that I wanted to and being given some finance to do that voluntarily with service user supervisors. So it was the choice of topic right through to dissemination. Mental health service user/survivor, Discussion group B*

*I feel strongly about user-led monitoring. I've been involved in some properly conducted, user-led monitoring surveys and these have produced recommendations of what users want but the managers don't act on this. I see user-led monitoring as providing the ammunition to get changes where the managers are saying that a service is brilliant. The users often know that it is not but they're in such a vulnerable position that they cannot say anything against the service because it will affect their care. I'm a great advocate of user-led surveys but only if they're done properly and independently so that the user is in a safe environment.*

Mental health service user/survivor, Discussion group B

*It would be useful to define some of the terms being used - user-led, user controlled, user-focussed - because they get used with different meanings and you assume that people are talking about one thing when they're talking about something completely different. We need to agree on some definitions.*

Disabled person, Discussion group B

Participants expressed particular concerns about collaborative and 'partnership' research and the validity of partnerships between service users and non-service users/'professionals' in research.

*In social research you can end up with users on one side and professionals on the other. This word partnership is bandied about but the power is still with the professionals. They are usually the ones commissioning the research, while the users are the ones being researched on, so I find this a bit of a grey area.*

Disabled person, Discussion group A

This reflects broader concerns frequently expressed among service users about the possibility of there being genuine partnerships between service users and service providers, given the imbalance of power there tends to be between them. As a result some service users reject the term 'partnership' and prefer terms like 'alliance'.

This said, an example was given of a positive experience of partnership:

*I read about one project where it had been a partnership between the professionals and service users and it looks as if the health authority is going to move forward with that, and I think that's because it was a partnership and that they had had equal input, so I think that there is definitely a place for that if it's done genuinely.*

Mental health service user/survivor, Discussion group A

The discussion of this point in this group concluded with the following comment, which drew general agreement, -

*I don't like the term user controlled research. I like the term user directed research. The association that I have with control is negative because so many so called professionals are trying to control us for their vested interests. I think that we can have collaborations with professionals that are very successful and I don't want to see us become ghettoised as trying to control services ourselves.*

Mental health service user/survivor, Discussion group A

The relationship between user controlled research and two other research approaches also emerged in the project. The first was with participatory research. While the latter is defined primarily in terms of participation, in the case of user controlled research, participation is only one element in how people define it. Crucial also, as we have seen, are goals of control, equality and emancipation. Thus participation emerges as a necessary but not sufficient condition of user controlled research. In this it is similar to emancipatory disability research. The similarities between these two approaches seem to go much further. Emancipatory disability research has tended to be defined in terms of:

- a changed more equal relations of research production;
- a commitment to individual empowerment, emancipation and social change;

- being based on a social model of disability.

Participants in the project defined user controlled research in the same way. The two terms seem to share very similar meanings. User controlled research only seems to be different in that it includes all groups of health and social care service users. User controlled research also appears to have been developed by other groups of service users as a parallel development to emancipatory disability research, rather than just being borrowed from it. The term 'survivor research' also appears to be very close if not identical in meaning to user controlled research (Faulkner, 2004a).

One last issue was raised by participants in response to this issue. We had thought carefully about the matter of 'who is a service user' before undertaking this project. It was not an matter which participants seemed to be particularly concerned with. One questionnaire respondent however did raise the issue of who constitutes a service user in relation to different types of research -

*I am not sure of definition of user controlled research in relation to NHS 'users' – is the distinction between long term users who experience on-going discrimination and episodic users? If so, where does this leave maternity users' research? Questionnaire 10*

Clearly this question raises broader issues which need to be addressed in future discussions about user controlled research.

# 3 The Findings: good practice for user controlled research

## 3.1 From the literature

Discussions about emancipatory and user controlled research have tended to focus much more on their principles and values than on the specifics of good practice. This is perhaps to be expected of more recent research approaches which are still establishing themselves and which have come in for considerable criticism from mainstream researchers. The principles of emancipatory disability research have served as a basis for defining good practice, although as we have seen, there isn't complete agreement about them. As we have seen these principles relate to:

- being based on more equal relationships between researchers and research participants;
- drawing on social models/approaches to disability;
- working to support the empowerment of service users; challenging their disempowerment;
- being committed to making broader political, social, economic change in line with the rights of service users (Oliver, 1996; Mercer, 2002).

Notions of good practice seem to have followed from these principles (Barnes and Mercer, 1997; Mercer, 2002).

Vernon (1997) sets out details of her practice as a user researcher, offering her own model of good practice. She involves participants at the start of a project and shares information with participants about the project and its purpose as part of the interview process. She also shares transcripts with them and offers them the opportunity to make amendments. At the same time, she recognises that there are limits to the process of involvement, describing her intention to hold a further meeting with participants towards the end of a project, which did not prove possible.

There do seem to be some underdeveloped areas in identifying good practice. These include, for example:

- Ensuring appropriate support for service user researchers and service users involved in other ways in research (Beresford and Branfield, 2001; Nicholls et al, 2003; Faulkner, 2004a and 2004b);
- Developing policy and practice to ensure equal access for service users, including, physical, communication and cultural access (Shaping Our Lives et al, 2003);
- User controlled research and black and minority ethnic service users.(Trivedi and Wykes, 2002).

Baxter, Thorne and Mitchell (2001) raise the issue of inclusion, stressing:

*Rarely do those people who are most marginalised and who could most benefit from the research take part. (p76)*

The Mental Health Foundation (2003) also saw involving the widest possible range of service users as a key task for the future of user controlled research.

On the other hand, there has been much more discussion and recognition of the importance of training and learning, information, (for service users and others) and developing discussion for and about user controlled research (Mercer, 2002; Shaping Our Lives et al, 2003; Beresford, 2002; Faulkner, 2004b; Barnes, 2004).

If emancipatory disability research laid down a set of widely applied principles for good practice, 'survivor' research seems to have played a particularly important role in exploring and articulating how to improve practice in user controlled research. Conspicuous in this development has been the Strategies For Living Project based at the Mental Health Foundation. It supported the development of user controlled research projects at local and national level, provided training and information about user controlled research and increased the pool of skilled and experienced service user researchers (Faulkner, 1997; Faulkner and Nicholls, 1999; Faulkner and Layzell, 2000; Nicholls, 2001; Nicholls et al 2003).

Until recently there had only been limited examination of issues relating to governance and ethics in user controlled research. Lindow (2001) suggested that ethics committees inhibited user research and user involvement in research. While she recognised the importance of ethics committees their role in protecting research participants, she pointed out that they tended to be made up of traditional researchers. Beresford (2003b) argued for service users to have a larger role in relation to ethics committees and governance. Lindow (2001) also pointed to particular ethical issues that can emerge in research with service users, such as how confidentiality can be observed in cases where an interviewee might need assistance or be in danger. There are also issues around support for service user researchers and she argued that there is a need to develop a comprehensive code of ethics for user research.

Perhaps the single most developed discussion of good practice in user controlled research, which both pulls together a wide range of user views and material and provides a synthesis of its own, are the guidelines for ethical survivor (user controlled research) subsequently produced by Faulkner (2004), herself a key figure in Strategies For Living. This not only sets out a series of underlying principles for survivor/user controlled research, but also guidance for:

- Planning and designing research
- Recruitment and involvement
- Training and supervision
- Involving participants

- Analysis and feedback
- Dissemination and implementation
- (Dealing with) research ethics committees

User controlled research projects, spell out elements that they see as central to good practice. The Citizens' Commission on the Future of the Welfare State, for example, (Beresford and Turner, 1997) was initiated by a small group of service users, who secured and controlled funding; established a steering group which then recruited a larger more diverse group of service users as commissioners. The research was carried out by service users and findings collated, analysed and written up collectively. The Commission placed weight on a 'bottom up' approach to dissemination and change, engaging and feeding back to service users and their organisations, as well as policy makers and policy making organisations and structures.

This research was taken forward by another user controlled project undertaken by Shaping Our Lives. Shaping Our Lives, which is made up of and works across a wide range of health and social care service users, is a user controlled organisation which has undertaken a number of controlled research projects. The Joseph Rowntree Foundation asked Shaping Our Lives to undertake a consultation with service users to identify what they saw as key issues to inform a new funding programme. Negotiations between Shaping Our Lives and the Foundation led to funding being made available to run a short start-up project that facilitated wider user involvement in designing the main project. This is a rare example of a funder being willing to fund and support work to increase the degree of user control over a project. Shaping Our Lives supported service users in two localities to develop user involvement in discussions about the future of social policy and services, as well as seeking evidence from service users more generally (Turner et al, 2003).

In another user controlled research project, Shaping Our Lives (Shaping Our Lives and others, 2003) worked with four local service user organisations to research and develop user involvement in work on user defined outcome measures. Shaping Our Lives supported each organisation to approach the issue in the way that they saw as most appropriate for them. One group, for example, opted to have more frequent meetings of its members to take the work forward; another adopted a more individualised approach to the subject. Each of the organisations worked in their own way to improve the outcomes and lives of participants, so that the emancipatory principle was evident in both process of the project and in its broader aim to influence policy and practice. The project report notes -

Perhaps the most important achievement of the project has been the personal benefit that individual participants have gained from being involved in the work. Participants have said that the project has made them feel valued and have expressed strong support for the work, as evidenced in the attendance record for all the groups. (p17)



Significantly much of what is identified as good practice for positive user involvement in research and evaluation is also identified as good practice for user controlled research (Hanley et al 2003). Faulkner makes a similar point, saying of her guidelines for ethical survivor research:

While (their) focus is on 'survivor research' or user-led research, they have significant implications for the involvement of service users in research initiated by academic and other researchers, (Faulkner, 2004, pvii)

## 3.2 What service users say

This project was intended both to explore definitions of user controlled research and to identify good practice in user controlled research. It has been difficult to separate the two in organising this report. The principles and values that service users see as shaping user controlled research are often very close to if not indistinguishable from its practice. As they see it, what constitutes user controlled research determines how it should be done. One participant made exactly this point:

*All (aspects of good practice are) affected by core values of user controlled research. Questionnaire 10*

This point was also illustrated by another comment, which was made in response to the question about values and principles, but which applies both to that and to good practice:

*Commitment to change, commitment not to exploit participants, commitment fully to involve participants in all possible areas of the research. Questionnaire 8*

While the close relationship indicated by service users between the principles and practice of user controlled research created difficulties in writing this report, it can also be seen as a strength of user controlled research – as service users see it. This close link is evidently one of its essential characteristics. Where traditional research emphasises its 'scientific' credentials and underplays the values underpinning it, user controlled research tends to take the opposite approach. It highlights its values and relates good practice closely to them.

Another participant summed up some key points of good practice, with which others agreed:

*User controlled research should ensure that its structures are accessible. It should involve all (service users) that it can, within its remit and not just rely on a few informed individuals/organisations. It should be appropriately funded and participants paid for their time. It should establish an effective reference group with good terms of*

*reference and good facilitation and support. The people involved should be kept informed about progress and the results effectively disseminated. Questionnaire 7*

Interestingly, discussions around good practice in user controlled research focussed mainly on issues around the involvement of service users in the research. The kinds of issues such as bias, objectivity, distance, replicability and rigour, which are usually the focus of attention in discussions about good practice in conventional research, tended to come up in relation to the problems and barriers facing user controlled research.

A range of other key qualities were also highlighted in discussion about good practice in user controlled research. These included:

- Clarity
- Confidentiality
- Empowering information gathering
- Access
- Paying research participants
- Feedback and reporting
- Accountability
- Follow-up action

#### **a) Clarity**

Participants felt that it was essential for user controlled research to have clear aims and objectives and for these to be clearly communicated to the service users who take part in research. For example:

*The aim of the research needs to be at the top. It also needs to be explained properly and clearly. I recently did an interview for a project where it was not explained very clearly and the purpose did not seem clear.*

Disabled person, Discussion group A

*People need to be told the aims of the research - they need to know what the benefits will be. Sometimes the research is done and we never here any more about it (after being interviewed).*

Disabled person, Discussion group A

#### **b) Confidentiality**

Issues around confidentiality and anonymity are a key concern for users taking part in any form of research. This is no less true for user controlled than any other form of research – especially as service users may be more confiding with other service users, as they feel they can trust them. Many users are in a vulnerable position when giving feedback on services that they depend upon and about service providers who are in a position to exercise considerable

influence and power over their lives. It is seen as essential for user controlled research projects to be able to guarantee the confidentiality of service users.

*Things like consent and confidentiality are essential in research on service users. It deals with a lot of personal and private issues.*

Disabled person, Discussion group B

While this point about confidentiality is frequently made about research both by service users and others, some service users in these discussions, highlighted the complexity of the issue and that for some, choice may be what is important:

*There is an issue about trying to organise things too much, even as far as confidentiality goes. It's easy to say there's always got to be confidentiality but you might find users who want their names to be used and you cannot say that they can't because that goes against their wishes so any guidelines have to be very flexible and focused on the project being done.*

Disabled person, Discussion group B

*It's about the individual versus the collective. Collectively we have a need for confidentiality but there may be individuals who want their name given on an issue they are campaigning on.*

Disabled person, Discussion group B

This is an important point which relates to two commitments of user controlled research which service users emphasise. First that it is linked with change (see below) and second that it take account of participants' individual and collective rights and allow for choice. Thus in some cases, service users with whom control lies may opt for their names to be used. This should not however detract from recognition of general principles of good practice in user controlled and other research regarding confidentiality and anonymity

### **c) Empowering information gathering**

There was some consideration of how interviews and information gathering should be conducted in a user controlled project and how this may be different from research which is not user controlled.

One participant gave this view of good practice. While this issue may also apply to other forms of qualitative research and 'new paradigm' research, it is an issue which service users emphasise in the context of user controlled research. An accent was placed on *reciprocity*.

*It's got to be a two way process. It's not just about the researcher finding out things from the service user. It's a two way relation where both sides are giving information, not just one-way traffic. The researcher should not be like a doctor figure who never says a thing about themselves. Where it's appropriate they will relate to the person in a way that supports their equality with the participant.*

Users/survivor, Discussion group D

Another user researcher looked at how user controlled research involves a more flexible approach to information gathering than other more traditional research:

*Traditional research tends to have a very structured agenda, like, ABC kind of questions whereas I think in user controlled projects you want to use semi-structured interviews with open ended questions that allow people to say what is of concern to them, even if it is breaking away from the agenda. In a chapter that I wrote about doing disability research shows talks a lot about how this can be empowering. For example, when we need to get someone to talk about access to transport but on the day they have got a real bugbear with other issues, say access to employment or education, or they have had a bad experience with a doctor or something that they want to get off their chest, it allows you to take in factors other than what you have gone out there to find.*

Disabled person, Discussion group D

This prompted another participant to add:

*If you want to do proper user control research, you don't start out with an idea that this is what we are going to prove. You go out there with an open mind, and work with what comes up rather than have something that you are going to prove.*

Disabled person, Discussion group D

This service user also thought that interviewers should be doing something more in user controlled research:

*There is perhaps something around that the interviewer has to give something of themselves to the interview. About their experience, why they are involved in this research and who they are. So they are a human being rather than just this person with a clipboard ticking things off.*

Disabled person, Discussion group D

It could be argued that all these points may apply equally to other forms of research. In the context of user controlled research that they tended to be stressed as an expression of working towards more equal research relations.

This concern with being egalitarian and respectful in user controlled research took other expressions. For example, there was some discussion about the length of time given to interviews and user controlled research giving more time to participants.

*I was part of a (non-user controlled) review last year and it was half an hour with mental health service users in hospital. We were just given half an hour to get people to tell us about their experiences and then we had to move on to the next one. I felt most uncomfortable with that.*

Mental health service user/survivor, Discussion group D

One user researcher gave an example of the practice which his organisation employs when conducting interviews.

*When we go in to do interviews we warn participants in advance that this may bring up difficulties and we make sure people have someone to talk to afterwards. We also give people lots of information about services that they can use, so we aim to leave in a better state - better informed - than they were before the interview. This is really difficult for academics doing research, so I think there's a real issue about caring for the people involved and you can only really do that as a service user because you know what's involved. There's a kind of system of mutual counselling involved. Some people can be traumatised and exhausted by the interview.*

Mental health service user/survivor, Discussion group B

Another participant summed this up as meaning that:

*The process of an interview should be life-enhancing.*

Mental health service user/survivor, Discussion group B

(This is a point that we return to in more detail in the section on the benefits of user controlled research.)

There was also some discussion of other approaches for gathering information in user controlled research projects. Issues of access are raised and some service users highlighted the importance of using accessible forms of information gathering. One spoke about using arts:

*The thing about the research project we're doing is that we can do it ourselves and drive it ourselves and do it in a unique way. That means we can encourage artistic expression, we're going to get singers in and do drum workshops and do things that are maybe a bit more interesting to service users than doing a questionnaire.*

Mental health service user/survivor, group A

Another person highlighted the use of action research -

*I think that user controlled research should be participatory/action research as far as possible and therefore involve not just the user group or user researchers but all people to whom the research outcomes may affect.* Questionnaire 11

Given the small scale of this project, it has not looked in detail at issues around methods relating to user controlled research, although as this section demonstrates, these were sometimes raised by participants. There may be scope for further work to explore methods of research in relation to user controlled research more fully. In this way it may be possible to determine to

what extent it is developing its own research methods and modifying existing ones.

#### **d) Access**

One of the discussion groups explored the issue of access more generally. This included physical access to venues where the research is taking place and access in terms of practicalities like the timing of meetings. While these are issues that it would be expected that all research would take account of (although clearly in the experience of participating service users, this was not the case), there was a clear feeling among participants that this an inherent aspect of a user controlled approach to research. Service users pointed to a range of access issues that need to be addressed -

*Thinking about issues like people becoming fatigued, having assistance for a person with a physical (impairment) to fill in a questionnaire - dealing with confidentiality if they need a person to them help to fill in that form. There's lots of small points that need to be thought about.*  
Disabled person, Discussion group B

A similar point was made by a questionnaire respondent -

*Don't use jargon without explaining what it means. Meet sufficiently often so that no one misses what is going on. Make sure everyone understands why something is done and what the constraints are in the way of time and money. Don't promise what you cannot deliver. Allow time for questions.* Questionnaire 1

In one group, service users saw the prioritising of accessibility as a defining factor of user controlled research -

*That is the biggest difference - taking account of access issues. Other research projects will nominally talk about access but it often doesn't do it fully.*  
Disabled person, Discussion group D

#### **e) Paying research participants**

Payments for service users for taking part in research projects and other forms of user involvement have become widely recognised as good practice. Participants saw it as an essential element of user controlled research.

*Users need to know what's in it for them. The first point is that service users have got to be paid for their time because our time is valuable and we shouldn't be taken for granted.*  
Disabled person, Discussion group C

*One of the biggest issues is making sure that the service user feels appreciated and that means paying people and making sure people's expenses are paid.*

Mental health service user/survivor, Discussion group A

*I don't like to involve people in research unless I have been able to make at least a gesture, even if it is just a gift token kind of thing. You don't often get payments in traditional research.*

Disabled person, Discussion group D

*Payment is good practice because everyone deserves reimbursement for their time, it is also useful because many service users feel researched out and have little interest in further involvement unless there is some reimbursement and a commitment to feedback and broad dissemination and influence. Questionnaire 11*

Some service users are no longer talking just about payment, but also principles for a payment policy. These include rapid and appropriate payment; payment at equal and appropriate levels; and payment consistent with current benefits policy and practice, which does not put service users in receipt of benefits at any risk.

One irony that emerged is that while service user controlled research pioneered payment to research participants, its advocates are not always in a position to pay people as they want to. Because user controlled research frequently has particular difficulty in accessing funding, as we have seen, sometimes service users have to pay research participants less than they would wish to.

Some participants in the project took a different point of view about payment. Again the issue of choice for the individual service user was raised:

*I have issues around payments. When I came to this area I was told that users would not do anything without being paid. In principle I can see that is an important thing, a good thing. But there are groups of people who go to meetings because they get paid and for no other reason. Or they'll because there's lunch or it's somewhere warm to sit. So there are issues around this where people are making a career out of being a mental health user consultant but they're not really doing it for users. I think that there should be a choice between being paid and volunteering.*

Mental health service user/survivor, Discussion group B

Another service user expressed concern that service users may feel pressured to give more than they are able to give because of payments. Someone else said that they had had positive experiences of a system of not being paid for meetings but paid for work outside of meetings and that people benefited from the experience they gained at meetings, concluding -

*That's a positive message because it started off with a lot of voluntary work and not much funding, and now people have got employment.*  
Disabled person, Discussion group B

While the majority of service users are in favour of payment for participation, there seem to remain a significant proportion who are not. Clearly a consensus has not yet developed. It seems appropriate that projects should offer payment as part of their good practice, but this good practice must also recognise the need for flexibility to respond to individual choices on the subject.

#### **f) Feedback and reporting**

As discussed earlier in the section on principles and values of user controlled research, there was widespread agreement (if not unanimity) that service users should be involved at every stage of research. This extended to service users being kept properly in touch with and informed of developments. This issue was again raised in discussion of good practice and seemed to be seen as a crucial minimum for adhering to a definition of user controlled research.

*User controlled research should keep participants updated all the way through.* Mental health service user/survivor, Discussion group D

*It allows people to change their mind about things when they have thought about it. If it is taped or they can see what you've written from it.* Disabled person, Discussion group D

*Meaningful involvement of people includes providing feedback to those who help in the research.* Questionnaire 6

*(There should be) regular feedback reports – for example, leaflets, bulletins or meetings - and opportunities to comment on and question research. There be involvement in variety of capacities and this means users have ownership of subject/study.* Questionnaire 9

*(There needs to be) open communication throughout the process.* Questionnaire 11

*Information, information, information. Feedback, feedback, feedback... Many projects say they involve service users and carers but tend to only take the parts of the knowledge to share that they choose to share. Good practice would be to give feedback and to say what happens with the knowledge. Where knowledge is not going to be used reasons should be given.* Questionnaire 6

Service users saw feedback to participants extending to opportunities to read and comment on draft copies of reports. This process was seen as part of making a project accountable to participants.

One user researcher gave a positive example of their experience of providing feedback.

*In the research I am doing at the moment I have a research advisory group of users. We designed the project and we meet up every month*



*to discuss each step. When I finish writing each piece of the report, copies go back to the women who took part in the research and they give their comments. This is included in the research procedure and goes on all the way through the project. I honestly do think that is a very good practice, It is bouncing from the people being researched to the researcher, and the researcher is one of the people who are researched, so it goes around and around. It is complex but you get brilliant results.*

Alcohol service user, Discussion group D

However, one person raised questions about the boundaries and limits of providing feedback, saying:

*There's then an issue about how far does that go? Who's got the ultimate decision about what goes into a report? It's still the researcher's work.*

Disabled person, Discussion group B

But the view that it should be the researcher who decided was not a common one. One service user offered a useful model of how this process could be managed and so avoid this type of difficult situation.

*(There should be) a group of users leading the process meeting regularly to make decisions at each stage. This group to decide how to involve other users at each stage as appropriate.* Questionnaire 10

It was also suggested that it is important for user controlled research to record the process of a project, as well as its results.

*When we do research we should write up an account of the journey of doing that research so that we record the problems involved.*

Mental health service user/survivor, Discussion group A

## **g) Accountability**

Accountability and representation are key issues for the disabled people's and service user movements and it is also a key principle for user controlled organisations. Only by demonstrating democratic accountability can they address the frequent criticisms they encounter from outside that they are 'unrepresentative', without a mandate for their views and demands. More important only by doing so, can they ensure that they have justifiable credibility with service users more generally.

Ensuring accountability was similarly seen by service users as a key component of good practice in user controlled research. There were differing views about how accountability should be effectively extended to user controlled research. Some participants highlighted the importance of demonstrating accountability as a positive move that brings its own benefits to research. Thus, for example:

*Research should always be accountable in some way, depending on the project and the funding. Ultimately the accountability is to the aims and purpose of the research and ensuring that these are met.*

Questionnaire 4

*Accountability brings responsibility. If service users want to come together and offer their expertise then they need to accept accountability to the wider community. One way that we have done this on projects I have worked on is to put out draft findings and see whether they agree with them or have anything to add. This brings in a new perspective and makes you accountable - not to every service user but to the wider service user community. That's the sort of accountability I would like to see.*

Mental health service user/survivor, Discussion group B

*There is a huge responsibility. I successfully applied for funding for a project and when I started involving other service users through an advisory panel the idea was broadened out. This was good to start with but it became broader and broader to the point where the idea was almost lost.*

Mental health service user/survivor, group B

*Accountability often equates with users feeling more confident about participating in research because they know their organisation is accountable either to them or their representatives. Access needs etc are usually built in to process and time allowed. Expectations are that research will be of good standard and useful (where there is accountability). Questionnaire 9*

*Accountability to service users makes sure that they are represented accurately. It also helps to ensure that service users are kept informed and involved for the life of the project. It helps with sharing the outcomes and means that participants can find out what a difference their contribution has made. Questionnaire 6*

*Involving service users is essentially an accountability process in itself. For example, we ensure that there is a practical application to all research, we rarely conduct research unless the researcher sits on the board of all participant agencies and provides ongoing feedback during the course of the project. Questionnaire 11*

*It's about empowerment - by involving networks it becomes shared responsibility and accountability. Disabled person, Discussion group B*

A point again raised in this last discussion was that by having user controlled research directly connected with a service users' organisation helped to ensure accountability and support for the research. In one discussion group such accountability was seen as an essential element of user controlled research.

*It should be users all the way through. Not just users who are looking to improve their CVs, but accountable users. who want to change what people think with users as equal stakeholders.* Mental health service user/survivor, Discussion group D

*It boils down to democracy. It's about everybody having a voice and being able to make decisions... You need representatives who will take note of other people's views and try to represent them as well as they can.*

Older person, Discussion group D

Some service users talked about user controlled research needing to be democratically constituted itself and they saw it being located within such a democratic user controlled organisation as a key route to making this possible.

*User controlled research needs to be democratic.* Questionnaire 3

*It probably needs to be seated in some kind of organisation, ideally a user controlled organisation. It should not be with an NHS trust or a university as this can raise difficulties of different interests and power struggles.* Questionnaire 4

*Users who commissioned research should have mandate from a larger user constituency.* Questionnaire 10

In emancipatory disability research accountability has conventionally come to be understood in terms of accountability to user controlled organisations, specifically organisations of disabled people. This can become an institutionalised and bureaucratised process, but it was clear that the service users involved in the present project had a much more active and meaningful idea of such accountability.

As well as talking about the need for user controlled research to be accountable to service users, there was also discussion about accountability to other interests involved. While primary concerns were with accountability to service users, other responsibilities were also taken seriously. This was particularly true in relation to accountability to research funders or 'commissioners' because funding often involves public money. One questionnaire respondent made the point that accountability to funders is important to the credibility of user controlled research and will enhance relationships for future work.

The democratic and egalitarian principles of user controlled research also raised issues here. One participant raised the issue of people working on a research project being accountable to each other, as an expression of them being supportive of and showing understanding to each other. There was specific discussion in one discussion group about holding researchers accountable and how accountability applies to projects carried out by universities.

Some saw the involvement and support of a university as empowering to user researchers, but others had less straightforward or positive experience. This person, for example, who had worked in a university as a researcher expressed concerns about universities taking control:

*The parameters are set by the university, so the only way that I can make it as user-led as I can might be to refuse to do it if they won't accept what I want to do.*

Mental health service user/survivor, Discussion group A

#### **h) Follow-up action**

As we saw earlier, service users in the project saw a strong link between user controlled research and making change. This means that it tends automatically to be coupled with taking follow-up action. This is seen as part of the package. Thus user controlled research can be seen as a form of 'action research' or of research and development combined, where the goal of making change is built into the research approach, rather than something that is separate and may or may not follow.

*It should aim to improve the lives and experiences of service users.*

Mental health service user/survivor, Discussion group C

*It has to be for making things better for service users - otherwise, what's the point? That's different to other research, which will sometimes say that it is to do that and will aim to do that, but for this research it is the absolute major purpose.' Users/survivor, Discussion group D*

The guidelines for ethical user/survivor research prepared by Faulkner raised highlighted elements for good practice which were remarkably similar to those identified by service users in this project (Faulkner, 2004a).

## 4 The Findings: should the researcher be a service user?

### 4.1 From the literature

The question of who the researcher should be – service user or non-service user - emerges as a controversial and unresolved one in the literature relating to user controlled research. The debate begins in the context of disability research. Zarb (1997) noted the emergence of concerns that disabled people/service users would bring their own agendas to emancipatory disability research, but pointed out that this can be an issue which can be raised with any researcher. The role of non-disabled researchers in disability research was both defended and challenged (Branfield, 1998). Barnes (1997) wrote about what he called 'the myth of the independent researcher', calling into question the notion of a researcher who was neutral and non-partisan. He argued that this myth was started and has been perpetuated by the academic system and the career benefits which it offers academics who conduct research within it. The academic research system in turn has been reinforced by the way in which funding works, as most funders have adopted a medicalised individual model of disability. Barnes therefore believes that the supposed independence of university research is compromised. This view, however, has also been challenged (Bury 1997). Initial disagreements mainly seem to relate to different views held by non-disabled mainstream researchers and disabled researchers associated with the disabled people's movement and to their different views about the neutrality and political nature of research. Barnes (1997), for example, embodies a common position held by advocates of emancipatory disability research, that researchers should take an explicit position:

*There is no independent haven or middle ground when researching oppression: academics and researchers can only be with the oppressors or with the oppressed. (P242)*

Some disabled researchers also highlight the particular strengths of involving disabled people as researchers. Vernon, for example, (1997) observes:

*As a disabled Black woman myself doing research on other disabled Black women, I am, both 'inside' the culture and participating in that which I am observing. In other words, my research is as much about my own experiences as it is about others. (P158)*

She also makes the point that no research is ever completely free of bias and refers to the importance of 'reflexivity' - the examination of how the researcher's identity influences their work. She also goes on to look at how her position as a disabled person influences the way that she carries out research. When she interviews people Vernon also shares information about herself.

She describes how she has learned to share things that are similar and that this helps with interviews as it lets people know that she is happy to talk, which encourages the participant to talk. Vernon sees this reciprocity as an essential part of what she calls 'insider research.'

Evans and Fisher (1999) report similar experience from the Wiltshire and Swindon Users' Network, saying that members of the Network had become disenchanted with taking part in research until they started participating in projects with user researchers. This led to more satisfied participants and meant that the data they produced was more reliable.

Lloyd et al (1996), however, look at the idea of reciprocity and research being carried out by 'alike people' and suggest that there are limits to this idea. They see other issues coming into play; class, life experience and so on and suggest that the power difference between researcher and researched will remain anyway. They suggest that the ethical answer may be to acknowledge that the power difference exists and to work openly with this reality.

Beresford and Evans (1999) see key issues around the control of a research project relating to the researcher. They argue that control means that users have a say in the appointment of a researcher, or that the researcher is a service user. Evans and Fisher (1999), on the other hand, seem to place more emphasis on where the impetus for the research comes from, than on who actually acts as researcher.

While some commentators have seen it as important to have disabled people and service users as researchers in emancipatory and user controlled research, others have added cautions that not all disabled people and service users will necessarily be suited to work as researchers. Barnes (2001) notes that having an impairment does not automatically mean that someone has an affinity with other disabled people or that they are able to become researchers in this field.

There has also been discussion of the practical implications of disabled people working as researchers. Zarb (1997) describes the difficulties involved with engaging disabled researchers on a project and highlights the financial implications that supporting disabled researchers had for the project. While the organisation that carried out this project was willing to address these issues, they clearly have an impact on funding which can reduce the viability of a project in the competition for funding.

Another issue raised in relation to disabled people and service users becoming researchers is that they may merely become a new level of 'experts'. Finkelstein (1999) raised the issue:

*In practice disabled researchers, as well as the disabled individuals who have a controlling interest in a research project, may only become the new 'experts', 'professionals' or 'elite', replacing people with abilities who have traditionally been in this relationship to those being researched. (p861)*

Shakespeare (1997) endeavours to address the point about disabled researchers becoming a new level of experts by looking at his own situation as a disabled person and an academic. He says that he supports the disabled people's movement, but sees his role as a researcher meaning that he sits outside so that he can be critical and suggests:

*It is the right, indeed, possibly the duty of academics to take an independent line. (P250)*

Shakespeare aims to be accountable to research participants but not necessarily to disabled people's organisations and movement (in this he takes a different position to writers like Oliver and Barnes. While admiring emancipatory research he has reservations about it and suggests it may be overly optimistic in its focus on achieving change. He sees change as being achieved through politics and that academic activity contributes to the climate in which debates and discussions take place. This clearly contrasts with the assertion of other commentators that research is a political activity and Barnes' suggestion that there is no neutral ground that researchers can occupy.

#### **a) What service users say**

The interview schedule and questionnaire we developed for the project included the question, 'Do you think the people doing the research in user controlled research should be disabled people/service users?' We raised this question because it has often cropped up in informal discussions (as well as in published writings) about user controlled research among service users and user researchers.

This proved to be one of the questions which gained the most interest in group discussions. Two groups discussed it in great detail and there was a great variety of views on the issue. This discussion highlights some of the key differences of opinion on user controlled research among service users, so it is worth looking to this particular issue in some detail. It may have something to tell us more generally about user controlled research. It raises all kinds of different views, relating to philosophy, ethics, practicalities and politics. It is also likely to be helpful to consider why there are such differences of opinion among service users on this issue, when so many others seem largely to be agreed.

When people discussed this question, they included as researchers (without always distinguishing between them), the range of people who undertake research, from interviewers to research managers.

#### **b) Arguments for**

Many participants who had taken part in research projects as subjects saw great advantages in relating to service user rather than conventional/non service user researchers. For example:

*One of the great bonuses about having a service user involved (as researcher) is that they will have quite a good understanding of the (issues) themselves and have a greater degree of empathy, which many professionals do not have. They can just ask the questions in a piecemeal way, where we are informed by our experiences and know more about what to ask and that brings a tremendous amount of reality to a project.*

Mental health service user/survivor, Discussion group A

*I don't find it hard to talk but the fact that I was being questioned by people who were mental health service users certainly made it a lot easier than if it was somebody I knew nothing of.*

Mental health service user/survivor, Discussion group A

*I want somebody who I feel is going to be empathic, somebody who I feel will be respectful, somebody who I feel is going to be non-judgemental. I tend to think that those labels apply more to people who have had difficulties in their lives than those who haven't - but maybe that's me being judgemental!*

Mental health service user/survivor, Discussion group A

Two questionnaire respondents saw the involvement of user researchers as a fundamental aspect of user controlled research:

*It's hard to see how it can be 'controlled' by service users/disabled people unless they are actually carrying it out. Questionnaire 3*

*I think that non-service users can do good research - but it isn't user controlled if it isn't being 'user-led' in all parts of the research. Questionnaire 4*

One participant identified the advantages of relating to service user researchers by referring to their experiences with a non-service user researcher:

*I was being asked questions that could bring up difficult feelings by an able-bodied researcher who really didn't know very much about disability who didn't understand some of the issues involved in what they were looking at. With this sort of medical research there is an element of 'the reason why we're trying to find this out is that we can eradicate this impairment' which means you are going to eradicate people like me, so that people like me are not born, which brings up all sorts of philosophical and quite difficult ideas. I said this to the researcher and she had had no thoughts about such issues.*

Disabled person, Discussion group A

Service users highlighted the insights that being a service user researcher offered.



*We are closer to the issues and can have particular insight. Service users might find it easier to research/interview other service users and obtain different perspectives to other researchers. Questionnaire 5*

*Service users and carers have more of an idea of what it is like to use services. They understand issues such as the barriers presented by society and can relate to other service users appropriately. The motivation for change comes from people who will themselves benefit. Additionally, service users trust other service users and will be more inclined to share experiences without feeling that they are being judged. Questionnaire 6*

Service user researchers also point to the advantages that they believe they have over other researchers.

*Being a service user you have a greater understanding of that person's position. Because of your own experience you have a better understanding of where to ask in-depth questions and get more information out where other professionals might just skim over issues. There's been lots of research that shows that where users are the workers the results are better.*

Mental health service user/survivor, Discussion group A

*In my service user group the facilitator is a non-disabled person. They've gone out and done interviews and then other service users and myself have gone out and people have opened up far more to us knowing that we have a disability too. It does matter what disability - it doesn't have to be the same (impairment)/user group) - I've worked with people with learning difficulties and mental health users/survivors. It's been interesting because we've found that we have had similar experiences. It might also be about authority figures - you get a professional coming in and some people feel threatened by that. If you get a professional researcher coming in that can cause barriers straightaway, whereas with a service user I've found that in my experience that will bring the barriers down.*

Disabled person, Discussion group B

*If you've got people who aren't service users, then they have a three year learning curve before they're any use. If they've got shared, common experience, then communication is on a much higher level and much earlier.*

Disabled person, Discussion group C

*The researcher might possibly know something about the subject and therefore can empathise with the user and conduct the interview in a way that, if you are not involved, you wouldn't have if you hadn't actually experienced things yourself in some way. Mental health service user/survivor, Discussion group D*

Similar issues were raised about the benefits of employing interviewers with direct experience as service users:

*All of the women I...interviewed recently said the reason they came forward was because I was a recovered alcoholic myself and that they wouldn't have come forward otherwise. Alcohol service user, Discussion Group D*

*On one a project that I worked on, we let people know that the interviews are being done by service users. We then went along - in pairs - and when we got in the only thing we said about ourselves was that we had used mental health services - and then, quite often, there was an audible sigh of relief. And I think people do come up with things that they haven't even told their GP, like using illegal drugs.' Mental health service user/survivor, Discussion group D*

### **c) Arguments against**

However, there was not complete support for the idea that user controlled research and other research should be carried out by service user researchers. Other participants saw potential problems around user researchers. Issues of identity, representation, methodology and practicality were raised. For example:

*When I am doing my own research as a disabled researcher, I am aware that people are aware of me as wheelchair user. They may have the same condition as me and not be a wheelchair user - so they see me as further along the road than they are (in terms of the progress of the impairment) and that will affect our relationship. It varies between individuals - it depends on their reactions and my reactions - and you can't necessarily say that that will be positive. It depends on their attitude and the way they feel about themselves and the way that they feel about disability. Some people who have not been part of service user-led organisations, who don't know about the social model etc and are only used to working with professional people, might only see someone as a professional researcher if they are a non-disabled person and they would prefer to talk to them.*

This person went on to say -

*That's a very emotive issue. It used to be said that you can only do user controlled research if you are a user yourself. I used to agree with that but now I think it's totally wrong. I only know about my own situation, it doesn't make me a representative of any other category of service user. I think it's about attitude. If you've got the right fundamental attitude about empowering people to say what they want to say then it doesn't matter. It's down to attitude, not whether you are a disabled person. Disabled person, Discussion group B*

Other service users also expressed uncertainty about whether they would be more open with a service users researcher than they would be with a non-service user, but they clearly found it a difficult issue to deal with.

*It's an interesting question. My gut says yes but my head says this is setting up another 'us and them' situation again. But I certainly feel a degree of safety when I'm talking with another user that I don't have with someone who is not a service user because I question what their motivation is. That may or may not be valid but my comfort zone says it should be a service user while in my head I don't want the 'us and them'. I worry that by doing this I am labelling people as 'service users' and 'professionals' and I get a warning light that this is segregation and that I am making an assumption that everyone who is not a service users does not have the understanding.*

Mental health service user/survivor, Discussion group A

*In social research I am much more comfortable with researchers who identify themselves as having (an impairment). However, I have to say that I am getting a little cautious about these people becoming 'professionals' and that that's their job. I think I have a tendency to think that because they are disabled people and have had similar life experiences to me and I think I might say things to them that I would not say to an able-bodied person. I've never had a problem - nobody has ever broken a confidence - but I've recently had doubts about whether they really have the same experience as me or whether this is just another job to them. I worry that I will say things that I'll wish that I hadn't... But I would still rather be interviewed by a service users because I they would understand and I would feel that I could open-up more.*

Disabled person, Discussion group A

*Users might see the subject in a narrow way and could be too close to the subject to see matters objectively. Questionnaire 2*

*Initially would say yes. But... while disabled people should be centrally involved throughout research process, not always essential that they are conducting all areas of research themselves. If its user controlled then providing researchers are managed/advised by users, they steer the study focus and agree/comfortable with methods used and rationale, then a researcher working within social model and emancipatory framework should put their skills at the disposal of users. Questionnaire 9*

Another questionnaire respondent saw a practical problem.

*(There) may be issues of trust for some service user participants and may be issues of confidentiality for service users from the same 'community', geographical area or interest, as the researchers (may know them). Questionnaire 8*

In order to probe the issue, the facilitator of the first group discussion introduced a scenario of a user controlled research project employing a non-service user researcher. The second group came up with the same scenario themselves, while the other two exhausted the issue before there was opportunity to suggest this. The scenario prompted this discussion in the first group:

*I would be very suspicious - I'd wonder what their motives were and what their drivers were for doing that work.*

Mental health service user/survivor, Discussion group A

*I'd question the organisation even if I trusted them. I accept that researchers should be paid - whether they are a service user or not - but I feel that there would be tokenism if their motivation is their employment by the organisation. I would want to question the organisation and find out why they weren't able to employ service user or support someone from within the organisation to do the research. In that scenario I would definitely question it.*

Disabled person, Discussion group A

*I question why men want to be gynaecologists and I think of it like that. We all have our own drivers - and just because we're users doesn't mean that we don't have unhealthy drivers too.*

Mental health service user/survivor, Discussion group A

One person commented that they would be pragmatic on this. If there was a good project that might lead to tangible change, they would take part with a non-service user researcher. In the second group, one of the participants who came up with the same scenario, put the question of what would happen if a worker in this position had their own agenda. This led to the following discussion:

*That is the issue - who's driving it, where is it coming from. If you can't be open and honest about that then the research is nonsense anyway.*

Disabled person, Discussion group B

*But is there any need for non-users? There are so many able people to do this. A lot of us are able to do research so why bring in other researchers?*

Mental health service user/survivor, Discussion group B

*There is certainly that argument, if somebody is qualified then do it but I don't think it's a necessity.*

Mental health service user/survivor, Discussion group B

*In an ideal world it should be the best person to do the job. Historically, unfortunately, it's been the case that it's been tokenistic. My view is that the best research is done in partnership with support from the health and social care professionals, so you have partnership between (non-disabled) people and disabled people and you get the different interest*

*groups buying in to the research... but in the short-term we have to shout for user-led research and try and redress the balance of what's been done in the past.*

Disabled person, Discussion group B

Others in the group remained pragmatic about the issue -

*I don't want to get bogged down in who does the research. My fundamental principle that I think you must adhere to is that the person doing the research - whether they are disabled or not - is to be totally independent. I see research being done into services - best value reviews, user satisfaction surveys - that are being conducted by people who have a vested interest in that service.*

Mental health service user/survivor, Discussion group B

People in other groups and questionnaire respondents were similarly pragmatic. While for some people user researchers were clearly the ideal, they tried to take account of current realities, while pointing out safeguards.

*It should be an ideal to have a service user but if those people simply aren't there, then if you have the right person with the right temperament and the right attributes and skills but is not a service user they shouldn't be disbarred on the basis of not being a service user.*

Mental health service user/survivor, Discussion group C

*If they are not a service user or carer then it is important that they are responsible to a panel who are representative.*

Mental health service user/survivor, Discussion group C

*The researcher does not necessarily have to be a service user. It may be the case that service users need advice/support/input of a skilled researcher. I'd prefer to see this to service users struggling and facing unnecessary difficulties that might jeopardise the project.* Questionnaire 5

*Ideally user controlled research should encourage the use of disabled researchers. However, in practice there may be capacity issues.* Questionnaire 7

*It is probably best if researchers are (service users), however, control of the work as described above is more important than carrying out the work. Sometimes it may be useful to be able to draft in people who are not (service users).* Questionnaire 8

*Many researchers are not capable of working under our control, but are few are and then it can work.* Questionnaire 10

*I don't think that it always matters who actually conducts research but in cases where interviewers without direct experience are being employed*

In one sense it can be argued that service users' discussion about who should be the researcher were inconclusive. Certainly there wasn't agreement. Perhaps a reasonable conclusion to draw from this discussion is that with the crucial caveat that the research is fully under service users' control, user controlled research does not have to be carried out by service user researchers. However, in most cases, it is probably better if it is, so long as there is an awareness that may be some limitations attached to this. It could be argued that some of the arguments against having service users' as the researcher were minor, inconsistent and perhaps temporary, as a wider pool of skilled and experienced service user researchers emerges. However the point is that this is what a diverse range of service users/service user researchers think now and this needs to be recognised and respected.

One service user put the issue of the relationship between researcher and interviewee into a wider context -

*You also have to question issues of gender, ethnicity, age... there are just so many variables.*

Disabled person, Discussion group B

This is a key point. As the participant said, there are so many bases to cover that it might be impossible to cover all of them. At the same time, the defining issue of user controlled research and service user involvement in research is people's identity as service users, so this has a particular centrality. Further discussion of the wider issue of difference in relation to user controlled research is likely to be helpful.

The project raises an additional point in relation to this. There have long been concerns that black people and minority ethnic groups face inequalities and exclusions in mainstream research. We were interested to find out more about this in this project. While a significant minority of participants in this project were black and from minority ethnic groups, there was not much mention of issues of ethnicity and 'race' equality. This is an omission which definitely needs to be addressed in future work.

# 5 The Findings: the benefits of user controlled research

## 5.1 From the literature

At the heart of service user conceptions of user controlled research (as of emancipatory disability research) is the aspiration to bring about change. While this stress on change-making is particularly associated with such research, it would be wrong to assume that other research has not also been committed to it. After all mainstream applied research including clinical disability and psychiatric research have also frequently prioritised the making of change. What distinguishes user controlled research is that the change is sought which reflects and embodies the kind of change desired *by service users*. As mental health service users have indicated, the multi-national pharmaceutical companies which have played a lead role in shaping psychiatric research globally have been interested in bringing about change, but change primarily related to *their commercial* interests. Thus user controlled research is identified with:

- a strong commitment to and capacity to make change in line with what service users want;
- supporting more equal research relationships;
- making involvement in research a more positive experience for participants;
- developing new issues of importance to service users.

The importance of the last of these should not be overlooked. Emancipatory disability research, for example, played an important part in making the case for the development of direct payments policy and practice, which has offered a new way for disabled people to secure appropriate support to live their lives on more equal terms with non-disabled people (Zarb, 1997; Zarb and Nadash, 1994; Hasler et al, 1998). The work of disabled researchers like Morris and Barnes has been identified as providing a basis for the introduction of anti-discrimination legislation (Barnes and Mercer, 1997).

There has been some specific discussion of the benefits of emancipatory disability research in the literature which is also relevant to user controlled research. Oliver (1997), for example, has asserted that as researcher, he is the main beneficiary of his work. Vernon (1997) similarly recognises the personal benefits of her work as a researcher, but also stresses that her emancipatory approach means benefits for the participants in terms of the research providing a starting point for empowerment and supporting people to have a voice and a say in their lives. However, she does also recognise that despite her efforts and good practice (detailed below), the power relationship remained essentially the same.

Barnes (2001) directly questions Oliver's point about researchers being the main beneficiaries of research, suggesting that being a researcher is no longer such a financially or socially secure position.

In discussions about user controlled research, its practitioners highlight that it can offer, ethical, practical, philosophical and methodological advantages over other research approaches (Vernon, 1997; Lindow, 1999; OpenMind 2002; Beresford, 2003; Faulkner, 2004a). They also see user controlled research as able to offer the views and experience of service users with the least likelihood of distortion and inaccuracy, because of the understanding that comes from shared experience (Beresford 2003; Rose, 2001 and 2003; UFM Network, 2003).

## 5.2 What service users say

Service users referred to some of the benefits that they associated with user controlled research when they talked about its definition, values, principles and good practice. They also referred to benefits in general discussion of user controlled research. As one member of our electronic steering group put it:

*It has identified new theories, new paradigms and new ideas which give explanation for our lives' experiences.*

But we also asked participants specifically what if any benefits they felt user controlled research had to offer. This question both highlighted fresh issues as well as confirming the importance that service users attached to some benefits to which they had already referred. User controlled research seemed to be seen as having more benefits than traditional research approaches.

### a) The capacity to be useful

Service users again placed an emphasis on the *usefulness* of user controlled research as one of its key benefits. It is more likely to address issues of relevance to service users because it follows from them and their concerns. Therefore it is more likely to be of use. The control and involvement which service users have are also seen as inherent benefits in their own right. It is concerned with change and is more capable of achieving change. For example:

*It provides the real experience of those using the service.  
Disabled person, Discussion group B*

*Good research means that it comes from service users. The project I worked on with women with learning difficulties came from them - they asked for the research, they wanted to know about health information, they were saying that when they go to the GP there isn't any information that they can access. It all came from them. So in a way you have to take a step back even from the first stage if there's going to be*



*true user involvement and research that we want that's going to make a difference in our lives and is going to be implemented at the end of it.*  
Disabled person, Discussion group A

*User-led research can enable intervention to become effective and economically efficient. I did a study of wheelchair users and interviewed 143 consumers. Every single one of them said that there were bits of their lives that they could do if they had the right wheelchair but nobody ever asked them what they wanted to do, so they never had the right wheelchair. So they couldn't get all round their homes, they couldn't get to work, they couldn't do their gardens, they couldn't look after their kids, they couldn't do their shopping. They'd been given wheelchairs that fitted the medical criteria and clinical judgement but nobody actually asked the consumer what they wanted to do and where they wanted to go. You can't give somebody a proper wheelchair without knowing these things, you've got to get all these details from the user. It's exactly the same in every other area of health and social care. If you don't find out what priorities an individual has but chose for clinical, medical or service priorities, then you are missing the target. The money is there to help the user but if the service provider decides that it is not going to listen to the user and their priorities and follow the service's priorities instead, then they are missing the target and wasting their ammunition.*

Disabled person, Discussion group C

*When I worked as a midwife we were doing some research on the effects of aspirin on blood pressure for the pregnant women and they were involved in every stage of the work so they were happy to take part. As a result there was a big breakthrough.*

Disabled person, Group discussion A

*If the questions have been set by someone who has been in the situation, they are totally different from questions that have been put forward by any other group because we have had the experience.*

Mental health service user/survivor, Discussion group B

*You are more likely to come up with what people need and want. You are more likely to ask the right questions.*

Older person, Discussion group D

*It has more relevant questions and an increased sense of involvement for participants.* Questionnaire 4

*(It produces) more reliable evidence about experience of service use and more especially whether it supports the quality of life to which people aspire. (It is a) more reliable process of collecting users' views.*  
Questionnaire 10

*Because it is nearly always participatory or action research it is direct experience rather than external values or management constructs that drive the process.*

Questionnaire 11

These benefits can apply across fields. Two participants pointed to potential benefits of user controlled research and user involvement in research in relation to clinical as well as social care research:

*I was involved in a clinical research project. It was looking at foliate levels in blood, which is related to my impairment, and they were taking blood samples from people with this impairment and from their parents. I got talking to the researcher and she had got very interested in other issues like relationships between disabled people and their siblings and there was so much more that they could have done with that research if they had had users involved, even with it being clinical. So there are some really positive benefits from involving service users.*

Disabled person Discussion group A

## **b) Developing new issues**

Another mental service user/survivor highlighted how user controlled research had already opened up new areas for development. She said: 'You get a fresh perspective' (Discussion group C) and pointed to the whole field of alternative approaches, including spirituality and spiritual healing, in which user controlled research has encouraged new interest and developments. Participants pointed to how the NHS has been adopting alternative and complementary approaches to health in the light of the evidence provided by service users.

Some service users suggested that they thought user involvement in research could offer its own helpful insights.. But they saw user controlled research going beyond this and offering more:

*User controlled research is working from the inside and going out whereas most research is people looking at something from the outside and going in, so the perspective is very different in user-led research because it starts from the inside.*

Mental health service user/survivor, Discussion group A

*What we can offer with our real life research is opportunities to improve services, opportunities to improve products and systems and make them inclusive and more profitable and more effective. Set this against academic interest. Academic interest means you can write papers on something for conferences but it doesn't necessarily have any feedback into real life.*

Disabled person, Discussion group C

*Indications are that the research is far more accurate and inclusive if carried out by people who have used services themselves... It also has*

*the credibility of coming from experienced people who know what they are talking about.* Questionnaire 6

*The outcomes are more likely to influence services and it empowers those involved and enables knowledge and new skills to be developed. (It produces) 'expert knowledge' as users know and live with issues often under discussion, so the results are not just a theoretical/academic debate or hypotheses.* Questionnaire 9

*(It is) better informed if done well; more relevant to the reality of living as a disabled person; more likely to challenge established perceptions and inform social change.* Questionnaire 7

### **c) More inclusive**

This respondent also believed that user controlled projects have a more inclusive approach to research. Another participant saw the benefit in terms of research being a form of collective advocacy. Other service users backed this up.

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

Mental health service user/survivor, Discussion group B

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

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

### **d) Personal benefits**

People were keen to point out that the benefits should not just be seen in terms of improved research. Several participants made the point that user controlled research was a positive experience for participants – as all research should be.

*A lot of user controlled research has a struggle to make things better for people's lives. But it can have a particular benefit in that it is a much more positive experience for people to be involved in, It's a positive experience for people to have other service users with skills doing it with them on the basis that they have a sense that (the researcher) will*

*have a belief in what they say and understand them.* Mental health service user/survivor, Discussion group D

*Being involved with projects can give people self-confidence. Giving people an opportunity to be properly involved is a very positive experience.*

Disabled person, Discussion group A

*Attending meetings can be a therapeutic experience... Research controlled by users can be profoundly healing.'* Mental health service user/survivor, Discussion group A

*It empathises with interviewees and liberation and confidence is increased.* Questionnaire 1

*It is empowering for participants and researchers.* Questionnaire 8

Service users not only see empowerment as a principle of user controlled research, they see it as one of its benefits. While for some participants such benefits are one of the gains of user controlled research, for others they are absolutely central so they see it as preferable.

*I think that that should be an aim of research that the research process should be built in such a way that it allows people to be reflective.*

Disabled person, Discussion group B

*I think that the very process of the research has got to be not only enjoyable, but it has got in itself some how be empowering, for want of a better word. So that when people come together and discuss things they feel better about themselves in some way.*

Disabled person, Discussion group D

One person made the point that participating in research can raise difficult issues for service users and that user controlled research addresses this properly.

*User controlled research is mindful of the subject matter and, for example, if you are doing research with disabled women who have experienced domestic violence then it is mindful of the fact that it may raise some very painful issues and it will have a list of support of mechanisms and organisations and other help that they can give to the person. It also informs the participant about the outcomes so that participants have a summary and a contact number for the researcher so people can get in touch. So it is not just going in for a quick half an hour, getting people to tell you about their experience and then saying good-bye.* Disabled person, Discussion group D

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

be helpful to relate this to research itself. Clearly if research is liberatory in intent, then its process needs to be empowering. Not only did some service users make clear this connection, but they see user controlled research as having a particular capacity to deliver it.

# **6 The Findings: the barriers facing user controlled research**

## **6.1 From the literature**

The rapidly expanding literature on emancipatory and user controlled research is a reflection of the progress that these new research approaches are making. But a frequent theme within this literature are the barriers such research still faces. Its 'newness' may be one reason for the barriers which such research encounters. The literature, however, identifies a wider range of obstacles.

Most common among these is the continued dominance of medicalised and clinical research – particularly in the fields of disability and mental health research (Oliver, 1996; Barnes, 1998 and 2003; Barton and Oliver, 1997; Beresford and Wallcraft, 1997). The Mental Health Foundation makes this point noting that most mental health research is still clinical and that mental health service user research is given very little value. In its view this means that both the broader social relations of mental health and non-medicalised responses like complementary therapies have not been given equal attention in research.

This medical dominance, in turn, has encouraged the maintenance of a traditional positivist approach to research, based on the valuing of criteria of 'neutrality', 'objectivity' and 'distance'. This has been associated with an emphasis on quantitative research approaches, particularly randomised controlled trials (RCTs), which have come to be seen as the 'gold standard' of research. Emancipatory and user controlled research approaches, with their explicit acknowledgement of subjectivity and bias and their frequent reliance on qualitative research methods tend not to be strongly valued in this context. There are clear tensions between the two research traditions (Barnes and Mercer, 1997; Faulkner and Thomas, 2002; OpenMind 2002; Beresford 2003).

Problems of accessing funding are frequently reported by service user researchers. This is frequently raised in the literature (Beresford and Wallcraft, 1997; Lindow, 2001; Barnes, 2003). It is also a common subject of discussion at gatherings of service user researchers, like for example, those of the Survivor Researcher Network established by the Strategies for Living project at the Mental Health Foundation. At the first workshop convened by INVOLVE (formerly Consumers in NHS Research), bringing together social care service users, the tiny proportion of funding allocated to emancipatory disability research and user controlled research, was one of the key issues identified.

Oliver (1997) reflects this view, seeing funding as a very difficult issue for emancipatory research, arguing that most funders have a limited understanding of the issue. Fisher (2002) quotes an examples of service users being extensively involved in a project but then being excluded from the writing

because it was thought that they would not be able to write in a way that would be acceptable to funders. Fisher (2002) suggests that unequal access to funding is a problem that will always be a restriction on user-controlled research. Beresford (2003) makes a call for more funding for user-controlled research, making the point that there just has not been enough user-controlled research so far to be able to evaluate it and that there is need for a programme of user-controlled research in order to explore its, 'strengths, weaknesses and disadvantages'.

Some of the key proponents of user controlled research have argued the importance of service user and mainstream researchers and research organisations working together. Faulkner and Thomas (2002) suggest that it is essential for the two groups to work together and for user controlled research to be given equal value. They also stress the importance of government placing greater value on such partnership work. However there seem to be suspicions and anxieties preventing this on both sides of the fence. Gibbs (1999) notes that attempts to bring disabled people and researchers together in the mid-1990s were frustrated as researchers believed it would mean further interference in their work, and that they already had too much of this from the government.

The arguments of user controlled research, however, have not always been welcomed by academic researchers. Bury (1997), for example, rejects Barnes' criticism of the university research system and his critique of the independence of academic researchers. He sees the main issue as research needing to be done well, without any restriction on what can be examined so that arguments and counter arguments can be developed. He believes that universities provide one of the few places that researchers can be properly independent in this sense. While he argues for academic freedom, service user researchers highlight the restrictions imposed on them and user controlled research. Lindow (2001) comments on how difficult it can be to place articles about user-controlled projects in academic journals. Barnes (2003) highlights the ways in which existing structures and priorities of research (including the university 'research assessment exercise (RAE)'), are weighted towards publication in peer review academic journals and place little value on publication in something like a user group newsletter.

It is also clear that there are still significant attitudinal barriers in the way of user controlled research. The scale of these barriers is evident in Walter et al's current review of improving the use of research in social care practice (2004). This includes a table which sets out different interest groups' roles in relation to research. The only roles identified for service users are taking part in research and then having input into the development of guidelines once research is completed.

Faulkner and Thomas (2002) go as far as to suggest that there is political resistance to service users being involved in research and helping to set the agenda for research. They argue that user-controlled research has developed from frustration with this situation within mainstream research. They also see

the inequalities facing user controlled research as constituting a form of discrimination.

## 6.2 What service users say

Asked initially whether they saw problems and barriers for user controlled research there was unanimous agreement among participants that such obstacles exist.

### a) Mainstream devaluing of user controlled research

In informal discussions among service users, as well as with mainstream researchers, user researchers frequently convey their strong sense that they face discrimination in research. This was strongly confirmed in the project. One of the key barriers in this project that service users identified in the way of user controlled research was the negative way in which they feel it is perceived and treated within mainstream research and research structures. The feeling is that they face routine discrimination.

*Service users are devalued and what they know is devalued.*  
Mental health service user/survivor, Discussion group D

*If it's user-led it does stand a better chance of achieving something. But when the research is finished and put into whatever body it's going to, there is a tendency for professionals to say, 'it's only done by users, what do they know?'*  
Mental health service user/survivor, Discussion group A

*There is no tradition of user controlled research. It is not considered of professional standard.* Questionnaire 1

*I was at a conference where a professor set out what he saw as the five levels of acceptable research. The first level was double blind, randomised control trials -that was 'absolutely spiffing' research. At the bottom was looking into the minds of skilled professionals. Consumers just weren't there at all.*  
Disabled person, Discussion group C

*When you start to work with non-disabled researchers on projects there is such a communication job that needs to be done. I was at a meeting about user involvement in health research and I suggested as well as having representation at all stages of projects there should be specific user controlled research and they questioned whether that is possible. They were interested and open to the idea - but the idea that you could actually have research that is controlled by users was a completely foreign one, it just wasn't (seen as) the proper way of doing things.*  
Disabled person, Discussion group C



*It has less credibility in wider fields with academics and the NHS - it doesn't meet their gold standard and therefore has less impact.*

Questionnaire 4

*There are not enough disabled people who have been able to develop the appropriate qualifications and skills to compete for research, so sometimes there is a perception within the research community of such research being crap... (There is) the arrogance of research organisations, institutionalised disablism and a lack of trust in our abilities. (Some may have) experience of some bad user controlled research.* Questionnaire 7

*(It is to do with) tradition and the professionalisation of existing research institutions.* Questionnaire 8

*I think that there is discrimination regarding the authenticity and status of the research on occasion. Also, as service users rarely have status in planning processes their research often needs a professional champion... And there are rarely negative consequences for service providers if they ignore it.'* Questionnaire 11

Others agreed but saw some hope. They thought that user controlled research was not always devalued. They did not see opposition to it as monolithic.

*It depends who's doing the valuing.*

Disabled person, Discussion group B

*I don't think Margaret Thatcher would find it very useful but a university might find it interesting. They might be a bit patronising but I think they would be open to the idea.*

Mental health service user/survivor, Discussion group A

*It probably has been less valued in the past, though my impression from my limited experience is that this is probably changing.*

Questionnaire 2

*It's valued differently because it is a specific research methodology.*

Questionnaire 5

One expression of the devaluing of user controlled research that people talked about was the frequent difficulty experienced in getting it published. This became a focus for discussion in one group. The difficulty of getting results of user controlled projects published acts as an additional barrier to its acceptance.

## **b) Just a temporary success?**

Some people see the situation for user controlled research and user involvement in general, as relatively good at present, but they are worried that

this may not always be the case and conveyed their sense of insecurity for user controlled research.

*Sometimes it's fashionable to ask certain groups their views.*  
Mental health service user/survivor, Discussion group A

*There are different agendas but it's often hard to say exactly what's happening... how the valuing process works.'*  
Disabled person Discussion group A

*It's a political question. Value is led by culture, society and policies. At the moment service user involvement is very popular and highly valued.*  
Disabled person, Discussion group B

*It's valued by people with the right attitude, whether they're a service user or a service provider. If they have the right attitude and they want to put the user first they will value user surveys.'*  
Mental health service user/survivor, Discussion group B

People with learning difficulties appear to experience particular prejudices about the worth and value of their work, as this person said:

*I've done a lot of research and it's good that we do the research. A lot of psychiatrists and professionals say we can't do good research because we're stupid but it's important for us to do this research and find things out for ourselves. We know more about our lives, we know what's best for us.*  
Person with learning difficulties, Discussion group A

### **c) The assumption of bias**

One of the reasons service users report for user controlled research being valued less than other forms of research and seen as inferior to other research, is because it is seen as representing a narrow range of views and, at worst, as biased. Participants discussed the issue of bias and most believed that to counter this, there is a particular need for projects to demonstrate rigour.

*We would assume that it's got to be as good as any other research. People sometimes think we're saying sloppier research but we're not.*  
Mental health service user /survivor, Discussion group D

*It has to be well supervised. It has to be good quality. The supervisors on the project I worked on were all service users and that was tremendously good. They were able to support people to become very good researchers.*  
Mental health service user/survivor, Discussion group B

*For it to be respected it's got to be a bit more than anecdotal for it to be taken seriously, with qualitative and quantitative information as*

*appropriate. You've got to play the game of presenting your research in a professional manner. If it's just a collection of anecdotes it's not going to get you anywhere.*

Mental health service user/survivor, Discussion group C

*It's got to be done so that it is scientifically validated, otherwise you're just shooting yourself in the foot.*

Mental health service user/survivor, Discussion group B

*It must be credible to funders and professionals even though it has different viewpoints and methods.* Questionnaire 1

One questionnaire respondent highlighted some potential difficulties of research coming from the perspective of the disabled people's movement, but still felt it had something special to offer.

*A commitment to the disability movement and the social model (of disability) can cause tensions and sometimes 'restrict' researcher's views or influence what is finally published – there can be conflicting issues between being 'objective' and being on side of the oppressed. Also, from experience, service users sometimes have difficulty keeping personal agendas/emotions separate from research questions and can be sceptical about purpose which in turn can affect not only how research carried out, but also knowledge outcomes. However, I believe the benefits far outweigh any disadvantages.* Questionnaire 9

One questionnaire respondent (Questionnaire 5) seemed to accept the dominant view that the 'subjectivity' of service users' research was a potential limitation. They also referred to the need to ensure adequate training for service user researchers and the need for rigour to make sure that user controlled research addresses the interests of *all* service users.

However, other participants felt that more is made of the potential for bias in service user research than it is in relation to other researchers. They saw this as a bias in itself. The point that all research can be seen to be subject to bias was made by several people:

*They always come across as objective, but I have often read articles and research as a black person that is so prejudiced and that is so biased.*

Mental health service user, Discussion group D

*A lot of research represents the interests of only one group, for example, psychiatrists or pharmaceutical companies. This needs to be openly acknowledged.* Questionnaire 3

Some people felt that what is presented as the 'bias' in user controlled research is something to be valued and not shied away from:

*We have the advantage of involvement rather than the disadvantage of bias.* Mental health service user/survivor, Discussion group B

*I don't think this (being seen as representing service users) is a problem. If people are researching services that are meant for them, their interests should be paramount.* Questionnaire 4

*It may be viewed as biased or one sided, but then service provision has been one-sided for far too long. Diversity is good. It provokes thought, action and change.* Questionnaire 6

*(There is bias) and quite right too, other interests have been served for too long.* Questionnaire 8

*Increasingly this is also being recognised as its strength. As long as the methodology is sound and the number of participants appropriate for the enquiry it is difficult to criticise it for this reason.* Questionnaire 11

*It has to be partisan for users and expose users' situations, needs, problems, barriers. It's in everybody's interests that users' views are brought out because that will help us get into the mainstream. But research must not be partisan for service providers, as so much research is secretly partisan for providers.*  
Disabled person, Discussion group C

This person went on to challenge the kind of interpretation often placed on user controlled research by conventional research and researchers.

*Frankly, I think 'anecdotal' evidence is fine because what anecdotal means is that people who know what things are like are basically saying what things are like. I am less and less prepared to dance the ritual dance of 'proper research'.* Disabled person, Discussion group C

This service user went on to give an example of research on access relating to spiral staircases, where only experimental data was regarded as valid. Yet people with visual impairments have regularly made it known that they have difficulty using them. This was not accepted as valid.

*I asked them whether they have to prove the obvious and they said 'yes'. I am about to have a row with them about this. I'm going to say that where the experimental research exists, that's lovely, but don't cut out direct user experience. That's got to be valid too.*  
Disabled person, Discussion group C

Service users were not saying that there aren't research issues which user controlled research may still have to address. But they did distinguished this from the ready tendency there still seems to be to reject it on the basis of assumed 'bias', because it is open about its values and philosophy.

#### **d) 'Sectional interests' and research**

The matter of bias relates to another concern that has been raised by some critics of user controlled research. This is that its explicit relationship with service users may undermine its credibility as a valid research approach. Thus one of the issues we were asked to examine in this project was the 'role of "sectional interests" in influencing research practice'.

Service users addressed this issue in various parts of their interviews and discussions and it is also explored in the literature associated with user controlled research. Service users mostly come to discuss it because the 'problem' of sectional interests in research has been raised specifically in relation to *their* research, rather than traditional or mainstream research more generally. As can be seen in this report, they offer a range of responses to this criticism, which has tended to come from mainstream research based on positivist values of 'neutrality', 'objectivity' and 'distance'. These responses include that:

- User controlled research itself represents a response and challenge to the sectionalism of traditional research. Service users have frequently felt that such research failed to address their perspectives and interests or treat them with equality. Because of this they developed their own research methodology;
- Other research has itself reflected sectional interests, being influenced, for example, by the professional interests of researchers; the interests of higher education and academics; of the service system and policy makers and of medical, rehabilitation and pharmaceutical industries, to the disadvantage of service users;
- User controlled research has been honest and transparent about its particular allegiance and political relations, while traditional research has tended to be framed more in neutral technicist terms, as 'neutral', 'scientific' and 'objective'. Service users, however, argue that it is also partial, in its priorities, focus and process;
- While user controlled research can be particularly sensitive to the concerns and issues of service users, this does not prevent it from being a rigorous and systematic research approach.

#### **e) Ensuring inclusion and diversity**

The issue of inclusiveness in user controlled research was raised by service users. Some participants pointed out that user controlled research can fall foul of criticisms that are levelled at user involvement more generally, in terms of not reaching and including a diverse range of service users. Service users emphasise the importance of diversity in relation to user controlled research, the obstacles there can be in the way of it and the need to avoid false claims of being 'representative'.

*There are service users who tend to be quite vocal but then they get tagged with the term 'professional service user' and they are seen as middle class people who do not represent all service users. That can sometimes undo the work that service users are trying to do.*

Mental health service user/survivor, Discussion group A

*I'm aware that many of the people who I was in hospital with weren't able to articulate their needs at all. We need to be really, really careful that it's not just a few articulate people who find it acceptable to be in a group whose voice gets heard. I think that we're in danger as well as everybody else of forgetting that. We're all here because we are able to be here, but there are many who are not able to get to events like this and it's a responsibility on us to funnel their voices as well.*

Mental health service user/survivor, Discussion group A

*You can be looking across large numbers and there are smaller groups within those groups and there is a danger that everybody with a physical (impairment) will be grouped under one umbrella and told that's the service on offer for that group with no choice offered because a big research project came up with the answer that this is what physically disabled people want. Disabled people may have been involved in the work but those people are only coming from their own experiences and they don't speak for everybody. There is this difficulty of representativeness.*

Disabled person, Discussion group B

Some service users reflected on how this issue relates specifically to research.

*Like any research there will always be people who are outside the study either because they choose to be or, as often happens with service users, outreach and access for example, has not been done, so people are excluded. Studies show that people from minority(ethnic) communities and people with learning difficulties tend to be absent from much research unless it is specifically aimed at them. Furthermore, users do not always have sufficient skills (are rarely empowered/given training in research thus maintaining status quo and mystique of research) or, more significantly, the resources to conduct major empirical or other studies, which would encompass wider groups.*

Questionnaire 9

*Service users are as diverse a group as any in society, philosophies range from anti-psychiatry and the social model to embracing the traditional medical model and valuing pharmacology. Any project is likely to point in one direction or another or even perhaps try to steer a more central course which will satisfy even fewer people.*

Questionnaire 11

*There can be a drawback in terms of generalising from subjective results. We have to see research at its right level and should not use results from one situation on a generalised basis to address another.*  
Disabled person, Discussion group B

Other participants agreed with this point but added that this was more likely to be a problem with research carried out by inexperienced service users and that carried out by service providers, rather than an inherent feature of user controlled research. One person suggested that most research has indicated the need for individualised services and a questionnaire respondent made the point that research itself is a way to explore the interests of different types of service users. A user researcher offered this example of good practice in reaching 'new' service users in a research project:

*I advertised in the local papers and on the radio and so on, and I think I accessed a load of different people and I went to their homes whenever they wanted me to as well. I think that changed the nature of the information that came back completely.*  
Alcohol service user, Discussion group D

A questionnaire respondent pointed out:

*Appropriately commissioned and designed research should have an integrity which is about the outcomes of the research itself and not the views of one particular interest group.* Questionnaire 7

But broader barriers were also identified which apply to user controlled research no less than other research.

*Everyone is a unique individual. Even two people with identical impairments will react differently to given situations. However, the collective view is more powerful when collated from individual views of life and service provision. It is unrealistic to expect to be able to represent everyone. The majority do carry some power but research benefits minority groups if it is also taken on board that there are differences.* Questionnaire 6

There was also recognition that user controlled research might face difficulties in including all perspectives.

*The perspectives of policy makers and providers can be ignored because users are unaware of them, so sometimes this dimension is missing.* Questionnaire 10

Working through service users' organisations, user controlled research can involve a wide range of service users, with different skills and experience:

*...Otherwise there's the danger that they will just go for the tame ones - the sandwich brigade who are happy with a taxi to the university, a nice cup of tea and some sandwiches, and then they'll answer researchers'*

*questions for a couple of hours.(There) it's just about getting the numbers in.*

Mental health service user/survivor, Discussion group D

One service user spoke about how difficult it can be to get new users involved and the impact this can have on active users

*It's difficult to challenge the unwillingness of some users to get involved while your own energies are so depleted. It's one of the drawbacks of research that if you don't see any good coming out of it I get tired and jaded and wonder whether you are really making any difference. I go into a project very open hearted and open minded to embrace everything but nine times out of ten it just ends up in a report on a bookshelf. It's soul destroying engaging that energy, it's heartbreaking.*

Mental health service user/survivor, Discussion group A

People felt that while these issues are crucially important, it is wrong to spend so much time on trying to be 'representative' that nothing ever gets done. In terms of research, one participant said:

*Stuff representative - authentic is what we have to go for.*

Disabled person, Discussion group C

This discussion led to several people saying:

*We cannot be democratic until we have proper funding.*

*(It is) conditional on users having sufficient resources, skills and commitment to reach the most marginalised users, for example, those without speech. Questionnaire 10*

## **f) Funding inequalities**

This leads directly to the issue of funding for user controlled research. There was strong agreement among participants in the project that user controlled research faces big problems securing funding. There is not felt to be a level playing field as far as the funding of user controlled research is concerned. People described the situation in the following ways:

*It has to be adequately resourced... you get academics being paid thousands to go and do papers that don't actually change anything.*

Disabled person, Discussion group B

*If we're looking for funding there is nothing with our name on it.*

Disabled person, Discussion group C

*User controlled research needs to be well resourced and it's very difficult for us to get that.'*

Mental health service user/survivor, Discussion group D



*Funding for research is determined by the agenda of central government, or the pharmaceutical industry or professionals, so it is more difficult for user controlled projects to get funding. Questionnaire 3*

*It does seem that funding is difficult to secure for service user organisations in comparison to universities and councils... It feels as though we have to prove ourselves twice as much because we do not all have degrees, but we are experts by experience. Questionnaire 6*

*(There is a) lack of confidence that disabled people have skills, competence and complete to timescale and a general bias based on low expectations/attitudes towards disabled people influences funders etc. Big academic institutions and 'names' are prime recipients of funding. Questionnaire 9*

*Service user groups are not always championed by organisations with experience in bidding and are not always seen as being viable organisations unless they partner with others, who may then be pulling the strings. Questionnaire 11*

Only one participant in the project said that they had not experienced difficulties with funding. In one group discussion, a support worker for two participants with learning difficulties outlined the difficulties they had faced getting funding to do their own research. The group worked out the project as they went along, but the funders wanted everything mapped out before it started, setting out exactly what was going to happen. They were not ready to do this, so they couldn't get funding. A disabled person who had worked with a group of women with learning difficulties described a similar experience.

*We weren't at the point where we could clearly map everything out. We wanted to do the research because the information wasn't there and they were saying they wanted to know things that we couldn't know because we hadn't done the research. That was really hard and in the end we didn't get the funding.*

Disabled person, Discussion group A

People also made it clear that user controlled projects incurred additional costs (see below). Some service users saw the funding situation becoming more, not less difficult.

In one trust area, service users had been involved in making funding decisions. This could have helped improve access for user controlled research, but other barriers had been left unchanged.

*In my area there is a mental health service user research forum that has been set up by the mental health trust because I think they have to have user involvement. So we look at all of the research applications that come to the trust. In theory we could also apply for those grants ourselves but in practice you have to have an academic partner and they say it has to be either qualitative or quantitative research and you*

*can't have something which crosses the two, which is daft. So there are people with good will.*

Mental health service user/survivor, Discussion group B

Lack of funding generated other barriers, for example, leaving needs unmet:

*Service users, carers and professionals aren't yet in a position to carry out user controlled research to best effect because professionals need training in the best ways to work with service users and carers, and service users and carers often need training in participating effectively and empowerment skills.*

Mental health service user/survivor, Discussion group C

#### **g) Different agendas**

Service users are a large and diverse group. The more that people work to be inclusive and address difference – one of the potential strengths of user controlled research - the more that issues can emerge relating to the different aims, agendas and cultures of different groups. Individuals and groups may be at different stages in their development and understanding. Understanding of your own issues, does not guarantee understanding of someone else's.

*There can be difficulties when different groups have vested interests. For example, people with physical (impairments) and people with learning difficulties and mental health users/survivors can have different interests at times. Even within physical disability there can be a definite hierarchy with the white male with a spinal injury at the top. We don't say but it is there and we can end up sending different messages from the different interest groups.*

Disabled person, Discussion group A

*It can be difficult when people in groups disagree.*

Person with learning difficulties, Discussion group A

*You do get discrimination that occurs amongst disabled people.*

HIV/AIDS service user, Discussion group C

*There is a limit to the services which can be provided. One group of users must not be allowed to hijack the best. Questionnaire 1*

*I have noticed a case in my own area where there is a particular group of service users in alcohol treatment who believe in a particular approach and but they believe their method is the only method. If they were they allowed to take control of a research processes it would be a complete disaster. I am not suggesting that is always the case but we have to be aware... I suppose what I am saying, fascism occurs in many places and we are not immune.*

Alcohol service user, Discussion group D

In one discussion, this brought out a particular concern that:

*We all come in with our own agendas. We can end up exploiting each other in the same way that professionals exploit us.*

Mental health service user/survivor, Discussion group A

#### **h) Problems for service user researchers**

An important barrier identified by service users was the difficulties raised for service user researchers undertaking research which could have a personal impact on them. There were numerous comments about this.

*We have vulnerabilities. I'm going to run a research project in a hospital and that's going to test my mental health so that's going to be difficult. My limitations may have an impact.*

Mental health service user/survivor, Discussion group A

*I think there's a real problem with user-led and user-involved research. When you are a service user yourself you can be too close to it and it can cause you lots of stress and difficulty without realising it. So user-involved research may be more effective the work is being done by somebody who is totally outside of the issues involved but being led by people who are on the inside who take the accountability. I'm not saying one way is right and the other is wrong but these are alternatives and how they are used must depend on the type of research being done and the strengths of the people involved.*

Disabled person, Discussion group B

*When I was conducting the interviews it was fine. I had no problems. However, when I came to transcribe them I could only do it for half an hour at a time and then I had to ring someone up and do something completely different. There is an impact if you are doing something around issues that have happened to you - you need extra support for yourself as well.*

Alcohol service user, Discussion group B

*I did research with people living in residential homes, and it was the most depressing thing. I couldn't do more than two interviews a day at the most.*

Disabled person, Discussion group D

*We are in groups/teams where people get ill and dealing with deadlines can create pressures.* Questionnaire 4

During one discussion of this issue, a person with learning difficulties noted that in the team of user researchers that they had worked with, 'some people were a bit sad' because of the issues that they had to deal with. A similar point was made in another discussion:

*Working on a research project can bring up lots of issues for yourself. Doing something where your heart and soul are in it can be quite a strain. One person I knew who was working on a user-led project did attempt to commit suicide, so there an ethical dimension about involving service users and what toll it takes. This is really important - a major issue.*

Mental health service user/survivor, Discussion group B

*When you're a service user having research done on you they come in and you have your interview then they go away and you forget about them. But when you're doing the work the pressures of your individual needs makes it hard and it can really affect your health.* Disabled person, Discussion group B

One user/researcher highlighted the need to ensure that service user researchers received good terms and conditions for their work:

*It's also about respect for the user researcher. A lot of researchers get very badly treated and I think that one of the issue for user controlled research is that, since the researcher is likely to be a service user, it's got to respect their needs, not overburden them, treat them properly and pay them properly. I don't think we talk about that enough.*

Mental health service user/survivor, Discussion group D

One participant made the point that non-service user researchers may also have to deal with personal effects raised by the issues that they are researching. It is important to respect this point, but we can expect that there are likely to be particular issues for service users because of shared experience and in some cases (as service users said) because they are more likely to experience difficult times. While as one participant said:

*If you seriously believe you are doing right, although it is stressful and you do get sleepless nights, it doesn't lead to depression.*

Mental health service user/survivor, Discussion group B

This emerged as an important issue in user controlled research, which clearly highlights a duty of care for service user researchers. There is a need for individual choice for user researchers and the provision of appropriate support:

*It's important that a level of support is built in to make sure that people are not damaged by doing that research.*

Mental health service user/survivor, Discussion group B

Some suggestions were offered for how this could be provided. One (questionnaire 5) was to use a pool of researchers who would be able to dip in and out of a project according to their skills and interests. This would also give flexibility in terms of people's health and ability to carry out work. Regular support meetings were also found to be helpful. One user researcher described how the service users on the advisory panel of a project they had worked on had become a good source of support.

This raises the issue of the cost of ensuring such support. This clearly places an additional financial requirement on user controlled research (which should equally be ensured in all research), which as we have already seen, faces particular financial barriers.

This issue, however, raises another important one. One of the most controversial issues which emerged in this project related to who should carry out user controlled research – service user or non-service user researchers. One of the reasons why some participants felt it need not be a service user was because of concerns about the negative effects such research might have on service users. Thus while many service users think it is important in user controlled research for the researcher to be a service user, in practice this may be difficult or have negative consequences. This difficulty highlights the importance of exploring and developing support arrangements for user researchers to minimise such problems.

One barrier facing service user researchers was raised particularly in relation to researchers with learning difficulties. However it can also apply to other groups of service user researchers. This is the barrier of conventional qualifications being required for service users to be appointed to research posts or even to be seen as eligible for more advanced training. Research posts and opportunities may require candidates to have degrees and even higher degrees, even though these may have little relevance to the work required. Service user researchers may not have such qualifications, but nonetheless have the relevant skills and experience to be able to undertake the research work capably and successfully. People with learning difficulties face particular barriers in relation to mainstream educational opportunities, so this can be seen as an issue that can have a disproportionate impact upon them.

#### **i) Skills and training**

Service users see the lack of adequate and appropriate training as a barrier in the way of the development and acceptance of user controlled research. Issues around the need for further skill development came up in various contexts in the course of group discussions as well as in questionnaire responses. The shortage of suitable good quality training is still restricting the supply of potential user researchers, while familiarity with and experience of user controlled research among mainstream researchers, research organisations and funders is delaying the acceptance and extension of user controlled research. There are unmet needs for education and training among all participants: service users, service user researchers, non-service user researchers and research related organisations.

There was a long discussion about training in one group. The group felt that there is a shortage of service users with the skills needed to do user controlled research. This point was also made by one of the questionnaire respondents.

*Resources need to be identified for training user interviewers, and developing user reference groups, this can also take time that other forms of research may not be limited to. Questionnaire 11*

There was a general recognition of the importance of training and learning if service users were to take forward their own research successfully:

*Induction is very useful for people who want to get involved in the research process so that they can fully understand it and make a full contribution.*

Mental health service user/survivor, Discussion group C

This comment was made in relation to service users, but when questioned, the service user suggested that the best way forward would be joint inductions for service users and other researchers together.

*That way service users can be learning from the professionals about the research process, and at the same professionals can be learning from the service users about how they would like to be enabled to engage properly. The idea of this must be to enable self-empowerment and to promote cohesive working - it is not to promote compliance. When you actually understand the research process and what happens you are better able to challenge it and ask questions.*

Mental health service user/survivor, Discussion group C

This individual was thinking about how best to do this within their own institution. Concerns were expressed about how this process might be hijacked by professionals, but there was equal recognition of the value of such training:

*We always need to be cynical and questioning of where the professionals are coming from, but also to try and appreciate when they are being genuine.*

Mental health service user/survivor, Discussion group C

One user researcher, however felt that issues could be made over complicated and pointed to the experience he had on one project -

*It doesn't take long to get a service user up to speed with doing the data collection... I trained interviewers for a project I worked on in one day and it worked incredibly well.*

Disabled person, Discussion group C

A respondent to the questionnaire described a positive experience of receiving training:

*I was fortunate to be able to attend a part-time course entitled 'Research Methods', which included involvement in a live research project. This made me aware of the value of some training and it built up my confidence. Questionnaire 2*

Service users indicated that if user controlled research is to develop effectively, then service users will need suitable research training (particularly from service user researchers) to take it forward.

# 7 The future

## What service users say

In the discussion about the barriers facing user controlled research, one service user said:

*There's far too little of it and far too little recognition of it and we face far too many vested interests.*

Disabled person, Discussion group C

When service users talked about the future for user controlled research, one expressed optimism:

*The future is good as there is more emphasis on service user involvement generally in health services.* Questionnaire 4

But many more highlighted a range of fears they have for user controlled research's future.

*There is a move towards user research but it's hard to say how strong it is.*

Disabled person, Discussion group A

*My fear is that it's a trendy thing of the moment and that it's going to just fade away and in a couple of years they'll be saying it's not the done thing any more.*

HIV/AIDS service user, Discussion group C

*The future will be a struggle.* Questionnaire 3

*I see empty promises and tokenism.* Questionnaire 5

*It will be a continuing struggle.* Questionnaire 7

*Continued struggle!* Questionnaire 10

Yet respondents were unanimous in thinking that user controlled research has a particular contribution to make to policy development. Some service users framed their comments in terms of their hopes for the future.

*I hope that it will become the norm, a regular normal thing to do.*

Mental health service user/survivor, Discussion group C

*I would like to see user research used more effectively because academics do a lot of research and it just ends up on the shelf. I'd like to see research used and shared - for it to become the driver behind service delivery.*



Mental health service user/survivor, Discussion group A

*I'd like to see the research go further to give people ideas in the future.*  
Person with learning difficulties, Discussion group A

*When service providers are looking at issues it should be taken for granted that there is some user controlled research going on, not just the provider research. It needs to be part of the thinking, an automatic thing that is there.*

Mental health service user/survivor, Discussion group C

*It should become part of the whole spectrum of research, policy and service delivery.* Questionnaire 1

*We need high quality user controlled research to give credibility and a collaborative approach by service users. Training is also important - there needs to be training for enthusiastic and interested service users and a training pack should be available.* Questionnaire 5

*The Department of Health and others seem to be sitting up and listening to service users and involving people at a higher level. I support this work and hope that service user and carer involvement in research goes from strength to strength to improve services.*  
Questionnaire 6

*I think that this is a good time as there are many central government policies and infrastructure groups such as PPI (Public, Patient Involvement) Forums who could support it. The rhetoric is finally moving toward patient choice and valuing direct experience. All trusts also have to have a PPI strategy so the environment exists for users to demand more research activities that may benefit them.* Questionnaire 11

One group of service users particularly highlighted the role that the internet can play in relation to user controlled research, making it easier and cheaper to share information. Many participants saw the need for both user controlled research and user involvement in research more generally:

*There should not be an 'us and them' in user controlled research, whether its between different groups of service users or between service users and professionals. We all do it but it should be at the forefront of our awareness so that we do it.*

Mental health service user/survivor, Discussion group A

Others highlighted the importance of user controlled research developing links:

*(We need) partnerships with academic agencies.* Questionnaire 9

However, service users still feel that user controlled research is currently at a disadvantage in relation to other forms of research. There need to be structural and attitudinal changes for this situation to alter:

*There needs to be a shift in the balance of power.*

Mental health service user/survivor, Discussion group B

*We should be included in their research programmes but also, we should have our budgets for our research as well, and they should be included in our research too. It should be a two-way process. If we never get a budget of our own we will never be able to persuade them to give up their money so that we can do our own thing.'* Disabled person, Discussion group C

*Packaging needs revisiting. If service users are to be seen as credible within research they need to be presenting as expert consultants on service user participation rather than just being seen as 'service users'.* Questionnaire 6

*(There needs to be) more, better, wider scale, and mainstreaming.* Questionnaire 8

*If user controlled research were to become part of the establishment, I would really see that as a positive because it's making it an acceptable, daily, normal thing to happen rather than it being something that happens as a special occasion.*

Mental health service user/survivor, Discussion group C

When asked whether becoming part of the establishment might compromise user controlled research, the reply was:

*If by becoming part of the establishment, it changes (it) and slants it towards us, then that wouldn't be a problem.*

Mental health service user/survivor, Discussion group C

One service user expressed concerns about what they saw as the growing incorporation of user controlled research -

*(As it becomes) increasingly valued, we have to make sure that it is localised when appropriate and that it does not become governed by national charities who are not managed by users.* Questionnaire 10

This point seemed to reflect concerns that some of the largest 'user controlled' research projects so far, have been based in non-user controlled voluntary organisations. This was not an issue that was specifically developed by participants in this study beyond this comment. However many service users when defining user controlled research earlier did attach importance to it being based in or linked with user controlled organisations. Where user controlled research is based may be an issue that needs further consideration in the future.

## Actions for the future

Service users identified four areas of activity for taking user controlled research forward. These are:

- Improving the relationship with research funders
- National coordination of user controlled research
- Strengthening the position of user controlled research
- Linking user controlled research with user involvement generally

### Improving the relationship with research funders

Service users talked about developing links, understanding and involvement with research funders. Several participants identified key issues around the relationship between user controlled research and funders.

*Ultimately more disabled people need to be involved in the commissioning level and within major institutions at senior levels. (There needs to be) more engagement and dialogue with the research community. Getting understanding of what user controlled research is and developing effective strategies to promote the social model is important. Questionnaire 7*

*(There needs to be) more dedicated funding and education for commissioners to enable more user controlled work to be funded. There should also be showcasing projects that have led to more satisfied service users, projects that have led to good value for money outcomes. Questionnaire 8*

*(We need) disabled people to sit on funding bodies and research councils and an expectation that any project requesting funding has number of disabled researchers in team or makes links to user groups. There needs to be monitoring of the influence users have on each funded project. Funders should allow part of budget to be used for user research, as the Joseph Rowntree Foundation has done. Questionnaire 9*

*(We need) lobbying of main research funders to get them to understand its credibility. More theorising like Peter Beresford's book\* which redefines value of our experience. INVOLVE needs to push user controlled research more in NHS research and development funding. (We need to) publicise the few examples there are of user controlled research. Questionnaire 10*

### National coordination of user controlled research

Service users and their organisations involved in and undertaking user controlled research tend to be overstretched and under-resourced. Sometimes they are relatively isolated. Service users highlighted the need to encourage

networking, to maximise limited resources and to increase the impact of user controlled research.

There are already some steps in this direction, like the Survivor Researcher Network established by Strategies for living and now supported by SURGE (Service User Research Group England), but there is as yet no more concerted developments, across user groups and specifically concerned with user controlled research.

*In the past students have come to service user groups and said they have needed to do this piece of research, done their bit of research, then saying thank you very much and going away with no end result. It would be useful to have a national pool that research could be fed into and then disseminated to different organisations would be a positive way forward.* Disabled person, Discussion group B

*For user research to become really valued - and not just tokenistic - then you have got to take on board all of the issues that we've been talking about here. There has to be action at the end of projects. Success stories need to be disseminated and used to provide benchmarks.* Disabled person, Discussion group B

*There need to be national and local networks of researchers.* Questionnaire 5

*(We need to) have our own loose association of user controlled research project directors to network and be a collective voice.* Questionnaire 10

## **Strengthening the position of user controlled research**

One group suggested that there should be a campaign to raise the profile of user controlled research and to highlight its importance. This related to a call for the development of tactics and materials to guide and reinforce user controlled research. People didn't seem only to be thinking about guidance about what it is and how to do it, but also how to support its effective development. For example:

*We need to develop a survival kit with strategies for how we can make ourselves indispensable to the providers. We can't afford to keep re-inventing the wheel all the time, if something works lets all do it.* Disabled person, Discussion group C

## Linking user controlled research with user involvement generally

There were also calls to see user controlled research in a broader context. Some service users thought it was important to make the connection between it and more participatory approaches to policy and practice more generally.

*Look at the Consumers Association model. That's changed the whole way that products are made and people's attitude. Even if you've never read an issue of Which? you've still got ideas about your rights as a consumer and consumer power. If state services were run on this sort of model, using user-led research, we'd be living in another world.*

Mental health service user/survivor, Discussion group B

The person who made the comment at the start of the section had a clear vision of the future of user controlled research -

*I see a 20 to 30 year development process and to do this we have got to win hearts and minds. We've got show them that we're presenting an integral and indispensable part of reality that is going to empower them by giving them a clearer view of their targets. We've got to change their attitudes and our own and build up our networks of influence so that we can make a proper contribution to research from the commissioning right the way through to delivery and implementation. We also have to get users into all the research learning settings as learners and as educators and teachers. It takes a long time to get a new approach recognised so we need to demonstrate why they need us.*

Disabled person, Discussion group C

Others had similar views of the future – While barriers might remain this was seen as an important route to take.

*I believe it is key to chip away at this problem. It is unrealistic to completely remove barriers as everyone is different and face different barriers at different times. This is not predictable and has to be worked on as and when. Only by educating professionals will we begin to chip away.* Questionnaire 6

## 8 Conclusions and recommendations

Taken together, existing literature and service users' accounts present a detailed and lively picture of user controlled research as an enterprise with its own values, principles and vision of good practice. It emerges as a carefully thought through and innovative research approach with its own body of knowledge and cannon of research work. Given how recent a development user controlled research is, there is a remarkable coherence in how it is now reported. It becomes clear just how much has been done and how much progress has been made. But what also emerges is the strong sense of the vulnerability of user controlled research felt by most service users. Both these points are strongly evident in the literature review and the direct input from service users.

Both the literature and the service users we spoke with, highlighted the coherence of the idea of 'user controlled research' and the strong support for it that exists among service users and service user researchers. However, this study also highlighted that strong distinctions are drawn by service users between user controlled research and service user involvement in research. A few service users use the two terms interchangeably as if they are synonymous, but this is not the general viewpoint. Widespread and major concerns are raised about user involvement in research; its tendency to tokenise service users and its limitations in practice. It is important to highlight this, since as yet most attention has been placed on user involvement on research and most resources allocated to it. There is a strong sense in both the literature and among many service users that user controlled research is disadvantaged. It is this concern which perhaps explains why so many service users seem to feel very positive and optimistic about the achievements so far of user controlled research, while at the same time worried and uncertain about its present and future.

Not everything is agreed about user controlled research, however. There is no consensus, for example, over whether the researchers in user controlled research should be service users; or how accountability is to be demonstrated – is it to service user organisations, to a wider constituency of service users or to particular values and principles? But this is not because these issues have not been considered. Rather because so far there seem to be different views. Similarly while people talk and write about user controlled research and seem to have a notion (with much agreement between them) about what it is, there are overlaps with related research approaches like emancipatory disability research and survivor research, with no clear and agreed lines drawn yet to distinguish them. Significant problems and barriers in the way of user controlled research are also highlighted.

The development of initiatives like Strategies for Living at the Mental Health Foundation and User Focused Monitoring at the Sainsbury Centre are signs

both of the progress and uncertainty in this field, since both have since been wound up. However, the success of the Service User Research Enterprise (SURE) based at the Institute of Psychiatry, undertaking user controlled and collaborative research and more recently, the establishment of SURGE (Service Users Research Group for England) to support user involvement and user controlled research in the new Mental Health Research Network set up by government, also offer grounds for hope.

One additional word of caution from the findings of this project may be necessary. Both the literature review and the service users who took part in this project prioritised *making change* as a key purpose of user controlled research. But this should not be taken to imply that research which is unable to achieve such change is therefore not user controlled research. It is the aim which is important. The achievement of change, of course is by no means always possible. A related discussion has taken place in the context of emancipatory disability research, where commentators have highlighted that often projects may not succeed in their emancipatory goals. The key issue is their realistic commitment to such goals.

One of the peer reviewers of this report raised another related issue, saying:

Why is it so important to distinguish between user controlled research and user involved research? Cannot user involved research also be emancipatory?

Clearly service users see feel it is important to draw this distinction. In our view too, there is no reason why user involved research cannot have emancipatory potential. But the literature review and the service users we spoke to generally seem to suggest that user involvement alone often may not be able to achieve this. They highlight issues of power inequality and tokenism which may have an important bearing on this. But these issues should not be taken to mean that user involvement in research cannot sometimes be emancipatory in its effect. Service users seem to take the view though that this is much more likely to be forthcoming with user controlled research.

This project not only provides its own findings. It also raises important questions. One of the peer reviewers who commented on our draft report, helpfully identified some of these:

- How can collaborative research between service provider organisations/universities (as proposed by Faulkner and Thomas (2002), be supported and conducted in an emancipatory fashion?
- Who should do user controlled research? How can academics and professionals who are also service users be most effective in this?
- How to provide training in research for service users that a) provides high level skills and b) does not detract from/dilute their expertise born of experience as a (service) user?

These are important and helpful questions. They can also be seen as just the tip of an iceberg demanding more resources and more work for the future.

This report describes the findings from a small-scale project and can perhaps most helpfully be seen as a first step in taking forward debate about user controlled research, both among service users and their organisations and amongst the wider research community and research funders.



# Recommendations

The findings from this project have implications for all the key stakeholders involved in research and the development of new approaches to research, including user controlled research. This includes research organisations and mainstream researchers, funders, commissioners, service users, user organisations, user researchers and those involved in research governance and ethics procedures. An effective strategy for supporting the development of user controlled research will need to address all of these.

## Sharing knowledge about user controlled research

- There is still considerable misunderstanding and misapprehension about user controlled research. Existing knowledge about user controlled research, including the findings from this project, needs to be widely disseminated to service users, mainstream researchers and research organisations, members of ethics committees and to research funders;
- Additional guidance on both the principles of and good practice for user controlled research needs to be produced to enable it to develop on equal terms with other research approaches. The findings from this project offer additional material to be used in future guidance and training resources;
- It is important to develop *accessible* materials about user controlled research. From undertaking the literature review it became apparent that some of the writings on this subject can be as difficult to understand as literature on traditional research. If user controlled research is to engage a wide range of service users and be widely developed by service user organisations, then information about it needs to be produced that is accessible as possible;
- Information and guidance need to be developed, particularly for research funders on how to support user researchers and user controlled research as part of their overall funding strategy and responsibilities;

## Recognising the resource implications of user controlled research

- User controlled research has particular resource implications. Ensuring equal access, enabling diverse involvement and supporting service users to carry out their own research on equal terms, all have resource implications. User controlled research, for these reasons tends to take longer and gives rise to additional costs. Both of these issues need to be recognised by research funders and research organisations;

## **Training to support user controlled research**

- More training (particularly user led training) about user controlled research needs to be developed for all key stakeholders, including mainstream researchers, service users, research organisations and research funders;
- There is no agreement among service users over whether researchers in user controlled research should themselves be service users. There are different philosophical viewpoints about this. But service users also highlight practical obstacles restricting the availability of suitably skilled user researchers. These need to be addressed;
- More training opportunities are needed for service user researchers, including further opportunities for research training. Unnecessary requirements to possess formal academic qualifications which can act as a barrier excluding service users with appropriate skills and experience, particularly service users with learning difficulties, should not be used to debar them from research employment opportunities. At the same time there need to be more opportunities for service users who wish to, to undertake undergraduate and postgraduate research training and PhDs with funding provided. Such training opportunities should be monitored;

## **Including black and minority communities**

- This project has unfortunately not provided much information about user controlled research in relation to black and minority ethnic communities. Further exploration of user controlled research from the perspective of black and minority ethnic service users is needed so that appropriate support can be offered to take forward this aspect of user controlled research;

## **Safeguarding the future of user controlled research**

- Service users feel very insecure about the future of user controlled research. Practical steps need to be taken to challenge this sense of insecurity and to safeguard user controlled research for the future and to make sure that it has the potential to make its full contribution;
- Both statutory and non-statutory research funders increasingly require evidence of user involvement from research projects seeking funding. In addition, the allocation of research funding should be monitored to record the scale and proportion allocated to user controlled research and emerging trends. In relative terms this proportion remains tiny and a key proposal of the first social care service user workshop convened by INVOLVE was that it should be increased significantly;

- More funding should be made available to support larger user controlled research projects, including ones employing quantitative, comparative and longitudinal studies;
- A significant proportion of what is identified as user controlled research is currently being undertaken by non user controlled organisations. This is particularly true of large research projects. This development needs to be monitored. More support is needed for user controlled research to be undertaken on equal terms by user controlled as well as other organisations;
- A coherent programme of evaluation of user controlled research projects needs to be established in order to maximise its contribution;
- Variations of research methods and methodology are already developing as a result of the introduction of user controlled research. These should be explored and collated in order to disseminate the learning they are providing.

# List of Source Material

This list below includes all the material which we have drawn upon in undertaking the literature review for this report, as well as a wider range of relevant material. Not all of these sources have been cited as references, but all are likely to be relevant to understanding of user controlled research.

In order to make this resource as useful as possible, we have organized it in two ways. First there are lists grouped according to some key categories relating to the subject of this report:

- User involvement and control
- Disabled people's and service user movements
- Social models and approaches
- Related research and user involvement in research
- (Emancipatory) disability research
- Survivor research
- User controlled research (general)
- Examples of user controlled research

Second we have provided an overall list of all material included in the categories in alphabetical order. We should make it clear that these categories need to be seen as flexible, rather than separate water tight compartments. Second, this is an initial resource list. It is not intended and could not hope to be complete or definitive, given the nature of this project. We hope it will provide a helpful starting point for readers.

There are some other points to bear in mind when using this material. We are concerned with service users understandings of user controlled research. It is difficult to draw a hard and fast line between research, evaluation and other forms of inquiry based on service users' knowledge and experience. We have tried to be inclusive, especially given the fact that as yet there are not yet clear and agreed definitions of user controlled research, or indeed some of the related research approaches. Some people might have included or excluded other material. Again as we have indicated, this is meant to be a basis for further discussion and development. We have tried to include material that sets the context for user controlled research; related research approaches that can help in understanding its origins and purpose and discussions of the theory and practice of user controlled organization.

## Helpful organisations

Joseph Rowntree Foundation  
Centre for Disability Studies, Leeds University  
Service User Research Enterprise (SURE), Institute of Psychiatry  
National Centre for Independent Living/British Council of Disabled People  
Research Committee

## INVOLVE

Shaping Our Lives

Mental Health Media

Action Research Centre For Inclusion, Bolton Institute

Centre for Citizen Participation, Brunel University

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# Appendix 1

## Participants in the Project

### Discussion groups

Four discussion groups were held to gain service users views about user controlled research. These discussion groups were held in Leeds, Birmingham (2) and London.

A total of 20 service users took part in the four focus groups. They included:

- 5 people with physical impairments
- 3 people with learning difficulties
- 11 mental health service users/survivors
- 1 user of HIV/AIDS services

Four participants were Black and from minority ethnic communities. Thirteen of the participants were people with experience of working on user-controlled research projects. The remainder were service users with an interest in research issues, some of whom had been participants in non-user controlled research projects.

### Questionnaire responses

There were 11 responses to the questionnaire. It was distributed widely through the Shaping Our Lives database and in response to enquiries about the project. All 11 respondents were white. All were people with experience of working on research projects. Of the 11 people who completed questionnaire:

- 4 were people with physical impairments
- 4 were mental health service users/survivors
- 1 was a mental health service users/survivor with a physical impairment.
- 2 were older people.

In practice, the focus group meetings and individual questionnaire took up virtually all of the time allocated to the project and this meant that it was not possible to complete all the tasks originally identified.

The project proposal identified 11 service user researchers with particular experience and expertise in user controlled research. It was only possible to make contact with five of these, although follow-up requests were made. This may reflect the heavy demands made on the time and limited resources of service users and their organisations. One completed a questionnaire; two replied saying that they were no longer involved in this type of work; one replied that were going submit information but did not; one did not reply.

14 organisations with relevant experience in the field of user controlled research were also identified in the proposal to be followed up. While it was not possible to undertake formal interviews with these as was hoped because of our limited time and resources, information was gained from six of them through the affiliations of the project's team and through individuals associated with them completing individual questionnaires and acting as members of the electronic advisory group .

# Appendix 2

## Project Questionnaire

### User Controlled Research – what is it and how is it to be done?

#### About the project

This questionnaire is for a nine-month project being carried out in the UK jointly by Shaping Our Lives and Folk Us with funding from INVOLVE.

The focus of the project is user controlled research.

We want disabled people and service users with an interest in this subject to have the chance to develop ideas about what user controlled research is.

For example, although there has been considerable discussion about it, there is not yet agreement about what constitutes a 'user controlled' organisation among disabled people's, health and social care service user organisations.

The development of user controlled research has been underpinned by similar aspirations, but so far there have been even fewer opportunities for service users/user researchers to work through systematically what user controlled research might mean; look like and achieve.



This hasn't discouraged the development of a significant and growing body of initiatives. Service users and service user researchers identify particular values in such research.

The project aims to coherently develop thinking about user-controlled research and subject it to rigorous review. It is working with a broad definition of social care service users that includes disabled people, mental health service users/survivors, people with learning difficulties, children and young people, older people and other groups.



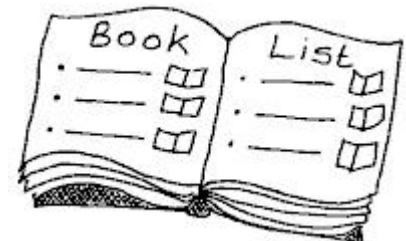
The project is starting with no assumptions about a 'correct' approach or definition of 'user controlled' research. There are likely to be a range of ideas about what constitutes user controlled research. We hope this project will help identify these.



For example, 'user controlled' might mean being primarily accountable to an independent user controlled organisation/the people being studied or research participants themselves.

We are carrying out a literature search and using this questionnaire to get direct input from service users who are involved or have an interest in research.

We would also be very interested to hear from anybody with recommendations for documents to include in the literature review.



In the early summer we will also be holding three meetings with small groups of users interested/working in this area. If you are interested in taking part please let us know when you return this questionnaire

#### Terms and conditions of taking part in the survey

All personal information will be treated in confidence and will only be used for this project. It will not be used for any other part of Shaping Our Lives' or Folk Us' work. It will not be given to anybody else.

No names will be used. All information will be anonymous. All individual information will be kept secure and destroyed when the project is complete

The project report will not identify people who have taken part in the project. We will give participants a chance to comment on a draft report before the final version is completed. All participants will receive a copy of the final report.

#### Help on filling in the form

This questionnaire is about your views and experience of user-controlled research.

We are particularly keen to hear about service user researchers' experiences of these issues but it is just as important that we hear other service users' views about participating in user-controlled and other research.

Please answer the questions as fully as you feel able to.

**If you would rather speak to someone and go through the questions with somebody over the telephone we would be happy to do this – please get in touch and we will arrange a time to do this.**

**If you would like a copy of this questionnaire in a different format please contact the Shaping Our Lives.**



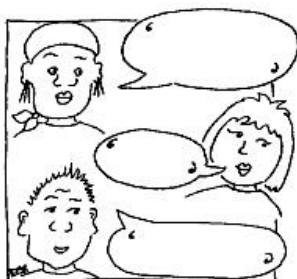


### Your experience of research

- 1 Would you describe yourself as -
- ☐ A researcher with experience of working on a user-controlled research project
  - ☐ A researcher with experience of working on another type of research project
  - ☐ A researcher with experience of working on both user controlled and other research projects
  - ☐ A participant in a user-controlled research project
  - ☐ A participant in another type of research project
  - ☐ A participant with experience of working on both user controlled and other research projects.



- 2 Do you have any other roles that might be relevant?



### Defining user-controlled research

- 3 In your view, what is user-controlled research?

- 4 Are there particular values and principles that you associate with user controlled research and which you think make it different from other types of research, (for example, like that carried out by other organisations or in different, more traditional ways?)

☐ Yes ☐ No ☐ Don't know



Can you say what do you think these values and principles are?

- 5 Do you think user-controlled research has particular benefits?

☐ Yes ☐ No ☐ Don't know

If yes, can you tell us what you think these benefits are?

- 6 Do you think that user-controlled research has any drawbacks or limitations?

☐ Yes ☐ No ☐ Don't know

Could you tell us what you think these drawbacks and limitations are?

- 7 Do you think user-controlled research can address the views/needs of all service users?

☐ Yes ☐ No ☐ Don't know

Can you say why you think this?

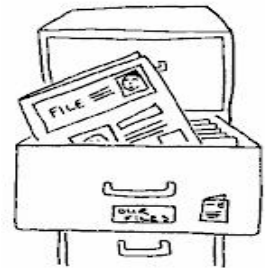
## Good practice in carrying out user-controlled research

- 8 What do you see as the elements of good practice in carrying out user-controlled research?

You may wish to look at good practice in terms of -

- i. How the research is carried out
- ii. The treatment of participants
- iii. How service users are involved
- iv. What the purpose of the research is

and any other areas you think are important



- 9 Do you think the people doing the research in user-controlled research should be disabled people/service users?

☐ Yes                      ☐ No                      ☐ Don't know

Can you tell us why you think this?



- 10 What do you think the aim(s) of a user-controlled research project should be?
- 11 Do service users need to be involved at every stage of a project for it to be user-controlled? The stages of a project are defining what is to be researched, planning how to do the research, carrying out the research, analysis and report writing, and disseminating the results.

Can you tell us about what you see as good practice in relation to keeping service users involved at different stages of a project?

- 12 Can you say why the points you have made constitute good practice for you? Do they suggest that there are distinct values and principles that can be used to define user-controlled research?

### The accountability of user-controlled research

- 13 Does user-controlled research raise particular issues of accountability?

☐ Yes ☐ No ☐ Don't know

If yes, can you tell us about these issues?

- 14 Who do you think user-controlled research should be accountable to? (For example, it might be accountable to user-controlled organisations, the people taking part, the group of people being researched (eg disabled people or older people) and funders.



- 15 What differences, if any, do you see between user-controlled research and research that involves service users?

### Potential barriers facing user-controlled research

- 16 Do you think there are barriers that affect user-controlled research?

☐ Yes                      ☐ No                      ☐ Don't know

If yes, what do you think these barriers are?

- 17 Is there a problem for user-controlled research being seen as representing the interests of only one group, that is service users?

☐ Yes                      ☐ No                      ☐ Don't know

If yes, what are your views about this?

- 18 Do you think that user-controlled research is valued less than or differently to other forms of research?

☐ Yes                      ☐ No                      ☐ Don't know

If so, why do you think this is?



- 19 How do you think that the different interests involved in research may affect how and what research is carried out? (these different interests may include service users, service providers, the government, researchers, research commissioners, universities and funders).

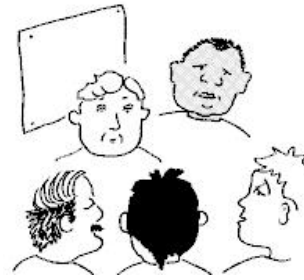
- 20 Do you think it is more difficult to get funding for user-controlled research than other types of research project?

☐ Yes                      ☐ No                      ☐ Don't know

If yes, can you tell us why you think this is?

## The future of user-controlled research

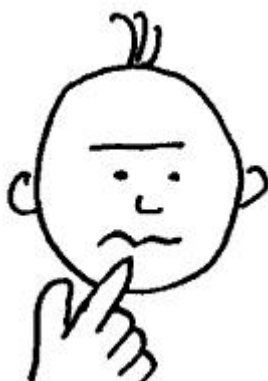
- 21 Do you think user controlled research has a particular contribution to make to policy development?



☐ Yes                      ☐ No                      ☐ Don't know

If yes, what do you see this contribution as being?

- 22 What would you like to see the future being for user controlled research?
- 23 What do you see as the future for user controlled research?
- 24 How can the barriers facing user controlled research, discussed above, be reduced or removed?
- 25 How can user-controlled research be promoted in the future?
- 26 Do you have any other points that you wish to raise that are not covered by the questions above?



### Contact details

This information is for us to keep in touch with you about the progress of the project. It will not be given to anybody else and it will not be put in the report of the project.

The details that we ask for about you are to help us monitor respondents to the questionnaire from an equalities perspective.

Name

Address

Telephone

E-mail

Are you happy for the project worker to get in touch if there are any questions he has about your responses to the questionnaire?

☐ Yes

☐ No

### About you

Are you ☐ Male

☐ Female

Do you identify yourself as a service user/disabled person?

☐ Yes

☐ No

Shaping Our Lives defines a service user as somebody who is, has or is entitled to use health and social care services, particularly on a long-term basis, for example, someone with learning difficulties, people with a physical or sensory impairment, users/survivors of mental health services, young people who are or have been looked after and older people.

Do you want to say what type of services you have used?

☐ Disability

☐ Mental health

☐ Learning difficulty

☐ Older people's services

☐ Young people's services

☐ Other:

Are a member of an ethnic minority.

☐ Yes

☐ No

If so, please tell say which ethnic minority you are a member of/identify with, if you happy to do so:

Thank you very much for your help. Just one final question - would you like to receive a draft copy of the report and have the opportunity to comment before it is completed?

☐ Yes

☐ No

If yes, what format would you like -

- ☐ Electronic (by e-mail)
- ☐ On paper, 14 point font size
- ☐ On tape
- ☐ In Braille
- ☐ Other - please specify -



# User Controlled Research: Its meanings and potential Final Report 2005

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## Further information:

The summary can be downloaded from the publications section of the INVOLVE website [www.invo.org.uk](http://www.invo.org.uk) or from the Shaping Our Lives website [www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)

INVOLVE ([www.invo.org.uk](http://www.invo.org.uk)) promotes public involvement in NHS, public health and social care research and is funded by the Department of Health.

Shaping Our Lives ([www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)) is a National User Network, funded by the Joseph Rowntree Foundation and the Department of Health.

For hard copies of the report or  
a large print version please contact:

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**Centre for Citizen  
Participation  
Brunel University**



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