Examples Of User Controlled Research

Report of a Project Commissioned by NIHR INVOLVE

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An Updating Note

This project report although commissioned by NIHR was not published by them when completed. However, with the increasing interest in user controlled research since then, it has seemed worthwhile to Shaping Our Lives to make its findings available. While they have been superseded by other research and reports that have been produced since, they may still be of use and interest because they offer an additional snapshot of the history of user controlled research.

Since this work was first undertaken, more user controlled research has been undertaken. Larger and more quantitative studies have been undertaken. Work with some groups of service users that was under-developed has been taken further forward. We would particularly suggest that readers refer to two references (Faulkner, 2010; Beresford and Croft, 2013). These highlight that while user controlled research has continued to make important progress it still faces major problems and barriers. We hope that this report will serve as a further helpful resource for people interested in both user controlled research and all forms of public, patient involvement in research and evaluation.

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Introduction

The purpose of this project was to identify and produce a summary of examples of user controlled research. This was to be done parallel to and in association with a survey of examples of user involvement in social care. The goal was to gain a better understanding of the nature of user controlled research projects concerning health and social care research in England to illustrate different approaches adopted and to highlight lessons learnt. Following this, Involve's intention was to commission a second piece of work which would involve selecting a sub-set of the projects identified, to illustrate in greater detail the processes and nature of involvement in the projects.

User involvement in the project

This project was itself user-controlled and sought to model good practice in user controlled research. Carers were not involved in the project or their views specifically sought, since the project's focus was *user* controlled research. It was carried out by a consortium of three organisations Shaping Our Lives, The Social Perspectives Network and the Centre for Citizen Involvement at Brunel University. Shaping Our Lives led and managed the project.

The main project workers, Michael Turner (Shaping Our Lives) and Vicky Nicholls (SPN) were service users, as was the project lead, Peter Beresford (CCP). All have extensive experience of user-controlled research. In addition to the core team, three further service user researchers were engaged to give specific input into the project from their particular expertise in the field (Alison Faulkner, Sarah Carr (SCIE) and Jayasree Kalathil. Jayasree was able to offer particular contacts and experience in work with mental health service user organisations in black and minority ethnic communities.

How information about user controlled research examples was collected.

The starting point for this project was the review of user controlled research earlier undertaken on behalf of Involve (Turner and Beresford, 2005). This provided the basis for the definition of user controlled research adopted in the project. Agreeing this was the first task to be undertaken in gathering information. The full definition that we used is included in this report as Appendix One. Briefly user controlled research was defined as research that was actively controlled by service users and accountable to them, although they might not necessarily be involved in all aspects and stages of the research and it was research committed to making change in line with their rights and needs. Such research is also known as 'survivor research', 'user research' and emancipatory disability research' and may involve a wide range of research methods. Because user controlled research is a relatively new development a start date of 2003 was decided on for this project, although some flexibility was envisaged to ensure that any particularly significant projects were not excluded.

To alert people to the project, announcements were made on key websites and internet forums, with notices posted on -

- SOLNET (Shaping Our Lives networking website)
- Disability Research e-mail list (based at the Centre for Disability Studies, Leeds University)
- Shaping Our Lives website (the national user controlled organisation)
- Involve's website

Notices were also carried in Shaping Our Lives and Involve's newsletters.

The following websites were also searched -

- Disability & Society
- Disability Studies (including papers from past conferences and its register of researchers)
- Disability Now magazine
- Community Care magazine
- Joseph Rowntree Foundation
- Social Care Institute for Excellence
- Evidence Network

Particular use was made of the search skills and capacity of the Social Care Institute for Excellence in seeking to identify examples of user controlled research, as well as its electronic library.

Undertaking the project

As we had expected, our extensive networks and the trust which we could generate as a user controlled project were of great importance in being able to identify examples of user controlled research. We were also aware from our own experience that when the aim is to involve people who use services and particularly a diverse range of service users, more time and resources are required. However, almost everything still took us much longer than we had expected! This included arranging and getting to and from meetings with co-researchers and Involve and developing the questionnaire, especially the online version, as well as work to put this into a format compatible with Involve's database). Online searches were slow. Some quests were fruitless, for example using evidencenetwork.org regarding definitions of and how to search for evidence, offered helpful advice but had no results. A scattergun or snowballing approach seems to be useful because it is unpredictable which contacts will result in a response or be fruitful. Meetings with expert colleagues tended to be helpful. However, nothing, for example, came back from the Care Services Improvement Partnership (CSIP) despite inclusion in several newsletters.

Engaging people in the project

It was recognised from the inception of the project that direct contact would be the main way in which user-controlled research projects would be identified. The starting point for this was an extensive list of contacts drawn up from the project team's wide-ranging links and networks with organisations and a number of individuals to be approached who were identified as having knowledge, interest and/or involvement in user controlled research. This included service user organisations, universities, organisations involving social care research, funders and the people who had been involved in the previous Involve project on user-controlled research. These were followed up. It was also decided that adopting a pro-active approach was also most likely to be suitable to identify examples of user controlled research. This would mean both reaching out to possible participants, rather than relying on them to make contact and also ~~on~~ offering any help projects or researchers might want to feed into this project.

Reaching out

Being able to go out to meetings and events and tell people about the project proved to be very useful. Examples of this included a Survivor Researcher Network meeting where we learnt about new projects and were able to send information about this project around the network. It might have also been helpful to make individual phone calls to network members, but there wasn't time for this. Involve's own 2008 'Invonet' event was also helpful. Here we heard about a research project being carried out by Thyroid UK, which was user controlled. We were thus able to follow up this contact and ensure that they completed a questionnaire.

As this indicates, particular efforts were made to develop contacts with specific groups of service users where we could expect that this would be helpful. Thus the need for specific contact work with service users from black and minority ethnic communities was identified at the start of the project and a service user researcher from this background was commissioned to undertake contact work. Information and questionnaires were sent out to the Catch-a-Fiya network, Fan the Flames regional network in the West Midlands, and other user/survivor networks.

The need for specific contact work with other groups of service users emerged as the project progressed. The main case where this happened was with people with learning difficulties as it became apparent that there had been limited contacts and few responses from their organisations. We frequently offered people the opportunity to have face-to-face meetings if they wanted support to facilitate their participation. It was generally not needed. However, it did lead, for example, to a meeting with the Director of national People First, an organisation controlled by people with learning difficulties, which provided the route to make contact with People First groups around the UK and helped identify some specific groups to contact.

Offering assistance

In developing and planning this the project we were sensitive to the fact that service users and their organisations face many pressures in terns of time and resources. This means that it is often difficult for them to respond to requests like ours to provide information and complete questionnaires. In order to overcome this potential barrier to the project, we decided to offer respondents any support they required to complete the questionnaire.

This was a worthwhile step to take. Questionnaires were completed by the project workers for one organisation, reporting on three projects, and two further questionnaires were completed by the project workers using information supplied by organisations. In all of these cases the completed questionnaires were returned to the organisations so that they could check and approve the response that had been written on their behalf.

The Examples

The methodology used for the project produced a larger number and wider range of responses from user controlled research projects than we had expected, given the amount of time and resources available. This included projects undertaken by people with learning difficulties, mental health service users as well as other service user groups. The focus of projects was wide, extending far beyond issues that might have been expected like involvement, advocacy, direct payments and personal assistants. There were also projects with a focus on breastfeeding support, chaplaincy and spiritual care, radio-therapy patient safety, friendships, relationships and sexuality and so on. Having said that, however, the largest group of examples came from mental health service users and people with learning difficulties. We were surprised at the overall number of examples we were able to identify. However, we certainly do not assume that our list is by any means definitive. In our view this is one of the significant issues emerging from this project. Also despite the diversity of respondents who completed questionnaires there were some significant gaps, which we discuss later in this report.

Breakdown of questionnaires

In total we received a total of 53 questionnaires from a very wide range of groups, individuals and organisations reflecting very different groups of people but with overlapping and shared interests. These included examples of user controlled research from and relating to:

• Mental health service users	(10)
• People with learning difficulties	(14)
• Young people	(4)
• Disabled people's organisations	(7)
• General user involvement issues	(6)
• Specific health issue/impairment issues	(6)
• Maternity and maternity services	(2)
• Health education issues	(1)
• Alcohol related issues	(3)
TOTAL	**53**

The majority of the examples were based in organisations that identified as user controlled. This was the case for 33 of the projects that we received details about, although several of these included collaboration with a university. Eleven projects were based at universities and five were by being carried out by service users with service provider organisations. Interestingly three were being carried out by individuals.

Issues emerging from the examples

The themes they addressed were so wide-ranging that it is difficult to draw out any patterns from the examples. Again it is important to highlight the diversity of focus, from issues for disabled people from the lesbian, gay and bisexual community, to evaluating a healthy living approach to community development. Several involved aspects of community – experiences of community-based psychotherapy, friendship for people with learning disabilities – and four looked at peer or mentor support. Twelve projects out of the total 53 looked at treatment or support services.

Several of the projects described themselves as being emancipatory research. These were by local People First groups of people with learning difficulties who had designed and managed the entire research and dissemination process themselves. Most of the projects we heard from were either based within or supported by user controlled organisations. Those that weren't had advisory groups steering the research process controlled by service users and service users managing and carrying out the research itself. Several projects highlighted how they worked across groups and interests in collaborative ways with service users in charge, and most spelled out exactly how service users were in control of various aspects of the research process. Most participants said that there was involvement at all stages of their project.

Involvement was often focused around advisory groups, but there were good examples of projects where service users had come together to identify an issue that they thought needed investigation and they set up and steered the project: Rainbow Ripples (issues for lesbian, gay and bisexual disabled people); Thyroid UK (testing for thyroid problems) and projects from the Young Researcher Network and the *We are not Stupid* project controlled by people with learning difficulties. The Women's Independent Alcohol Support project was interesting as it was started by an independent service user who was able to get support from a health trust and then used the finances to involve users in an advisory group.

One of the projects which highlights some of the complexities as well as the possibilities of research which is controlled by service users, is based at the University of Leeds. This project aims to develop and carry out pilot field testing of user-mentor support for patients with head and neck cancer, to support them in the period after discharge from hospital after primary radical therapy.

The research lead for the study is a service user who leads the focus groups and work within the research team to develop the training package. She acts as mentor and support to the user-mentors undertaking the training. The proposal was developed as part of a competitive call for user-led research. The outline proposal was agreed and supported by a member of the Consumer Liaison Group of the National Cancer Research Institute (NCRI). She and the User Research Lead have been full members of the study team throughout its development.

Such an example is open to argument as to whether it is strictly user-controlled, as it is based in a university and probably under the leadership of an academic department – an issue we will return to. Other projects, such as that carried out at the Centre for Recovery in the University of Hertfordshire, have been apparently more straightforwardly user-controlled, as the research was designed from the start by someone with a diagnosis of ‘bipolar disorder’ who sought funding and led on research processes involving other service users along the way, for example, in reviewing the training that was being piloted.

We were able to review 20 of the completed questionnaires in detail, from which a plethora of funding sources emerges (from Big Lottery to local Councils to local and national voluntary organisations).

Design: over half of those reviewed involved a study of views or experiences (11), including focus groups (12), interviews (10), surveys or observations (6 and 7 respectively).

User control: over half of those reviewed stated that users controlled the research planning (11), around half the design (10), managing (9), carrying out (9) and analysis of data (9). Six had been responsible for arranging funding, and four for training other people to undertake the research.

Emerging strengths of user controlled research

User controlled research seems to give service users the opportunity to focus on issues that they think are important and want to address and then carry out the work. This seems to apply to most examples. The Young Researcher Network was interesting as it was a funding scheme set up specifically to give young people the opportunity to identify and undertake their own research. It led to projects on addressing difficulties for young people living in care, involving young people in care in reviews, support for young people with learning difficulties at a specialist college and the effectiveness of a health trust's young people's liaison officers.

As we have said most examples were linked with user controlled organisations. In some cases at least, research seemed to be regarded a key part of user involvement and central activity of the service user movement. It was a way that people could get their voices heard. One respondent, Independent Living Alternatives, pointed to the importance of working from a social model of disability perspective and said that this brought the reality of service users' perspectives to the project.

But the process could also work the other way round. The Women's Independent Alcohol Support project came together to carry out a research project and then stayed together as a user group. The same could also be said about Shaping Our Lives, the national organisation and network, which began as a research project and then developed its own user controlled identity and structure. Some participants also referred to the importance of ensuring that participants benefit from involvement in research. There were also some indications that service users might prefer to participate in user-controlled rather than other research projects

User researchers

The employment of user-researchers was important. Sometimes this was as part of a team. WECIL/Norah Fry Centre employed two people with learning difficulties to work on their research team for a project on personal assistants (PAs) and people with learning difficulties. Disability Information Training Opportunity employed freelance service user researchers for their three projects. People First Carlisle had a person with learning difficulties as the lead worker with support from a co-worker. The need for training and support were also highlighted Examples included training for user researchers and users involved in advisory groups (WECIL/Norah Fry and the workers on the Young Researcher Network projects) and support without formal training (Shaping Our Lives' projects/People First Lambeth).

Innovative research methods

The examples gathered also highlight that there is no one way to undertake user controlled research. Indeed flexibility, innovation and originality in approach and methods seem to be at a premium. The project included examples where very different research methods were employed. WECIL/Norah Fry used video in work with people with learning difficulties, and Change/Leeds University used drama with people with learning difficulties (Beresford, Nicholls, and Turner, 2009).

Gaps in examples

Overall the scope of active control of aspects of the research process by service users of all sorts and right across health and social care is impressive. It is encouraging to see the range of user-controlled research taking place within user-controlled organisations. During the information collection process there was sometimes a feeling that we were missing swathes of undiscovered research, and the likelihood is that we were. At the same time, the project does seem to have heard from a good cross-section of community and user groups and such initiatives may hopefully encourage many more to keep on researching.

User-controlled research by mental health service users on mental health issues seems to be particularly well organised and represented in this project. Such ‘survivor’ research has a strong tradition, but it is difficult to be sure why it has gained such prominence. However there were also some significant gaps in this project which need to be highlighted.

Gaps – Deaf people

We began to realize that we were not getting any responses from the Deaf community. When this emerged as a problem, we contacted the British Deaf Association – both its Head Office and three regional offices, but still received no response. We also contacted the Deaf Studies Unit at the University of Central Lancashire and the Deafness Cognition and Language Research Centre but again got no response. This is clearly an area that needs to be followed up further.

Gaps – Older people

We were aware of research being undertaken by and alongside older people, for example, work supported by the Joseph Rowntree Foundation and the Centre for Policy on Ageing but we were not contacted by them and we were unsuccessful in pursuing these within the resources of the project.

Gaps – Emancipatory Disability Research

There was a surprising lack of responses from organisations of disabled people. Despite extensive contact with organisations of disabled people, only seven projects specifically related to disability/impairment were identified (defining this in terms of physical and/or sensory impairments) Yet there is a strong disability studies tradition in the UK and emancipatory disability research, a form of user controlled research, has been in existence for 30 years. We know that disabled people's organisations face serious problems of limited capacity, inadequate and insecure funding. This may affect both their ability to undertake user controlled research as well as to spend time assisting projects like this.

There appears to be extensive activity in the field of emancipatory disability research although it seems to be particularly based in academic settings. Reviewing the Disability Studies website identified a range of projects on disability issues but all were based in universities. Contact was also made with researchers on the Disability Studies website and some of the responses to this indicated that their work in addition to being university based was not perceived to be user-controlled research.

We did not see user controlled research and being based in a university as mutually exclusive categories. However, our initial findings do raise the issue that research on disability issues may be particularly concentrated in academic settings, linked with the development of disability studies as an academic discipline and that such settings may discourage user controlled research. This point has been made in a recent journal article (Postle et al, 2008).

It was the disabled people's movement which first advanced emancipatory disability research and encouraged the development of disability studies. However the limited resources of disabled people's organisations in recent years may have eroded this base. Another effect of the lack of resources for organisations of disabled people is that several organisations that have had a track-record of undertaking user controlled research have closed. Examples include Greater London Action on Disability and Disability West Midlands. The umbrella organisation, the UK Council of Disabled People has had to reduce its activities significantly and closed the research committee it jointly developed with the National Centre for Independent Living.

This does raise issues about the degree to which user controlled research will continue to be undertaken and fostered by user controlled organisations – its natural and original home – even though a high proportion of the examples we encountered were based there. We know that much user controlled research undertaken by mental health service users, particularly large projects is currently based in non-service user organisations, including notably traditional medically based institutions like the Institute of Psychiatry. This may have implications for both the long term sustainability of user controlled research and also its basis of accountability to service users and their organisations. We know, for example, that two key initiatives in user controlled research by mental health service users, Strategies For Living (Mental Health Foundation) and User Focused Monitoring (Sainsbury Centre for Mental Health) were arbitrarily ended when the charities that had been their home decided on changes in structure and direction.

Gaps – BME communities

Another gap relates to projects run by service users from black and minority ethnic communities. The efforts of the highly skilled consultant engaged to work on this area did produce some initial interest in terms of requests for information and questionnaires - in particular there were requests for hard copies of the questionnaire, suggesting that there may be a lack of access to the internet for organisations in black and minority ethnic communities. However, this initial interest did not result in any responses from black and minority ethnic user organisations. The contact work carried out in this area did reveal some examples of good practice in involvement of black and minority ethnic service users in research, but significantly, little indication of user-controlled projects.

The reflections of the consultant offer some helpful additional insights. It is perhaps important to note that issues she raises in relation to user controlled research, may often also be seen as ones applying to research overall. Her experience and networks lie particularly in the context of mental health research, so her views may not apply equally to other service user groups. However, there seems to be little indication that this is actually the case. As she said:

> *One issue that I'm aware of as a survivor researcher working mainly in the area of BME mental health is that there is very little investment in user-controlled research looking at race, culture and mental health. We often come across the viewpoint that BME service users are mostly "subjects" of research and have little opportunity as developers, planners and deliverers of research.*
>
> *I'm often finding BME service user research in between a rock and a hard place. In mainstream user-controlled research, there is very little opportunity and attention to BME specific issues and concerns and areas that we want to explore are sometimes neglected. In BME mental health scenario, the acceptance of "experts by experience" has a long way to go. Could this be one of the reasons why there has been little engagement with this project?*
>
> *Your point about needing more outreach is very relevant. Perhaps we need to explore ways in which we can reach people in a way that they feel enabled to respond to a survey. Region-wise meetings with local organisations? A workshop-like structure? People may not have responded for several reasons – lack of time, lack of resources, lack of uptake of the objective of the research itself. More interactive ways of data collection may be required to overcome all of these. Of course there is the possibility that there aren't many user-controlled research projects within the BME mental health sector!*

Clearly much more work needs to be done to get a clearer idea about the situation and nature of BME user controlled research, what barriers it faces and how these may be overcome.

Further steps to take.

This project was a modest first attempt to begin to chart the field of user controlled research by identifying examples. It was recognized to be such from its inception and part of its value lies in the issues which it raises, some of which may benefit from additional examination. There are quite a few such issues. A number of these offer an immediate advance on our understanding of user controlled research. Others will indeed benefit from further analysis and consideration. Below we detail these.

It is clear that there are many different ways of undertaking user controlled research, in terms of where it is located, who is involved, at what stages user involvement is undertaken, how it is controlled and what research methods and approaches are adopted. User controlled research is already being employed in an unexpectedly wide range of contexts, exploring a surprisingly wide range of issues – with some apparent success and benefit.

User controlled research was identified in unexpected areas with a wide range of groups. The project highlighted the importance of a pro-active approach in identifying examples of such research. As a result it is likely to be helpful to get a fuller picture of user controlled research to follow up service user and other non-user led groups and organisations working with related populations to check what if any user controlled research may be taking place among them. This a task beyond the resource of this initial project. Groups may include homeless people, people with experience of prison and the criminal justice system, people with drug and alcohol problems, etc.

There are some groups which this project clearly indicates need to be followed up if a fuller picture of user controlled research is to emerge and it such research to be adequately developed and supported in the future. These notably include;

- Black and ethnic minority service users

- Refugee and asylum seeker communities
- People with physical and sensory impairments
- The Deaf community
- Older people

At the end of the project through a related initiative established by Involve in association with the ESRC, contact was made with the Children's Research Centre at the Open University. It is apparent that this pioneering initiative has supported many user controlled research projects to be undertaken by children and young people. The work of this Centre needs to be included in future explorations of user controlled research. Its analysis is likely to be of broader value in this field.

The project team recognized in designing this project that the definition of user controlled research could be complex and subtle (See Appendix One). This issue has been reinforced during the course of this project. Where projects have taken the view that they are user controlled, we have not seen it as our role to challenge their definition. But there is undoubtedly a grey area in such definition. It is becoming increasingly difficult to be clear that organisations and initiatives are user controlled or would be widely seen as such. With traditional charitable organisations 'for' disabled people, like Mencap and Scope presenting themselves increasingly as 'user led organisations' and with the close involvement of universities, where restrictions can apply to the reality of user control, it becomes increasingly important to pay additional attention to the definition of user controlled research.

A related issue arises with user controlled research undertaken by people with learning difficulties. This project identified a significant number of such projects being undertaken with assistance from universities and other organisations. A new as yet unpublished PhD research study - 'A qualitative enquiry into the process of supporting self-directed researchers with learning difficulties – highlights a frequent failure in such cases to make clear where control lies and what role supporters actually play. This highlights the value and importance of exploring and setting out as clearly as possible how such research is carried out and how disabled people are able to maintain control.

While user controlled research is not only located in user controlled organisations, these certainly play a central role in housing and supporting it. The bulk of responses to this project either came from user-controlled organisations or academics working with user-controlled organisations This highlights the obvious importance of supporting such user-controlled organisations if user controlled research is to thrive. Yet all the evidence indicates that user controlled organisations are inadequately and insecurely funded and as a result are insecure and difficult to sustain, despite government commitments to establish a national network of such local user controlled organisations. A key requirement for user controlled research to prosper is likely to be that such user controlled organisations are better supported for the future.

The importance of training and capacity building for user controlled research emerged strongly from the examples identified in this project. Service user trainers and researchers are likely to have a particularly central role to play in such training and this will create a need for ‘training for the trainers’.

As the project team we all have good networks in the field of user involvement in research and user controlled research. Yet as a result of this project we have learned about many projects we had never heard of as well as not getting a response from some we did. There is a big job still to be done of sharing knowledge and experience about user controlled research. This is likely to encourage people to undertake user controlled research as well as helping them in the process. Involve’s Invonet resource could play a helpful part in supporting networking of user controlled research. A specific networking facility might also be helpful, particularly one which was able to include smaller scale projects, including unfunded ones and PhD and other post graduate academic studies. It would be helpful in further work to explore the need for such a resource and what form it could most helpfully take.

References

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Appendix One

Working Definition of User Controlled Research for the 2008 Examples of User Controlled Research and Public Involvement in Social Care Projects

Summary Bullet Points

- User controlled research is research which is actively controlled by service users and is accountable to them
- Other terms used for user controlled research include ‘survivor research’, ‘user research’ and emancipatory disability research’
- User controlled research can include a wide range of research methods and methodologies, including both qualitative and quantitative research
- Service users are likely to be involved in all aspects and stages of the research, but not necessarily so. What is crucial is that they control the research.
- User controlled research is committed to making change in line with service users rights and needs although there is recognition that this may not always be possible.

Background information

It is suggested that the information provided below is used together as the basis for defining user controlled research. Information contained in Section 2 elaborates and adds to the core definition contained in Section 1.

Section 1 The definition of user-controlled research used in INVOLVE's Public Involvement Information Pack

User controlled research is research that is actively controlled, directed and managed by service users and their service user organisations. Service users decide on the issues and questions to be looked at, as well as the way the research is designed, planned and written up. The service users will run the research advisory or steering group and may also decide to carry out the research.

Some service users make no distinction between the term user controlled
and user led research, others feel that user led research has a different, vaguer meaning.

They see user led research as research which is meant to be led and shaped by service users but is not necessarily controlled by them. Control in user led research in this case will rest with some other group of non-service users who also have an interest in the research, such as the commissioners of the research, the researchers or people who
provide services.

Supplementary information re the definition of User Controlled Research drawn from: Turner, M. and Beresford, P. (2005), *User Controlled Research: Its Meanings And Potential, Final report*, Shaping Our Lives and the Centre for Citizen Participation, Brunel University, Eastleigh, Involve.

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. (The review essentially took them all as expressions of user controlled research and synonymous with it generally) 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) organizations. Emphasis is placed on control of research not lying with non-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.

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

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;

While service users tend to highlight the importance of use 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.

Much of the definition that emerged in the 2003 review of user controlled research for Involve was concerned with identifying components for good practice and characteristics associated with it. The component most closely identified with it was a commitment to making change in line with the interests and rights of service users at individual level (empowerment) broader levels (political and social change)

Appendix Two

Breakdown of Organisations Undertaking User Controlled Research

<u>Service user organisations</u>

1. Carlisle People First Cooperative-
8. Bristol Mind
9. Raise Mental Health Limited
11. Open University and Carlisle People First Research
14 Inclusive Living Sheffield
15. Carlisle People First Research Co-operative
16. Disabled Person's User Led Organisation
19. Connect in the North
23. Restricted Growth Association, with Newcastle University
24. Thyroid UK
25. Herpes Viruses Association
28. Disability, Information, Training, Opportunity
29. Disability, Information, Training, Opportunity
30. Disability, Information, Training, Opportunity
31. Independent Living Alternatives
32. People First Carlisle
33. People First Lambeth
34. Rainbow Ripples
35. WECIL (West of England Centre for Inclusive Living) with the Norah Fry Centre at the University of Bristol
36. Wiltshire People First
41. Women’s Independent Alcohol Support (WIAS)
42. Women’s Independent Alcohol Support (WIAS)
43. Women’s Independent Alcohol Support (WIAS)
44. Shaping Our Lives
45 Shaping Our Lives
46. Shaping Our Lives
47. Shaping Our Lives
48. Shaping Our Lives
49. Hertfordshire PASS
50 Strategies for Living
51 Strategies for Living

27. CHANGE/ Leeds University

Users with service providers

10. Crisis Resolution Home Treatment team research project
21. Women's Therapy Centre and Brigid Morris (service user)
37. Young researcher network / Bradford City Council Voice and Influence team: Get the Life You Want
38. Young researcher network/ North Tyneside Council: Have Your Say
39. Young researcher network/ Mencap: Pengwern College
40. Young researcher network/ Investing in Children: Patient and Public Involvement Group
52. Northumberland Care Trust and breastfeeding peer supporters

Universities

3. University of Manchester ESI School of Education
4 Centre for MH Recovery, University of Hertfordshire
5. University of Leeds Oral & Maxillofacial Surgery,
6. Sustainable Health Action Research Project - Swansea University
12. University of Southampton
13 University of Manchester School of Nursing, Midwifery & Social Work
17. University Of Manchester ESI, School of Education
18 UEA
20. University Of Manchester ESI, School of Education
22. University Of Manchester ESI, School of Education
26. User Involvement in Health and Social Care in Nort

Individuals

2. Self researcher mental health
7. PHD Student (David Armes) history of community care and survivor movement
53. Mi

Appendix Three

Additional Information About User Focused Monitoring (provided by Brigid Morris)

Projects not mentioned in the UFM network publication list - see below):

User-Focused Monitoring of Mental Health Services in the London Borough of Havering, Morris, B, Rose, D, Mackintosh, G and Ford, R Nov 1998

User-Focused Monitoring of 3 Community Support Services in Camden Morris, B., The Camden User-Focused Monitoring Group, Rose, D. and Ford, R. May 1999

User-led Monitoring of the process of Discharge from inpatient care in N Hampshire, The N Hants, User Interviewer team, Payne, G., Morris, B Jan 2001

Matrix inpatient research

BME research with SULC

Additional User controlled research known of

- Making Waves - loads of evaluation work since 1999 – contact Torsten Shaw
  - SULC - current contact Ingrid Stuart - loads of evaluation work - particularly All Talk http://www.spn.org.uk/fileadmin/SPN_uploads/Documents/All_talk_research_report.pdf
  - INGRID STUART <ingrid.stuart@btinternet.com> julia.smith@ebmind.org <julia.smith@ebmind.org>

  Users Support service - "How Do You Cope?: Services and Support for people Who self harm in Northamptonshire: A user-led project. Mar 2004 (I have a copy) USS: 01604250745 53 Whitworth rd, Abington, Northampton, NN1 4HG
- NSF - The experiences and view of self management of people with a schizophrenia diagnosis David Martyn
- Vernon, A, Hughes A and Wilkinson L and Leeds Involvement Project. Are You Being Supported?: A user-led evaluation of mental health home support schemes in Leeds.
- Safe as Houses: residential Care and Mental Health Service users

in Haringey. A report by the Matrix Research Group in consultation with Frank Curran, LB Haringey and J Homshaw, Middlesex University Nov 2004

Worth following this link:

http://www.ufmnetwork.org.uk/publications.htm - links of key organisations and publications

And from the SCMH website
www.scmh.org.uk/pdfs/**ufm**_reports_list.doc **document copied below (more key organisations and publications):**

UFM Network Publication List : all arms length projects

Any links given here are current at the time of writing but their location might change. If you know where any of these reports might be found, please let us know. Thanks.

Nutan Kotecha, UFM Network Coordinator, 020 7827 8344 or email nutan.kotecha@scmh.org.uk.

Region	**Project**	**Subject**	**Report**	**Date**	**Author**	**Report available at:**
London	Letting Through Light	Local Mental Health Service Audit conducted by Black and minority ethnic Service Users	Letting Through Light: Ealing Service User's Audit	Oct. 2003	Dominic Makuvachuma Walker, Premila Trivedi, Peter Ferns	http://www.londondevelopme
London	Ealing Service User Involvement Project	Day services	CAPE & MAC Centres User Survey Report	May 2002	Amanda Bergin	
London		Staff and user views on inpatient care at St	Life on the wards	Mar. 2004	Matrix Research Group and Middlesex	

		Anns, Haringey			University	
London	The KCW Mental Health Monitoring Users' Group		In Our Experience: User Focused Monitoring of Mental Health Services in Kensington & Chelsea and Westminster Health Authority	1998	Diana Rose, Richard Ford, Peter Lindley, Libby Gawith,	
London	KCW User Monitoring Group	Site visits	KCW Mental Health User Focused Monitoring: The Site Visits	1998	Diana Rose, Richard Ford, Gabriel Mackintosh, Brigid Morris	
London	KCW User Monitoring Group	User interviews	Kensington & Chelsea and Westminster HA User Focused Quality Monitoring: User Interviews - Second Phase	1999	Diana Rose, KCW User Monitoring Group, Richard Ford, SCMH UFM Team	
London	KCW User Monitoring Group	Site visits	KCW Mental Health Monitoring: The Site Visits - Second Phase	2000	Brigid Morris, KCW User Monitoring Team, SCMH UFM Team	
London	KCW User Monitoring Group	Community interviews	User Focused Monitoring Community Interviews - Phase Three	2001	Sarah Lewis, SCMH UFM Team, KCW User Monitoring Group	
London	KCW User Monitoring Group	Site visits	User Focused Monitoring of Inpatient Services in Kensington & Chelsea and Westminster Health Authority: Site Visits Report - Phase Three	2001	Sarah Lewis, SCMH UFM Team, KCW User Monitoring Group	
London	KCW User Monitoring Group	Evaluation	User Focused Monitoring: User Led Evaluation of Community Mental Health Services in Kensington & Chelsea and	2002	Karen Doherty, The UFM Interviewer Team	

			Westminster: Phase Four			
London	KCW User Monitoring Group	Site visits	User Focused Monitoring: Site Visits Report: A User Led Evaluation of Inpatient Mental Health Services in Kensington & Chelsea and Westminster - Phase Four	2002	Karen Doherty, The UFM Interviewer Team	
London	KCW User Monitoring Group	Evaluation	User Focused Monitoring: User Led Evaluation of Community Mental Health Services in Kensington & Chelsea and Westminster: Phase Five	2003	Karen Doherty, The UFM Interviewer Team	
London	KCW User Monitoring Group	Site visits	User Focused Monitoring: Site Visits Report: A User Led Evaluation of Inpatient Mental Health Services in Kensington & Chelsea and Westminster - Phase Five	2003 / 2004	Karen Doherty, The UFM Interviewer Team	
London	Opendoor UFM project	Community Support and Residential Services	Opening the Door to User-Led Services User-Focused Monitoring of Opendoor Housing Trust :	Sept. 1999	Opendoor UFM Team & SCMH	
London & National	UFM projects carried out by SCMH	Inpatient and community care	Users' Voices : The perspectives of mental health service users on community and hospital care	2001	Diana Rose	
South East	North Hants User Interviewer Team	Discharge from Inpatient Care	User Led Monitoring of Process of Discharge from Inpatient Care in North	Jan. 2001	Basingstoke UFM team /SCMH	

			Hampshire			
South East	Slough User Led Consultation Project (SULC)	Experiences of Talking Therapies	All Talk	2004	SULC	www.spn.org.uk/index.php?i
South East	Priorities and concerns for change to mental health services in Slough, Windsor & Maidenhead	Recovery	Focus on Recovery	2004	East Berkshire Mind with Slough and WAM localities to provide experience led research	
South West	Bristol User Focused Monitoring Project	3 Inpatient Services	User Focused Study of Inpatient Services in Three Bristol Hospitals	2002	Bristol Mind	www.bristolmind.org.uk
South West	UFM - Bristol Mind	Crisis	Crisis – what crisis? Experience of being in crisis in Bristol	2004	UFM team, Bristol Mind	www.bristolmind.org.uk
South West	Bournemouth User Focused Monitoring Project	External elements of care programme approach	Users Views on the External Elements of the Care Programme Approach	2001	Bournemouth User Focus Monitoring Team	
Wales	National Centre for Public Policy University of Wales, Swansea	Inpatient study	Improving Mental Health Services: The CEFN COED Quality Improvement Programme	Jan. 2002	Jackie McKay & Stephen Craine et al	
West Midlands	Letting Through Light Project	Letting Through Light: Service User Audit	Letting Through Light Service User Audit for North Birmingham MH Trust	July 2002	Dominic Makuvachuma Walker, Premila Trivedi, Peter Ferns	
East Midlands	Springboard Project, Derby	Enhanced CPA	UFM of Enhanced CPA in Southern Derbyshire Mental Health Services NHS Trust	Dec. 2000 Reprinted March 04	Derbyshire UFM team Graham Saxton	
East	Springboard	Experience	User-focused	Sept.	Derbyshire	

Midlands	Project, Derby	of accessing mental health services	Monitoring of what people think about 'access experience' of Mental Health Services within Southern Derbyshire Community & mental Health Services NHS Trust	2002	UFM team Graham Saxton	
East Midlands	Springboard Project, Derby	Non attendance at CMHT follow up appointments	User-focused Monitoring of why people "did not attend" follow up appointments for Mental Health Services within Derbyshire Community & Mental Health Services NHS Trust	Dec. 2002	Derbyshire UFM team Graham Saxton	
East Midlands		Quality of life / care and relation to CPA process	How CPA is linked to the quality of care and life of patients and service users in Southern Derbyshire	Mar. 2003	Derbyshire UFM team Graham Saxton	
East Midlands	Users Support Service, Northamptonshire	Users ASSURT themselves	Service user Audit of the Care Programme Approach in Northamptonshire: 2002	Nov. 2002	ASSURT (Action by Survivors/Service Users Research Team)	
East Midlands	SUMS : Service Users Monitoring Services (Nottingham)	UFM work with three units applying for Practice Development Accreditation (and outline of other work done by SUMS)	The Story So Far …A look at the first two years of work undertaken by SUMS	Oct. 2002	SUMS (now Making Waves)	http://www.makingwavesonli

East Midlands	Making Waves, Nottingham	Survey on use of arts in mental health	??	??	Making Waves	http://www.makingwavesonli
East Midlands	Making Waves, Nottingham	Employees on ‘restricted earnings’	??	??	Making Waves	http://www.makingwavesonli
East Midlands	Making Waves, Nottingham	Audit on service user involvement	??	??	Making Waves	http://www.makingwavesonli
East	User-focused Monitoring of Mental Health Services in Huntingdonshire	Local Mental Health Services	“Services need to think support rather than control”	June 2000	Huntingdon UFM team and SCMH	
?	SULC	Crisis	Crisis Response Team	2004	SULC	
?	Patients Council User Study	Intensive Support Service	Intensive Support Service User Study	1999	Patients Council	