

User Controlled Research

Its meanings and
potential

Report Summary
(Large Print)

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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.

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Further information:

The summary can be downloaded from the publications section of the INVOLVE website www.invo.org.uk or from the Shaping Our Lives website www.shapingourlives.org.uk

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