User Controlled Research

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Introduction

The focus of this scoping review is user controlled research in social care. Growing interest in, and application of, this research approach highlights the timeliness of such a review. The aim has been to produce a review that will be accessible to lay and researcher readers. We have placed user controlled research in its historical and methodological context. We look at the characteristics, strengths and limitations of such research, explore its theory and use examples to illuminate its policy and practice. Social care is concerned with meeting the support needs of a wide range of people, including disabled people, mental health service users, older people and people with learning disabilities. Insights from user controlled research may improve our understanding of social care – how it is offered and also how needs for social care support may be reduced.

Meanings and concepts

User controlled research is the most developed point along a continuum of user or public involvement in research. User controlled research is usually taken to mean research that is actively initiated, controlled, directed and managed by service users and their organisations, exploring subjects and questions that concern them.

The origins and history of user controlled research

Two sources of promotion for user involvement in research can be identified: (i) that from the state, those working in statutory or independent services and mainstream researchers, and, prior to that, (ii) research pioneered by disabled people and other service users and their organisations and movements. The latter have been concerned with developing research that service users themselves are in control of, which is true to their experience and viewpoints, committed to the equalizing of research relationships between researcher and researched and the democratization of the research process. The main aim of such research is seen as liberatory; supporting the empowerment of research participants and the achievement of change in line with service users' rights and self-defined needs and interests.

Such user controlled research has generally been based on:

• social rather than medicalised individual approaches and understandings;

• the rejection of positivist claims to 'objectivity'; and

• a commitment to personal, social and political change.

The concept of control in research is not a simple one. It may be defined in different ways and open to different interpretations. Service users and their movements, however, have identified user control as the defining characteristic of research which advances user knowledge, rights and interests. A series of principles have been identified as the basis for ethical user controlled research.

Policy and practice of user controlled research

User controlled research is not narrowly associated with any particular research methods, although it does have implications for research methods, tending to encourage participatory methods consistent with its principles of democratising research and supporting change and empowerment. It has been particularly associated with qualitative research methods, although to some extent this is because funding restrictions have often prevented the use of larger scale, more costly quantitative and mixed methods. User controlled research has also encouraged the development of innovative research methods, including film, video, social media and activity based methods.

There are many examples of user controlled research in social care from a wide range of service user groups, addressing issues of diversity and a broad range of policy and practice subject matter. While the defining feature of user controlled research is that it is controlled by service users, service users can also be involved in every aspect of undertaking research, from interviewing, to analysis, writing up, dissemination and follow-up action. Some projects are located in user controlled organisations, but others are partnerships or based in university and research organisations. Different routes have developed to ensuring user control in such projects. Helpful insights are also offered by user controlled research in related policy areas, notably in mental health research, where some highly advanced user controlled research has been undertaken, including developing both systematic reviews and randomised controlled trials.

Gaps in user controlled research

While much progress has been made in user controlled research in recent years, there are still significant gaps and weaknesses. Some groups of service users are less well represented among those undertaking user controlled research than others. This reflects broader barriers facing some service users who seek to get involved and this has come to be understood in terms of 'hard-to-reach groups' or 'seldom-heard voices'. Two groups that appear to be particularly under-represented in user controlled research are older people and black and minority ethnic service users. These are important gaps, first because older people are the largest and fastest growing group of social care users and, second, because people from black and minority ethnic communities are known to have unequal access to much social care support and to be more likely to receive devalued and compulsory services than valued, highly regarded ones.

Strengths and benefits of user controlled research

A wide range of benefits are associated with user controlled research. These include:

- the use of service user researchers: who have credibility with and gain the trust of other service users;

- supporting service users to gain new confidence, skills and experience;

- prioritising service users' own concerns and agendas instead of just supporting those of state and service systems: because service users are more likely to ask the research questions that service users see as important;

- a social perspective-based approach to research which takes account of the wider context of service users' lives and does not just see them narrowly in terms of personal deficit and pathology; and

- a particular capacity to achieve change, both because it is a priority of this research approach and because the central involvement of service users and their organisations means that there is a constituency committed to using the research findings to achieve change.

This association with making change connects closely with a current research emphasis on 'impact'; the potential of research to make a social and economic difference. Impact is a complex concept in research. It is particularly associated with the formal measurement of quality in academic research, where it has more recently been framed in terms of advancing social and economic impact. In the context of user involvement in research, impact has also been taken to mean how involvement improves the quality and outcomes of research. Research shows that user controlled research can have a significant and positive impact on research, participating service users, services and national policy (Cotterell *et al.* 2011).

Challenges facing user controlled research

User controlled research currently faces a number of challenges, including inferior access to funding as well as problems of credibility and discrimination. These seem to be rooted in the continuing privileging of positivist research values of 'neutrality', 'objectivity' and 'distance', all of which user controlled research itself calls into question.

Paradoxically at a time when there is increased official and public interest in research which has an influencing impact, the commitment of user controlled research to making change and improving people's lives, rather than solely generating knowledge, has created difficulties for it. Questions are raised about its rigour and impartiality. It is only likely that these will be resolved when user controlled research is sufficiently resourced to be associated with all research methods, mixed, qualitative and quantitative.

Next steps for user controlled research

User controlled research has developed as a significant new research approach in a relatively short time. It has pioneered research in new areas and resulted in a very diverse range of research projects, involving a variety of service user groups. At the same time there are still some uncertainties about its definition, highlighting the need for further work to explore how such research is carried out and how service users are enabled to maintain control and what this actually means.

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There are still serious questions raised about the sustainability of user controlled research. Some of its practitioners remain uncertain about its future. Strategies will need to be developed to address issues of its inadequate and inferior funding, its current limited credibility and what have been described as 'incidents of direct discrimination during the course' of research projects. A series of steps for putting user controlled research on a firmer, better established and better evidenced basis are:

■ strengthening the theoretical basis of user controlled research – to deal better with criticisms of its principles and methodology;

■ building research education and training – both to support the development of user controlled research and to help those concerned with research more generally gain a better understanding of it;

■ rationalising welfare benefits – although involvement in research can offer some service users routes into paid and unpaid work, the direction of travel of the benefits system currently increasingly obstructs rather than supports this and requires reform;

■ equalising access to funding – at present user controlled research receives a disproportionately low level of funding and this situation needs to be reviewed in the light of what user controlled research may have to offer;

■ comprehensively evaluating user controlled research – involving service users and their organisations to gain a better understanding of it, including in an international context;

■ addressing diversity – there still seem to be barriers in the way of some groups of service users undertaking user controlled research, reflecting broader problems in user involvement. Work needs to be done to improve access to undertake such research for older people, black and minority ethnic service users and refugees and asylum seekers;

■ fostering user-led organisations (ULOs) – ULOs provide a particularly supportive home for user controlled research. At present they are under-resourced and insecure, and policy to strengthen their position is key to securing the development and future of user controlled research;

■ including user controlled research in research structures – its proponents need to be ensured equal access to research publications, peer review processes, grant funding systems, reviewing possible barriers and ways of overcoming them; and

■ building alliances and sharing knowledge – much still needs to be done to share the learning from user controlled research including work done by different groups and building new networks and relationships is likely to help with this.

KEYWORDS

User controlled research, social care, methods, public and patient involvement, service user involvement, survivor and emancipatory disability research.

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INTRODUCTION

The focus of this scoping review is user controlled research in adult social care. User controlled research, or as it has also been called, user-led research, is a relatively new research approach that has grown out of the emergence of service user movements and increasing political and policy interest in user involvement.

The aim here will be to set out a comprehensive account of user controlled research in social care that is accessible to both lay and researcher readers. To do this, the review will explore the following:

• meanings and conceptualization;

• origins and history;

• principles, policy and practice;

• research methods;

• current examples;

• gaps;

• strengths and benefits;

• challenges; and

• next steps for the future.

The context of social care

First, it will be helpful to look more closely at social care itself. It is important to acknowledge that social care is not a tightly boundaried area of policy or practice. Traditionally in the post-war welfare state, what has come to be understood as social care have been those services primarily organized by local authorities to provide social support for people. This includes a wide range of adult groups, including people with physical and sensory impairments, older people, mental health service users, people with learning disabilities, with alcohol and drug problems and other long-term conditions, and people nearing the end of their lives. While in the UK, health and social care policy have developed separately and differently, there are overlaps and grey areas between the two. What has encouraged their separation has been the different ways in which they are funded and their separate organizational structures. Thus social care continued after the creation of the welfare state to be a means- and needs-tested local service, while health became a central government responsibility still essentially provided on a universalist basis, free at the point of delivery.

While health and social care are still essentially separate, distinctions between them are frequently not clear-cut, although efforts to integrate them remain unresolved. Also many social care staff, including social workers, are employed in non-social care services. Some services, for example those related to mental health issues, cross over significantly

between health and social care. In addition other broader policies also have a strong bearing on the need for specific 'social care' interventions. More recently there has been an interest in looking beyond specific social care policy and provision to meet 'social care needs', with ideas like 'place-shaping' and 'total place' reflecting the importance placed on preventing and addressing such needs in a joined-up way in all policies (HM Treasury, 2010). We can conclude from this that it is likely to be unhelpful in undertaking this review to take a narrow view of the policy field to be examined, while nonetheless having a primary concern with policy and services concerned with offering long-term social support.

Meanings and conceptualisation of user controlled research

In scoping user controlled research, it is probably clearest and most helpful to begin with a broader focus on user involvement in research or 'user involvement research'. Three strands of such research have been identified (Beresford 2003a; INVOLVE 2012a). These are:

- user involvement in research: where involvement is added to existing research projects, initiatives, organisations and other arrangements;

- collaborative research: where service users and/or their organisations and researchers and/or their organisations jointly initiate, undertake and are involved in the governance of research; and

- user-led or user-controlled research, which is initiated, undertaken and controlled by service users and their organisations.

There are now numerous examples of each of these three approaches to involvement. However, while the distinction drawn here is helpful, overlaps can also be identified (Evans and Fisher 1999). For example, the *Standards We Expect* project, a national study focusing on social care and 'person-centred support', highlighted that while it was a collaborative project, it was also based on principles of user-led or user controlled research (Beresford *et al.* 2011). Some projects which might be categorised as only offering user involvement, through their genuine commitment to meaningful participation, may actually be seen as offering participating service users an effective degree of control. INVOLVE*, the body set up by government to advise on user involvement in health, public health and social care research, also highlights these overlaps, noting:

> In the past we have used the terms consultation, collaboration and user controlled research to describe different levels of involving people in research. Over time it has become clear that in practice researchers can use a combination of these three and it is more helpful to describe them as approaches rather than levels (INVOLVE 2012a, pp. 21–24).

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* http://www.invo.org.uk/

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Thus the categorisation of involvement in research, as indeed its conceptualisation, practice and definition, is complex and subtle. There tend to be overlaps and uncertainties. What this scoping review can helpfully offer is general guidance, rather than narrow or hard and fast rules. Having said that, the commonest and dominant approach continues to be the first of these three approaches – user involvement or consultative research.

The potential reach of user involvement in research is broad. It can extend to:

- identifying the focus of research and research questions;

- commissioning research;

- seeking, obtaining and controlling research funding;

- undertaking the research;

- managing the research;

- collating and analyzing data;

- producing findings;

- writing up and producing publications;

- developing and carrying out dissemination policies; and

- deciding and undertaking follow up action (Beresford 2003a).

User involvement may take place in none, some or all of these domains. There may also be different degrees of such involvement, ranging from low to high, with user controlled research representing its most developed form. We now have accounts of virtually every aspect of user controlled research, from becoming a researcher and the experience of undertaking it, to discussions of the issues raised for user researchers through a wide range of projects (Sweeney *et al.* 2009).

In 2005, INVOLVE published the first detailed exploration of the definition and potential of user controlled research (Turner and Beresford 2005a). This study was based on both a survey of existing user controlled research and feedback from service users with an interest in such research. INVOLVE's aim was not to impose a single definition of its own on user controlled research, but to get a clearer idea of service users' thinking about its definition. This revealed considerable consensus among service users about how user controlled research might be defined. The views of other stakeholders, like mainstream researchers, have not yet been sought in a coherent way. INVOLVE (2007) subsequently offered its own short definition of user controlled research, drawing on this study, which states that:

> 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.

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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 (p. 23).

Because of the lack of agreement and ambiguity that this suggests, and because this term is now more commonly used, in this scoping review the term user controlled research is used in preference to user-led research.

THE ORIGINS AND HISTORY OF USER CONTROLLED RESEARCH

There have been two overall strands to the development of user involvement in research. This reflects the development of user involvement more generally. The origins of these developments can be described as:

1. researchers, research related organisations and broader political pressures for participation; and

2. service users, their organisations and allies.

1. Broader pressures for involvement in research

A significant date relating to the emergence of user involvement in research was the establishment in 1996 of the government body *Consumers in NHS Research* (subsequently NIHR INVOLVE). This body was established to advise on how best to involve members of the public in health research. By 2001, its role had been expanded to include public involvement in public health and social care, as well as health research (INVOLVE 2011). People with experience as service users and from service user organisations are included in the membership of INVOLVE's advisory group.

Public, patient and service user involvement has increasingly become routine more generally in research – in many cases it is required in both statutory and independent research. Evidence of such involvement in formulating and undertaking research is increasingly demanded by research funders and commissioners. Such user involvement is also beginning to take place more often in:

• identifying and setting research agendas;

• research structures, institutions and organisations;

• in research project advisory and steering groups;

• purchasing research;

• the development of research methods and methodology;

• in the selection of research for funding;

• in the recruitment and promotion of researchers;

• research training and education;

• in research publications;

• in editorial roles and peer review processes in research journals and other publications; and

• in the organisation of conferences and contributing speakers and speaking on research platforms

Examples of all of these can readily be found, although it would be a mistake to assume that such involvement is now comprehensively and systematically in place, or an accepted feature of the research landscape.

There is now a very wide range of examples of user involvement in social care research. These range from projects assessing the accommodation, health and social care needs of gypsies and travellers and surveying carers of people with heart disease, to studies exploring the impact of involvement on palliative care service users and identifying lesbian, gay, bisexual and transsexual people's needs and achieving change in local services ((TwoCan Associates 2010; Cotterell *et al.* 2008; Browne *et al.* 2012).

The focus of mainstream interest in user involvement in research has generally been on seeking and including the views of service users in the research process. In this it reflects broader interest in user involvement in policy and practice. Here the aim is to obtain external input which initiating agencies, which may be central government, service providers or local policy makers, decide what to do with. This can be seen as very much a market research or consultative approach to involvement. This approach, which primarily has its origins in managerialist/consumerist ideology, also seems to underpin prevailing interest in user involvement in research. Research serves as both a means of enabling such involvement, as well as a site for its operation (Beresford 2003a; Littlechild and Kemshall 2000; Lowes and Hulatt 2005).

2. Pressures for involvement in research from service users, their organisations and allies

As Marian Barnes (2002) has argued, self-organization among users of social care and welfare services preceded the consumerist developments of the 1980s and early 1990s. Interest in research from service users correspondingly began much earlier than broader interest, first emerging from the late 1960s and early 1970s. This was led by disabled people and, significantly, they identified research as a key area of concern. The starting point for this was the desire of a group of disabled people to 'live independently' outside of a residential home. The origins of the emancipatory disability research developed by disabled people is frequently traced to this event (Oliver 1996; Barnes and Mercer 1997a).

Feeling that their views were ignored, these disabled people thought that the Leonard Cheshire residential home, Le Court, where they lived, might take more notice of research evidence. They therefore invited academic researchers in to study the situation. However, the researchers concluded that these disabled people were not capable of 'living independently' outside of institutions, but instead saw them as 'parasites' (Miller and Gwynn 1972). As a result, the disabled people involved saw the research as tied to the assumptions and values of the service system, which they experienced as discriminatory and oppressive, rather than independent. One of the disabled people involved, Paul Hunt (1981, 1998), who has subsequently been identified as a founder of the UK disabled people's movement, in turn described such researchers as 'parasites', questioned the 'balance' and 'neutrality' of traditional disability research and raised the question of 'whose side are you on?' which subsequently became a central concern of disability research.

This experience had far-reaching effects for disabled people and their emerging movement. They concluded that they could not trust existing research but instead must develop their own. This led to the emergence of the 'emancipatory disability research paradigm'. This should not be seen as an isolated development. Disabled researchers came to be influenced by the 'critical' and 'new paradigm' research of feminists, black writers and educationalists who allied themselves with oppressed groups (Reason and Rowan 1981) and who challenged traditional positivist assumptions about the possibility and appropriateness of values of neutrality and objectivity in research (Friere 1972; Roberts 1981; Maguire 1987; Morris 1992).

The ideological basis of user controlled research

While mainstream interest in user involvement in research has reflected the prevailing managerialist/consumerist approach to involvement in public policy and practice, interest among service users and their organisations seems to reflect the democratising impulse which has characterised modern movements of disabled people and service users more generally. This is primarily concerned with people having more say over their own lives and over agencies, organisations and institutions which impact upon them. Thus, service users' interest in participation has been part of broader political and social philosophies which prioritise people's inclusion, autonomy, independence and the achievement of their human and civil rights. Participation has been one expression of a concern for people to be able to act and speak on their own behalf. It has been framed primarily in terms of involvement through collective action through people's independent self-organisation (Campbell and Oliver 1996; Campbell 1996; Oliver and Barnes 2012).

Although there are undoubtedly overlaps, there are also important differences between these two approaches to participation – the managerialist/consumerist and democratic – which are likely to have significant ramifications for user involvement in research. Both approaches may be concerned with influencing and achieving change. However, the first approach is concerned with gaining external input which the initiating agencies – state, service providers or policymakers – retain control of, and themselves decide what to do with the knowledge produced.

The latter, democratic, is concerned with enabling participants to have the direct chance and capacity to influence change. It is concerned with power and the redistribution of power. Thus, the two approaches to user involvement do not necessarily sit comfortably together. One is managerialist in purpose the other liberatory. The logic of the democratic approach is for user-led or user controlled services and research. The managerialist/consumerist approach is compatible with the maintenance of a provider-led approach to policy, provision and indeed research (Beresford 2000, 2003b).

Principles of user controlled research

While the origins of user controlled research can be traced to the disabled people's movement, other groups of health and social care service users also began to undertake their own research. This included older people, mental health service users/survivors and

people with learning disabilities. Different terms have come to come to be used to describe such research, for example, 'user research' and 'survivor research'. An INVOLVE study concluded that user controlled research was closely linked with emancipatory disability research and 'survivor research'. It took the view that it was not always clear whether these terms demarcated different research approaches or were used interchangeably. Essentially they could all be used as expressions of user controlled research and synonymous with it generally (Turner and Beresford 2005a). Control by service users is seen as the key and unifying characteristic of such research.

In the context of disability, as we have seen, user controlled research has been framed primarily in terms of research playing an emancipatory or liberatory role in people's lives. User involvement is thus seen as a necessary, but not necessarily sufficient condition for research to improve the lives of disabled people collectively and as individuals. It has generally been treated by disabled researchers much more as a means to undertaking helpful research rather than as an end in itself. Thus the emphasis has been on emancipatory rather than participatory research (Mercer 2002).

Over twenty years ago, Mike Oliver (1992), the disabled activist and academic, saw the emancipatory disability research project in these terms:

> The issue then for the emancipatory research paradigm is not how to empower people but, once people have decided to empower themselves, precisely what research can then do to facilitate this process. This does then mean that the social relations of research production do have to be fundamentally changed; researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose (p. 111).

This raises the question of whether such research can be truly emancipatory. The key point is that its aim is to be so, not that it can always achieve this goal (Oliver 1997). After reviewing existing discussions, Emma Stone and Mark Priestley (1996) identified what they saw as six principles characterising the emancipatory research paradigm. These were:

- the adoption of a social model of disability as the ontological and epistemological basis for research production;

- the surrender of falsely-premised claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation;

- the willingness only to undertake research where it will be of some practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers;

- the devolution of control over research production to ensure full accountability to disabled people and their organisations;

- the ability to give voice to the personal while endeavouring to collectivise the commonality of disabling experience and barriers; and

- the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people (see also Priestley 1997).

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The social model of disability

As can be seen, these criteria include how such research is conceived as well as how it is undertaken and its purpose. Stone (1997) observed that the emancipatory research paradigm has been 'inseparable from the social (oppression) model of disablement'. This model, first highlighted by the Union of the Physically Impaired Against Segregation (UPIAS) (1976) and subsequently developed by Mike Oliver (1996), has been central to the UK disabled people's movement. It draws a distinction between disabled people's individual perceived *impairment* and the (negative and discriminatory) societal response to it, which it describes as disability. The social model of disability is a contentious and developing idea (Thomas 2007). Stone (1997), for example, has argued that where the social model 'falls short', where it proves 'culturally and linguistically untranslatable' or where it has not adequately been developed in relation to some groups, for example, mental health service users, people with learning disabilities and people from some black and minority ethnic communities, then it may be an unhelpful basis for an emancipatory paradigm.

However, it can also be argued that the social model of disability is dynamic rather than monolithic. There is no reason why emancipatory disability research should be tied to a narrow or static interpretation of the social model. Nor are its alternatives, traditional medicalised understandings of disabled people and service users, likely to be helpful as a basis for research – although they are still central to much disability and mental health research. Significantly, other user groups undertaking research also place an emphasis on the value of a social/barriers approach as an underpinning feature (Faulkner 2009), while the problems of medical models continue to be highlighted by service users more generally (Beresford *et al.* 2010). So, while it might be unhelpful to constrain any understanding of user controlled research through the imposition of a narrow interpretation of the social model of disability, an emphasis on social approaches does seem to have characterised user controlled research. However, as mental health service users/survivors, for example, highlight, this should not be taken as meaning an acceptance of, or even familiarity with the social model of disability (Beresford *et al.* 2010).

Three core concerns characterise the emerging emancipatory disability research paradigm. They are strongly associated with user controlled research developed by other groups of service users. These are that research is:

- concerned with changing and equalising research relationships between the researcher and the researched;

- seeks to advance the personal empowerment of participants and service users; and

- prioritises making broader political and social change in line with the rights and interests of service users.

These concerns constitute the core methodological base of user controlled research.

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Whose research?

User controlled research has its origins in controversy and conflict. There has been significant disagreement over who can do emancipatory disability and other user controlled research. The personal and 'political' position of the researcher has come in for scrutiny. Can only disabled people or service users undertake such research (Stone and Priestley 1996; Priestley 1997)? Paul Abberley (1992), the disabled sociologist, for example, highlighted and challenged the traditions that disabled people are treated predominantly as 'passive research subjects', while researchers tend to be non-disabled people (Abberley 1992). This can perpetuate feelings of exclusion or passivity among participants (Priestley 1997). As Tom Shakespeare (2006) has written:

> Ever since [Miller and Gwynne's] research there has been a suspicion of non-disabled researchers who have been seen as parasitic on the lives of disabled people…The idea that having an impairment is vital to understanding impairment is dangerously essentialist (p. 195).

He added:

> Just because someone is disabled does not mean they have an automatic insight into the lives of other disabled people. One person's experience may not be typical and may actively mislead them as to the nature of disability (p. 195).

Since then further insights have emerged about who might be undertaking such research through exploration of who should be in control of it. This brings us back to the issue of control in relation to user controlled research.

The complexity of control in research

Control of the research by service users, as might be expected, emerged as the key and defining characteristic of user controlled research in the INVOLVE study (Turner and Beresford 2005a). Such control was variously seen to lie with service users generally, service users who were the research participants and also with service users' (self) organisations. Emphasis was placed on control of research not lying with non-service users. Service users saw 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. However, while service users tended to highlight the importance of user control in all aspects and stages of user controlled research, it was not always seen as essential that service users undertake all research tasks and activities. Where there did seem to be agreement was that people should be under the control of service users. This issue was a particular subject of discussion in relation to whether a researcher should be a service user. The INVOLVE study reported no consensus about this. People seemed equally split on the issue. Arguments for and against using service users as researchers were raised by service users themselves. Thus, the question of who can do research seems to have been superseded by the issue of who controls the research, as far as service users are concerned.

But the question of who is in control is not easy one to answer. A national study of networking and knowledge among service users highlighted some of the complexities associated with the nature and meaning of user control and user controlled organisations (Branfield *et al.* 2006). Typically, a user controlled organisation has been defined as one where at least a majority of those in control, through the management body or board of trustees, are themselves disabled people or service users. However, in Branfield and colleagues' study, participants felt that control should exclusively lie with service users, who should make up the whole governing body, otherwise, non-service user representatives might take over. Even if the entire board comprised service users, there were concerns about non-service user staff taking control. In recent years, with the rebranding of traditional large disability and other charities, some have presented themselves as user controlled, although some service users would argue that their culture, goals and operation remain essentially unchanged and do not reflect the values and goals of self-organisation.

Branfield and colleagues' networking and knowledge project highlighted a strong perception among many service users that, in practice, not all organisations which claimed to be user controlled actually were. Another problem reported by service users and their organisations was that the fragility and inadequacy of their funding restricted their freedom and forced them to pursue activities for which they could gain funding, rather than those which they might prefer to prioritise. Thus, they were essentially funding-driven rather than user-led. Particular problems in maintaining user control in both organisations and projects have also been highlighted by people with learning disabilities, who can come under especial pressure from non-disabled collaborators, supporters and service providers (Taylor *et al.* 2008).

Issues may also be raised where research projects which are themselves essentially controlled by service users are nonetheless located in organisations which themselves do not claim to be user controlled. This has particular resonance for survivor research since many of the best known and largest research projects have been located in such organisations. This has, for example, been true of the original user focused monitoring project based at the Sainsbury Centre for Mental Health (Muijen 1998; Rose 2001; Davies 2009) and the Strategies for Living project based at the Mental Health Foundation (Faulkner and Nicholls 1999; Faulkner and Layzell 2000; Nicholls 2001). Each of these developed major innovative programmes of work in relation to user controlled or survivor research, developing research and training, building capacity, pioneering new research methods and approaches. Non-service user controlled organisations may not have the same priorities as user controlled ones and this can affect the importance they give to user controlled research (Lindow 2001; Beresford 2004). Thus, both the Sainsbury Centre for Mental Health and the Mental Health Foundation decided to end the important initiatives that they had established in this area, despite the value attached to them by service users and service user researchers.

User Controlled Research

However, another side to the story is highlighted by the Service User Research Enterprise (SURE) project based at the Institute of Psychiatry, King's College London (SURE 2002). The project undertakes large-scale mixed method research projects. Being based in a university has helped it gain access to funding for large-scale, international projects. On the issue of 'control' Diana Rose (2010), its Co-Director, as a service user researcher, says:

> It is a non-user-controlled setting. It all depends what you mean by control. Over the years I have developed more autonomy in research projects. I get a lot of scope [for user control] because I manage the projects. But I don't feel I have complete control when it comes to what goes into the publications (personal communication).

Ethics for user controlled research

Alison Faulkner (2009) , a survivor researcher and consultant, drew on two key sources for undertaking ethically based survivor research or service user involvement in research: SURGE (2005) and Faulkner (2004). She reiterated principles, which have wider relevance for user controlled research and which, as we have seen, are frequently identified, of:

- empowerment;

- a commitment to change;

- clarity about the underlying theoretical approach employed – to make explicit the values and beliefs signed up to; and

- accountability.

She also highlighted some additional principles:

- clarity and transparency – crucially to help build trust between researchers and service users – 'the importance of … honesty cannot be overstated, and is closely connected with the second principle, respect';

- respect;

- flexibility; and

- accessibility – which takes account of service users' possible lack of familiarity with research settings, their need for support to be involved on equal terms diversity – the need to address diversity and people's access needs (pp. 14–15).

Service users' discussions about the principles and ethics of survivor research go far beyond concern with ethics procedures and are much more concerned with how such research is able to ensure the more equal relations and transparent process of research that have been prioritised by proponents of user controlled research. Indeed existing research procedures, like research ethics committees, tend to be seen as problematic and another barrier in the way of inclusion and involvement in research. A distinction is often drawn between existing procedures and participatory values (Fulford and Wallcraft 2009; Glasby and Beresford 2007).

Ethics and research governance

In some of the earlier writings about user involvement in research, there was a tendency to underplay the need for research skills and competence because of concerns that this would perpetuate the appropriation and professionalization of research. User involvement in research, and no less user controlled research, is as likely to require skills, experience and training as any other form of research. However, the nature and focus of such skills, experience and training may sometimes be different. All the issues that apply and tasks that are required for traditional research are likely to be needed for user controlled research. This includes matters like safety, confidentiality, data protection and storage, team working and management – all the activities that come under the heading of the administration, ethics and governance of research. User controlled research is actually defined in terms of its governance i.e. control by service users. The key issues this raises for ethics and research governance are that service users are central to the process and purpose of research. As Faulkner (2009) has highlighted, research structures need to allow for this; enabling the building of relationships between service users and researchers (including user researchers), if control is truly to lie with service users.

POLICY AND PRACTICE OF USER CONTROLLED RESEARCH

Research methods

In one sense, user controlled research has not been associated with any particular research methods (Barnes and Mercer 1997b). As the first INVOLVE study concluded, it can include a wide range of research methods (Turner and Beresford 2005a). What seems to be key to the methods used in such research is that they are consistent with the emancipatory and egalitarian values and goals that it has developed. As Oliver (1997) has commented:

> I am not sure whether interviews, questionnaires, participant observation, transcript analysis, etc., are compatible or incompatible with emancipatory research. I am convinced, however, that such techniques can only be part of an emancipatory project where, and only where, the social relations of research production have been changed (p. 21).

This has had implications for research methods. The aim has been to equalise and humanise them. Thus, emphasis is placed, for example, on research interviewers having shared experience with mental health service users/survivors who will understand the experiences of research participants, value and believe what they say and be better equipped to frame questions in appropriate and meaningful ways to them. This has been a commitment of the user focused monitoring project (Rose *et al.* 1998). Similarly, the emphasis on feeding back to research participants to keep them informed about findings and what has been done with what they have said is a central principle.

As we have seen, while it has not been tied to any particular methods, user controlled research has been particularly associated with qualitative research approaches. This is significantly because of their association with less mechanistic and more human methods of gathering and sharing information and knowledge. But this tendency has also been related to the resource restrictions operating on user controlled research and the fact that there have been fewer opportunities to undertake larger mixed method and quantitative research projects.

The examples of user controlled research surveyed for INVOLVE (Beresford *et al.* 2009) highlight that there is no one way to undertake such research. Indeed, flexibility, innovation and originality in approach and methods seemed to be at a premium. The project included examples where very different research methods were employed. West England Centre for Independent Living (WECIL) and the Norah Fry Research Centre at Bristol University used video in work with people with learning disabilities, and Change/Leeds University used drama with people with learning disabilities (Beresford *et al.* 2009). The case studies of user controlled research subsequently reported by INVOLVE used a variety of methods. These included focused events in which people shared their experiences, and the more conventional use of questionnaires, interviews, and focus groups (Faulkner 2010).

The final part of the Joseph Rowntree Foundation's Independent Living programme entailed the making of a film, *Who Has The Power In Your Care Set-up?* (Hevey 2012). This

was led by a 'Service User Reference Group' and in the view of the research officer responsible for the project was an example of user controlled research (Alex O'Neil, personal communication, September 2012). The Reference Group selected the winning bid, decided on the focus and script, and met regularly with the filmmaker. The film focuses on the views and experiences of eight people who are social care service users. Significantly, there were mixed views about the final cut of the film, although it worked for a majority of the Reference Group. The film has subsequently been widely shown as part of a process of seeking to make change in policy and provision.

Examples of user controlled research

The survey of user controlled research projects commissioned by INVOLVE identified 53 projects in the UK (Beresford *et al.* 2009). The themes they addressed were so wide-ranging that it was 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 looked at treatment or support services. Not all of the projects could be said to have a social care focus, although a large number did.

Twenty of the projects surveyed were studied in more detail. This revealed that over half involved a study of views or experiences (11), focus groups (12), interviews (10), surveys or observations (6 and 7 respectively). User controlled research seemed to give service users the opportunity to focus on issues that they regarded as important and wanted to address and then to 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 disabilities at a specialist college and the effectiveness of a NHS Trust's young people's liaison officers (Beresford *et al.* 2009).

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

User Controlled Research

A year later, NIHR INVOLVE's (2010) *Changing Our Worlds* study reported in detail seven case study examples of user controlled research. Five of these were closely concerned with social care. Their focus was on:

- what people wanted from personal assistants as a basis for providing training for them;

- exploring hate crime against disabled people;

- identifying the needs and hopes of lesbian, gay and bisexual disabled people in a local area;

- influencing and shaping children's and youth support services; and

- finding out about the issues, barriers and needs encountered by different service users involved in building networks and relationships locally.

The INVOLVE study examined the origins and control of each project, things that helped and things that hindered it, what difference it made and what advice to others undertaking user controlled research. The projects employed different approaches to undertaking the research. Some employed service user researchers, some adopted a 'capacity-building' approach in which service users were trained and supported to participate as researchers, and one undertook a clinical study coordinated by the group. Common to all of the projects was a shared identity between the researcher(s) and the research participants (Faulkner 2010). The projects also reflected much user controlled research more generally in that most were based in user controlled organisations. Some of the projects identified in INVOLVE's 2009 survey of examples of user controlled research were also based in universities and some in partnerships between them and user controlled organisations (Beresford *et al*. 2009). The main benefits identified for user controlled research in Faulkner's (2010) study were:

- making change happen;

- improving access and trust;

- empowerment; and

- increased credibility.

Nearly all the projects included in the study 'had achieved what they had set out to do, in making change happen' (p. 9).

Shaping Our Lives is an example of a user controlled organisation which has a history of undertaking user controlled research. It has undertaken large- and small-scale research projects, on both a local and national scale, and has also been involved in some international research developments. Research projects have been funded by both government and independent research funders. The focus for projects has tended to develop from the wider work of Shaping Our Lives, seeking to increase the involvement of service users and improve the quality of their lives and support. This means that the research agenda has tended to respond to the concerns of service users and their

organisations more generally, particularly following the development of Shaping Our Lives networking website, SOLNET*. While it has undertaken distinctly user controlled research projects, it has also been involved in collaborations (Branfield *et al.* 2006, 2009, 2010; Moriarty *et al.* 2007; Beresford 2013).

A major example of mixed method user controlled research undertaken in the context of disability studies was Barnes and Mercer's (2006) study of user-led disability services. This was a user controlled research project, employing an emancipatory research approach, based on a social model of disability and using mixed methods. It included nine case study sites. The research was carried out at the Centre for Disability Studies at Leeds University (formerly the research unit of the British Council of Organisations of Disabled People). Initial aims and objectives were identified by a steering group of disabled people's organisations and the project was steered by a committee of disabled people. The three main aims of the project were to:

- provide a critical evaluation of the development, organisation and services provided by Centres for Independent Living (CILS) and similar user-led initiatives in the UK;

- to identify the principal forces – economic, political and social – hindering their future development; and

- to produce and disseminate, in a variety of accessible formats, findings and recommendations to disabled people, their organisations and policymakers in both public and private sectors.

The range of groups involved in such research

The diverse range of service users undertaking their own research was a feature of the two studies of examples of user controlled research commissioned by INVOLVE (Beresford *et al.* 2009; Faulkner 2010). While the first of these studies included projects undertaken by people with physical and sensory impairments, older people, people with learning disabilities and mental health service users, it also included other service user groups, including young people and people with alcohol issues. Having said that, however, the largest group of examples came from mental health service users and people with learning disabilities, although this distribution does not necessarily reflect the overall picture of social care users (Beresford *et al.* 2009). We might still expect people with physical and sensory impairments to be most active here.

People with learning disabilities

One of the groups of social care service users that has offered particularly helpful insights into undertaking user controlled research are people with learning disabilities. In the early days of user controlled research a common question raised – even if it was not publicly stated – was how much were service users actually capable of undertaking research themselves, particularly good quality research? A group where such doubts and suspicions

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* www.solnetwork.org.uk

have lingered (again generally not formally spoken) has been people with learning disabilities, a group, of course, which has significantly been defined by the perception of intellectual impairment.

Knowledge about people with learning disabilities has traditionally been produced and controlled by other groups, predominantly non-disabled, professional people. Such knowledge was used to justify their segregation and institutionalisation. As Boxall (2004) has highlighted 'the role of the dominant epistemology of the academy … works to prohibit people with learning difficulties from being producers or knowers of their own knowledges' (p. 3).

In the last few years several initiatives have developed to enable people with learning disabilities to undertake their own research. One of the problems with much of this, however, has been that it has been difficult to be clear what the role of people with learning disabilities and their supporters and non-disabled researchers has actually been. This problem has been accentuated because often the language used and the forms employed have looked more like the product of conventional researchers than of anyone else. This issue has been explored in detail by Vic Forrest in his 2009 study of supporting people to undertake their own research project. While he highlights the frequent lack of detail in accounts of the process of research ostensibly being undertaken by people with learning disabilities, he also sets out in detail how a truly supportive role can be played by non-disabled people, which can enable a diverse range of people with learning disabilities to undertake their own research and to follow it up with dissemination and action. A powerful example of this is the associated study by a group of people with learning disabilities, called *We Are Not Stupid*, which explores the barriers they face and how they think these should be overcome (Taylor *et al.* 2008).

Ensuring user control

There are different ways in which service users seek to maintain and express their control over research projects. Involvement is often focused around advisory and steering groups, but there are also good examples of projects where service users have come together to identify an issue that they thought needed investigation and they set up and steered the project. The Women's Independent Alcohol Support project was started by an independent service user who was able to get support from an NHS Trust and then used the finances to involve users in an advisory group (Beresford *et al.* 2009).

As we have seen, the idea of user control is complex and much discussed. There is not complete agreement about what it means. Faulkner (2010) concluded that:

> Absolute control depended on service users having independent funding (and having control of that funding) as well as a user controlled organisational base

adding that:

> although the extent of control varied across the seven projects, having control over the research was seen as vital by all of them (p. 43).

On the other hand, sometimes the issue of user control appears to be more straightforward, as in, for example, one study carried out at the Centre for Recovery in the University of Hertfordshire. Here 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 (Beresford *et al.* 2009).

USER CONTROLLED RESEARCH: LEARNING FROM RELATED AREAS

While the focus of this scoping review is user controlled research in social care, it is likely to be helpful, for a number of reasons, to extend the scope of enquiry beyond social care. Since user controlled research is research shaped by service users and reflects their agendas and priorities, it does not necessarily follow the administrative boundaries of conventional public policy. Instead it is much more shaped by their broader life concerns. Thus, it tends not to be narrowly fixed in specific social care activities, crossing over into other policy areas that may concern them.

In addition, the overlaps between social care and other policies, for example, physical and mental health policy and provision, means that there is much to learn from these related areas, which work with and involve similar groups of people. Given that one of the problems relating to meeting social care needs is the failure to ensure adequate integration of services, notably between social care, health and housing, it may be helpful to draw on examples of user controlled research both from related policy areas and which cross-over policy divides. Fourteen of the 53 examples of user controlled research identified by INVOLVE (Beresford *et al.* 2009) could be linked with fields that either overlapped with or came outside social care. These included projects concerning with:

- general user involvement issues;
- specific health issue/impairment issues;
- maternity and maternity services;
- health education; and
- alcohol-related issues.

There were projects with a focus on breastfeeding support, chaplaincy and spiritual care, LGBT issues, radiotherapy, patient safety, friendships, relationships and mentoring (Beresford *et al.* 2009).

As we have seen, the development of user controlled research has been particularly advanced and conspicuous among mental health service users. Particularly important here has been the work of SURE, where service user researchers have developed new approaches to quantitative research which are more consistent with the process, aims and values of user controlled research. Given the priority and credibility conventionally attached to quantitative research, this development has a particular significance.

SURE has carried out large-scale international systematic reviews and randomised controlled trials (RCTs). While RCTs have been seen as offering a research 'gold standard', service users have questioned the assumed 'neutrality' of their measures on the basis that their outcome measures are typically defined by clinicians and researchers. Survivor researcher Diana Rose and her colleagues have developed a different approach based

primarily on service users' views and experiences. Here the process is to:

- bring together focus groups of service users with relevant experience with user facilitators;

- tape record and transcribe discussions and check frequency of issues identified for discussion at follow up focus group meetings;

- create a mixed method questionnaire with open and closed questions to be discussed and checked by 'expert' panels of service users with relevant experience, facilitated by service users. Check accessibility of language and correct duplication of questions; and

- pilot the questionnaire through a feasibility study with 50 service users completing the questionnaire, to gain their views, and modify accordingly.

This process has now been employed in four studies, including studies of acute mental health wards and of continuity of care (Rose *et al.* 2008, 2009). An RCT has explored differences between conventional and service user interviewers and a model for developing user-generated outcome measures (Rose *et al.* 2011a, 2011b; Evans *et al.* 2012).

Rose and colleagues have also developed 'patient-centred' systematic reviews, the best known of which explored service users' views of ECT (electro convulsive therapy). This was undertaken by two user researchers who had themselves received ECT and it included so-called 'grey literature' and personal testimony as well as conventional peer-reviewed journal articles (Rose *et al.* 2003, 2005).

New technology is also making possible novel methods of undertaking and disseminating user controlled research, including making use of social media and networks. This has been demonstrated in the related field of welfare reform, which is having an unprecedented impact on social care users. User-led initiatives like the 'Spartacus Group' sum up this new development. Inspired by disabled people and service users, they have generated massive interest and powerful and celebrity supporters, and made an enormous impact through their effective use of social media. The first Spartacus report, *Responsible Reform*, challenged the Government's evidence for its Disability Living Allowance reform. The report was entirely written, researched, funded and supported by sick and disabled people, their friends and carers. Its publication gained high visibility and widespread support (Diary of a Benefit Scrounger *et al.* 2012; Butler 2012). The report went 'viral' and helped in inflicting several House of Lords defeats for the Government's welfare bill. A follow-up report focused on the economic ineptitude of proposed reform to the Motability Allowance (Campbell *et al.* 2012).

GAPS IN USER CONTROLLED RESEARCH

Overall, a wide range of service users seem to be carrying out user controlled research. Examples from a wide cross-section of user groups can be identified. While interest in user involvement more generally, across policy and practice, has developed since at least the 1980s, some groups are still much more likely to be heard and listened to than others. We know that some people and groups face particular barriers and are especially likely to be excluded from involvement initiatives (for example, Robson *et al.* 2003; Begum 2005; Rainbow Ripples and Butler 2006; Morrow *et al.* 2012; Beresford and Branfield 2012). Such groups have come to be called 'hard-to-reach' or 'seldom-heard voices'. A Department of Health-funded project focusing on such exclusions found that a very wide range of service users tends to be left out (Beresford 2013). The reality is that people who face barriers to their involvement in wider society and are more likely to be socially isolated are also more likely to be excluded from participatory arrangements in society. Such exclusions seem to be linked with five key issues:

- equality issues (gender, sexuality, disability, culture, class, race, etc);

- where people live (in institutions, homeless, travellers, etc);

- communication issues (not communicating verbally, english not first language);

- the nature of impairments (having complex and multiple impairments); and

- unwanted voices (offering challenging and different viewpoints).

Such exclusions are reflected in user involvement and user controlled research. INVOLVE's first study of examples of user controlled research referred specifically to gaps in relation to deaf people, projects from the emancipatory disability research tradition, older people, and black and minority ethnic communities (Beresford *et al.* 2009). These last two seem to demand particular attention.

Older people

Older people are the largest group of social care service users. Yet they are undoubtedly under-represented in user controlled research. This reflects the broader situation in user involvement, where older people tend to be left out. There may be many reasons for this, not least the level of ageism in our society, the reluctance of many older people to associate themselves with this identity, or to see themselves as disabled people with the onset of impairments.

There are examples of older people's involvement in research (see, for example, Seymour 2011). There are also exceptions to the lack of older people's involvement in user controlled research. One such is a co-operative of older people, Older People Researching Social Issues (OPRSI), who both carry out their own research and collaborate with other researchers in undertaking user involvement research. For example, members of OPRSI carried out a user controlled research project exploring older people's perspectives on the

role and importance of hospital visiting. Data were collected from nine focus groups whose participants' ages ranged from 50 to over 90 years (Hawkes *et al.* 2008, Green *et al.* 2012; Cornes *et al.* 2008).

Another is the Shaping Our Age Project, a three-year UK national research and development project funded by the Big Lottery Research Programme, exploring older people's definitions of and involvement in improving their wellbeing. This is a partnership project between the WRVS and two universities, and is organised on principles of user controlled research, i.e. it has involved older people in all its aspects and is steered by an Older People's Reference Group (OPRG) (Fleming *et al.* 2011; Hoban *et al.* 2011).

However, in general, older people's involvement in user controlled research does seem to be under-developed and this point was made by one academic supporting such older people's research:

> [There is a] lack of user controlled research. For me the main issue is around a lack of understanding about what this actually is. What was disappointing about [one project] was that the usual happened in that the people who commissioned the study all got moved on (the Primary Care Trust got abolished) so very little use was ever made of it. Also, no one ever seemed to grasp just how special a study it was, given its status as 'user controlled' (Cornes, personal communication, September 2012).

Black and minority ethnic communities

While black and minority ethnic (BME) service users are involved in some user controlled research projects, so far relatively few BME user controlled research projects have been identified. INVOLVE's 2009 report on examples of user controlled research did reveal some examples of good practice in involvement of BME service users in research, but significantly, little indication of user controlled projects. The reflections of the consultant involved in that project offer some helpful additional insights. The issues she raises in relation to user controlled research, may apply to research overall. 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! (Beresford *et al.* 2009, p. 15).

STRENGTHS AND BENEFITS OF USER CONTROLLED RESEARCH

While critics of user controlled research have sought to challenge its rigour and effectiveness, criticizing it as partial and subjective, its advocates and initiators make the case that it can bring additional strengths and benefits to research. They do not see this as just a moral or ethical argument, that user involvement in research and user controlled research are better for reasons of principle, although this has also been seen as one of its values and virtues. They also advance the intellectual argument that it leads to better quality research.

Faulkner (2010) rehearsed some of these arguments in her report of examples of user controlled research. She reinforced other reports from the examples she studied, highlighting that service users were empowered in the process of undertaking the research and that the research served to increase the credibility of service users and their organisations. Service users, their organisations and others have identified a range of benefits which they particularly associate with user controlled research. These are key to the impact they see it as having and can be classified in the five following areas.

The use of service user researchers and interviewers

While this is not restricted to user controlled research, it is particularly associated with it. The User Focused Monitoring project, for example, which explored service users' views about the quality of services and support, highlighted the value of having service user, rather than non-service user interviewers, in building trust, improving communication and encouraging research participants to offer fuller, more frank responses (Rose 2001, 2009b). Faulkner (2010) reported that:

> The increased accessibility that this shared identity brought with it was central to the success of the research. The value of this was illustrated by, for example, a Deaf researcher who could communicate with Deaf participants using British Sign Language, young people in care talking to other young people in care, and the value of people with learning difficulties seeing a person with learning difficulties facilitating and leading a group. This essence of trust established through breaking down the barriers of power between the researcher and the researched was important to all of the projects (p. 46).

Exploring service user agendas for research

In 2002, the Department of Health organised a consultation with mental health researchers to identify future priorities for mental health research and development. This strategic review included a national consultation with mental health service users/survivors. It revealed that service users' research agendas were different from, much broader and more socially related than those of existing researchers, which were much more narrowly focused on the psychiatric system and individualized responses to mental health issues (Department of Health 2002). User controlled research is based on the

principle of starting from the research concerns and research questions of service users and their organisations. The 'insider knowledge' it is based on also ensures that the research addresses 'the right questions, and [is] interpreted by people with an understanding of the nature of that lived experience' (Faulkner 2010, p. 47).

A social perspective based approach

User controlled research tends to be based on social rather than narrow individualised understandings. It generally challenges dominant medicalised individual models which service users frequently find unhelpful adopting a more social perspective (Tew 2005; Faulkner 2010). This is of value for social care research, where social and personal factors operate in complex inter-relation and where traditional medicalised research has frequently failed adequately to address all aspects of the issues affecting people.

A particular capacity to bring about change

A frequently expressed concern of service users is that they do not want research just to result in publications that gather dust in office cupboards. The concern with research being linked with action and resulting in change is articulated by all service user groups who undertake their own research. This is a core concern of such research and has been since the early days of emancipatory disability research pioneered by the disabled people's movement. We have heard it called 'a form of collective self-advocacy' at its best. Not only is there a commitment, therefore, to personal and political change, there is also a greater potential to take it forward. This is because services users, their organisations and movements represent a collective constituency which works to exert influence and achieve change. From the earliest days of the UK disabled people's movement to the present, there has been this strong link between research and collective action.

Two major examples of this can be identified from the disabled people's movement. First is the research undertaken by disabled researchers and their organisations to establish the evidence base for direct payments – state funds made directly available under their control to disabled people to purchase the kind of support that they preferred rather than just receiving services provided on their behalf (Zarb and Nadash 1994). The second is the major mixed method national research project earlier referred to undertaken to explore user controlled services and support (Barnes and Mercer 2006). In both cases, the findings were subsequently widely used to work for change. In the latter case, an elaborate and inclusive programme of dissemination and influencing was included as part of the project. As Faulkner (2010) found, not only were service user researchers particularly anxious to bring about change, but their research was particularly successful in doing so.

Impact

This last issue connects with a major current concern in research. There is now a growing official and research interest in the impact of user involvement in research (Staley 2009, 2010). This has been reflected in the setting up of several projects to explore the issue. This widespread interest seems to be inspired by the view that the moral and ethical

arguments for equalising research relationships and including service users and their perspectives in research alone are not sufficient reason for their involvement.

Impact is a complex concept in research. It has been institutionalised in academic research, for example, through the former UK Research Assessment Exercise (RAE), to mean how it is judged by research 'peers', particularly through the publication of 'peer-review journal' articles and the number of academic citations such publications receive. Such definitions of impact are unlikely to be supportive of user controlled research since they define impact in terms of individual researchers' competitive activity in relation to a narrow range of academicised outputs (Fisher and Marsh 2003; Gambrill 2002; Shardlow *et al.* 2004; Postle *et al.* 2008). The Research Excellence Framework (REF) system of assessment, while it is meant to highlight social and economic impact which might fit well with the concerns of service users and service user researchers, has, however, come in for criticism as open to narrow economistic interpretation with the same dependence on a narrow range of traditional academic outputs (Glendinning and Dean 2010).

In the context of user involvement research, impact has been taken to mean how involvement improves the quality and outcomes of research. Since the development of user involvement research has been an ideological as well as methodological departure, a focus on research efficacy and efficiency could be seen as unduly narrow and restricted. Impact might equally be concerned with effects on policy and service users themselves. User controlled research demands a reconception of impact in terms of both its own values and increasing interest in the 'utility' of research; that is to say the helpful role it can play in influencing planning, policy and practice in public policy. Advocates of user controlled research feel that it is particularly equipped to make an impact because of both its process and aims. As yet, there has been very limited evaluation of the impact of user controlled research. However, it can be seen as having relevant strengths by:

- supporting the empowerment of service users through its commitment to developing more equal research relationships and processes;

- prioritising the making of individual and broader change in its underpinning objectives; and

- having the support of a constituency – service users and their movements – to take forward its findings to bring about change.

In the INVOLVE review of 2010, a number of areas for possible impact were identified and explored in the literature. These were impact on:

- research ethics;

- people involved;

- researchers;

- research participants;

- the wider community;

- community organisations; and

- implementation and change.

The INVOLVE study did not focus specifically on the impact of user controlled research, although it did highlight that such research did seem to focus on areas that did not get the attention of conventional researchers and policymakers (Staley 2009). A systematic review of impact highlighted the impact of user-led/controlled research for service users. It concluded that it was:

- more patient-focused (with its concern with user-led outcomes);

- more empowering for service users than collaborative or consultative approaches to user involvement in research; and

- involved service users in all stages of the research (Stanisewska *et al.* 2010).

The INVOLVE study of examples of user controlled research reported positive impacts for service users and making change (Faulkner 2010). The study highlighted a range of domains where it was concluded that user controlled research had a significant impact, concluding that the impact of projects 'was disproportionate to their size' (p40). These domains were impact on:

- service users;

- the research;

- services; and

- national policy.

The study found that impact on research extended to:

- Increased access to research participants;

- a relationship of trust between researcher and researched leading to a greater level of openness and honesty (less suspicion);

- improved accessibility for participants – and hence, inclusivity;

- selecting topics and asking the right questions, based on 'insider knowledge';

- more relevant analysis and interpretation of findings, based on a service user perspective; and

- dissemination that reaches the service users from whom the research originated (e.g. training by people with learning disabilities; accessible formats for findings to reach people with different disabilities) (pp. 41–42).

Alison Faulkner, the survivor researcher who undertook the project, concluded from her findings:

I have been surprised how much local user controlled research projects can influence and impact on practice. Influencing has been a major part of their

projects. These tiny projects achieve a massive amount with a small amount of money. They tell us where other research is failing. They are important, they make a difference. I have seen how valuable such research is; how much it can do with a small amount of money, filling gaps, addressing the needs of people neglected in mainstream research, facing multiple discrimination. User controlled research crosses the translational gap from research to changing practice. Traditional research is failing to do that to improve services (personal communication, 2010).

CHALLENGES FACING USER CONTROLLED RESEARCH

User controlled research currently faces many challenges. Those identified include its inferior access to funding and problems of credibility, as well as broader problems of discrimination facing service users personally and by virtue of the focus of their research (Faulkner 2010). However, most of these problems seem to relate to the methodological challenges that face user controlled research.

In the context of health research, particularly mental health research, given the prevailing medicalised approach to understanding, there has been a particular reliance on randomised controlled trials and systematic reviews. This is now also spreading to social work and social care research (Beresford and Boxall 2013). Powerful hierarchies for the production of knowledge and evidence still operate in research. These significantly disadvantage much if not all user controlled research. They continue to underpin the work of government organisations like the National Institute for Health and Clinical Excellence (NICE 2005). The hierarchy set out in Table 1 clearly illustrates this. It reflects the prevailing thinking concerned with developing the evidence base for health care interventions. While this hierarchy, which puts the findings from much user controlled research at the lowest level of credibility and validity, is based on belief in the 'randomised control trial' (RCT) as the gold standard of research, has been criticized, it continues to predominate (Cohen *et al.* 2004; Glasby and Beresford 2006). Yet as we have already seen, service users are developing large scale mixed methods research and developing RCTs with user

Table 1. A conventional hierarchy of evidence

Hierarchy	Type of evidence
Type I	At least one good systematic review, including at least one randomised controlled trial
Type II	At least one good randomised controlled trial
Type III	At least one well designed intervention study without randomisation
Type IV	At least one well designed observational study
Type V	Expert opinion, including the views of service users and carers

Source: Department of Health (1999).

involvement and control, which highlight the value and contribution of a much wider range of research approaches, including user controlled research.

Methodological challenges

While all research which includes user involvement has come in for some measure of questioning, user controlled research has been the subject of particular methodological challenge (Rose 2009a; Sweeney *et al.* 2009). These criticisms do not necessarily surface formally. They are more likely to be part of informal and hidden discussions. Significantly, when the UK Social Policy Association surveyed its members, only 24.9% thought that it was 'very important' that service users were involved appropriately in all stages of research (Becker *et al.* 2006; Becker *et al.* 2010).

Another example was the December 2005 Social Research Association Conference. Its focus was public and user involvement in research and its title significantly was *Necessity or nuisance? The role of non-researchers in research*. This title was a cause of some concern among some service users before the conference. The conference was structured with a presentation looking at the possibilities of user involvement in research (Beresford 2005a) and another one focusing on 'some perils and pitfalls of participatory research'. The Time Higher Education Supplement covered the conference and reported it under the headline 'Research by public could be "unreliable"' (McCall 2005). This was followed by a flurry of correspondence attacking and defending user involvement in research.

As Mike Oliver (2009) has argued in his critique of Hammersley's (2000) defence of 'objective social research' or 'foundationalism':

> Almost all social research continues to proceed on the foundational assumption that there is a real world out there and that by using appropriate methods we can investigate it and hence produce worthwhile and workable knowledge about it (p. 113).

User controlled research can both expect and has already frequently experienced challenges as biased and lacking in rigour. Its apparent links with a democratic approach to participation highlight its ideological relations. As we have seen, it tends to be seen by its advocates as a primarily political activity, rather than a neutral 'fact-finding mission' (Beresford 2009). It is concerned with improving people's lives rather than solely with generating knowledge. Therefore, fundamental questions are raised about the relation of user controlled research with traditional positivist research values of 'objectivity', 'neutrality' and distance, even though user controlled research, like other new paradigm research has made its own challenge to these (Hammersley 2000; Sweeney *et al.* 2009; Rose 2009a; Beresford 2003a, 2007). Findings from such research can expect to be questioned as partial and partisan. Questions are raised about the problems which user controlled research may pose because one sectional interest is seen to be dominant – that of service users. It is challenged in relation to criteria of 'validity' and 'reliability'. Questions are raised about who is a service user and the 'representativeness' of service users involved. All these create major barriers in the way of user controlled research

securing equal recognition and resources alongside other more traditional research approaches, both quantitative and qualitative.

Additional constraints seem to be operating on user controlled research, imposed by the nature of mainstream research publication and dissemination processes and structures. It may also be more difficult for research to be user controlled in universities and other conventional research settings. Universities, for example are constrained by research assessment criteria which may conflict with the nature and goals of user controlled research (Postle *et al.* 2008). Service user organisations may be the ideal home for user controlled research, but it cannot be assumed that they are the only place where it can be carried out effectively under genuine user control, or indeed that they can always ensure this.

Proponents of user controlled research can find themselves caught in a vicious circle. Their methodology is granted less credibility, which in turn undermines their authority and legitimacy, which in turn reinforces the vulnerability of their research approach. This is why work like that of Colin Barnes, Diana Rose and their colleagues developing participative quantitative and mixed methods research is so important. It is unlikely that current heirarchising of research methodologies will fundamentally change in the short term. It is therefore essential that user controlled research cannot be marginalized by only being associated with qualitative research. At the same time it has an important role to play in advancing qualitative research and of dealing with some of the criticisms made of it.

NEXT STEPS FOR USER CONTROLLED RESEARCH

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 there is user involvement, how research 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 diverse array of issues – with apparent success and benefit. The definition of user controlled research can be complex and subtle. There is undoubtedly a grey area in any 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 is important to pay additional attention to the definition of user controlled research. This highlights the value and importance of exploring and setting out as clearly as possible how such research is carried out and how service users are able to maintain control.

This scoping review has examined the history, ideas, policy and practice of user controlled research and explored many of the problems it currently faces, as well as the benefits associated with it. The last part of the review highlights challenges for user controlled research for the future, building on what is now known currently. While user controlled research has made enormous progress over a short time, establishing itself as a new and valued research approach, making its mark on research discussions and structures, as well as resulting in a growing number and range of research projects and developing qualitative and quantitative research methods, its position is not secure.

Proponents of user controlled research are not sure whether it and broader current interest in user involvement in research mean a shift in research, or are only a blip linked with temporary fashions in politics and policy making (Turner and Beresford 2005a). INVOLVE's (2010) study of examples of user controlled research highlighted the challenges encountered, which it said were common to many research projects involving service users. It stressed the need to establish support strategies to sustain such research and researchers through difficult times. It referred to problems of inadequate resources, problems of lack of power and personal distress, as well as in some cases 'incidents of direct discrimination during the course of the research' (Faulkner 2010, p. 53).

One leading user researcher has highlighted that she sees the future of user controlled research as far from assured:

> I do not think the climate is a good one. The push seems to be in getting as many people as possible to be participants (read subjects) in research, not to have service users actually doing research. In respect to social care, what does the 'bench to bedside' agenda mean for social care research? It privileges research into medical and psychological treatments because of the methodology they use. I don't think

our 'toolkits' for doing user controlled research are valued – participatory research, qualitative research, value-driven research – pass muster really. I think we have both said this – the hierarchy of evidence does not recognise these, in fact can undermine them (personal communication, September, 2012).

Concerns like this, which are far from isolated among service users and service user researchers, emphasise the importance of working to safeguard the sustainability of user controlled research for the future. This is unlikely to be an easy task at times of retrenchment and severe restrictions on public spending, but it is clearly necessary. As well as acknowledging the difficulties user controlled research may face there are also a series of important active steps that need to be taken if it is to serve as an effective element in the overall spectrum of research. The next sections of this review outline possible approaches.

Strengthening the theoretical base of user controlled research

The first step is the strengthening of the theoretical base of user controlled research, which is where it is most vulnerable to its critics. This highlights the importance of the underpinning social approach that user controlled research has brought with it. Emancipatory disability research has been based on the social model of disability and the philosophy of independent living. While the social model has come in for criticism, it has been developed over time and has provided a theoretical basis for such research which has supported its development and maintained its relevance to the rights and interests of disabled people. Other groups developing user controlled research do not seem to have had a comparable clear theoretical or detailed value base. While they have generally favoured more social approaches to research, they have not developed their equivalent of a social model perspective or necessarily found the social model of disability helpful or relevant to their situation.

What is likely to be helpful is developing a social approach, which builds on the learning gained from the development of the social model of disability, rather than being constrained by a narrow interpretation of it. We are already seeing such a social model considered in relation to different service user groups, such as people with alcohol problems and mental health service users, as well as in relation to difference, including cultural and international difference. Oliver (2009) contrasts the social model approach of emancipatory disability research with what he describes as 'methodological individualism', which sees explanations essentially in terms of the individual. He cites the political philosopher, Steven Lukes (1974), who says such research 'excludes explanations which appeal to social forces, structural features of society, institutional factors and so on' (p. 122). Support should be given to service users, service user researchers and their organisations to explore such social approaches as part of a broader consideration of the theoretical basis of user controlled research. As yet this is an under-researched area.

Discussion of user controlled research – and indeed all user involvement research – focuses attention on a wide range of underpinning issues for research. These issues are ones

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which all research needs to address. There is nonetheless a need for advocates of user controlled research to address them too. This includes exploring issues around the validity of different knowledge standpoints and knowledge claims; the ownership of knowledge and its interpretation; dominant hierarchies of credibility; the nature of the relationship between knowledge and direct experience; the meaning of 'evidence-based' and what counts as 'evidence'. Service users involved in user controlled research are beginning to explore these issues (Beresford 2003b; Armes 2009; Rose 2009b).

Research education and training

Education and training are key components for successful research. User involvement in research, and particularly user controlled research, raises particular issues for training and education. Here what is needed is not only technical training, but also learning how to work in innovative ways in new and different relationships with stakeholders. Service users and service user researchers are likely to benefit from such training, but so too are research stakeholders, including mainstream researchers, research managers, research organisations, and funders and commissioners. Only through a concerted approach to sharing learning about such research is everybody likely to gain a reliable understanding of its particular strengths and vulnerabilities, what it actually means and entails and how to take it forward most successfully (Sweeney *et al.* 2009). It will be particularly helpful in mainstreaming user controlled research to make available more training for researchers generally to help them better understand this research approach and be able to work within it and in collaboration with it. Service user trainers and researchers are likely to have a particularly central role to play in this and it will create a need for 'training for the trainers'.

There are growing numbers of examples of such research, as we have seen, and some highly experienced user trainers providing it, but it is still at a relatively early and ad hoc stage. It is important that user controlled research is also included as a part of all research training. Research training opportunities need to be further opened up to service users and service user researchers. Service user researchers are beginning to undertake PhDs and become academic researchers. Widening participation in research studies alongside ensuring the inclusion of user controlled research methodology in research learning will be important for the development and sustainability of such research.

Welfare benefits

There has been a growing enthusiasm for user involvement in public policy and practice on the part of governments of all political parties since at least the early 1990s. As we have seen, this extended towards the end of the last century to embrace user involvement in research and evaluation. There has been an increasing rhetoric as well as requirements for such involvements. Yet still welfare benefits policy and practice fits this aspiration poorly. While public policy conceives of such involvement as a form of civic contribution, benefits policy still makes it difficult, sometimes impossible for people in receipt of a wide range of contributory and non-contributory benefits to take part without putting their

benefits at risk (Turner and Beresford 2005b; INVOLVE 2010). Instead of such involvement being seen as a positive, it still appears to be treated with suspicion as if it offered evidence that the person need not really be on benefits but instead could actually be in paid employment. This creates strong disincentives to the involvement of service users in research, particularly some of the most disadvantaged.

At the time of writing [November 2012], the issue of benefits policy and practice in relation to involvement in research remains problematic and unresolved after years of high level discussion and negotiation between service user, research and other major organisations and the relevant government department, the Department for Work and Pensions. People's benefits have even been at risk where no payment has been involved, where their participation has been construed as evidence that they could be in paid work. Yet involvement, while not necessarily signifying such a capacity, can build skills and confidence which result in people being able to enter or re-enter the labour market. Welfare benefits policy and practice must be reviewed if all service users (including those on benefits) are to have equal opportunities to get involved in research, as well as undertake their own research. Unfortunately, at present a policy emphasis on welfare reform which highlights fraud and abuse is making the situation for service users wishing to get involved in research and gain research skills more, rather than less, difficult.

Funding for user controlled research

At present user controlled research receives a tiny proportion of social care and indeed health research funding. This is true for both statutory and non-statutory funding. In 2009, not one of the 40 projects which successfully applied for funding from the last round of Big Lottery Research Programme (which is specifically focused on funding for third sector/voluntary organisations), was led by a user controlled organisation. Unequal and restricted access to funding is limiting the nature and range of methods of user controlled research that it is possible to undertake. This is inhibiting the progress of such research and makes it difficult to assess its potential contribution and effectiveness. A programme to monitor the scale and proportion of research funding that is allocated to user controlled research needs to be initiated to provide a basis for determining if and how it can be supported on equal terms with other research approaches. Research funders should also be encouraged to review their understanding of, and approach to, user controlled research.

The systematic and comprehensive evaluation of user controlled research

One of the most immediate barriers inhibiting the development of user controlled research is that it tends to be understood through the lens of traditional research approaches. Two key and related elements disadvantage it. These are, first, traditional hierarchies of evidence and, second, traditional positivist research values and the interpretation of user controlled research within them as ideologically based and biased. User controlled research needs to be evaluated as part of the broader evaluation of user involvement in research more generally. Only in this way are we likely to get a reliable

picture of its strengths and weaknesses and potential impact. This needs to be a process of evaluation in which service users, their organisations, research participants and user researchers, alongside other stakeholders, are involved fully and equally, drawing on their plural perspectives. This should extend to exploring developments in other countries beyond the UK. It should also be based on a broad and inclusive understanding of the impact of user controlled research.

Addressing diversity

Social research has historically been an exclusionary and hierarchical domain and activity (Vickers *et al.* 2012). User controlled research highlights the importance of addressing inclusion and diversity in all its expressions and seems from existing evidence to be particularly suited to achieving this. Nonetheless, ensuring inclusion and addressing diversity (particularly along the dimensions earlier identified in this review) in both its process and focus, must continue to be goals that are actively and determinedly pursued, if they are to be effectively achieved. Guidance is now available to help make this possible (INVOLVE 2012a, 2012b). However, there are some groups which this scoping review suggests user controlled research is not adequately including, notably;

- black and ethnic minority service users;
- refugee and asylum seeker communities; and
- older people.

Fostering user controlled organisations

While as we have seen the definition of user controlled research is complex, and where it is located can vary, user controlled organisations seem to be a key base to support its development and undertaking. Yet in spite of government commitments to such 'user-led organisations' (ULOs), they remain vulnerable and insecure. The 2007 Government's Independent Living Strategy made a commitment to establish a national network of such local organisations (Office for Disability Issues 2008). Sadly, this is still far from assured and while some new ULOs have been successfully established, others have closed. If user controlled research is to develop and prosper then it is likely there will be a need for a strong infrastructure of user controlled organisations as a key base for it. Such research will both be a resource for ULOs, as well as providing them suitable conditions and perhaps training to support it. Such ULOs will also need capacity building support to undertake research more routinely. It is also important for universities and other research organisations to develop better understanding of, and links with, ULOs, since as we have seen, partnerships between the two are also a fertile source for user controlled research.

Including user controlled research in research structures

Similarly, if user controlled research is to thrive, while retaining its independence, it also needs to be included in mainstream research structures. This will mean supporting and monitoring the inclusion of those involved in user controlled research in the structures,

organisations and decision-making processes of research, including peer-review processes for publication and the awarding of grants.

At present, while reliable evidence is not yet available, there seem to be significant difficulties and barriers in the way of the publication of outputs from user controlled research, particularly in traditional 'scientific' peer-review journals. This inhibits the extent to which 'user control' can operate in such research since it may mean that its focus and emphasis have to be changed to secure publication. This certainly is a concern expressed by user researchers, particularly those who wish to ensure the dissemination of their findings in mainstream research publications. A more systematic exploration of the publication of such research is likely to be helpful, as also will be examination of the extent to which service users, user researchers and user controlled research are represented in the membership and expertise of journal editors and editorial boards.

Building alliances and sharing knowledge

To maximise its strength it is important that different groups undertaking user controlled research develop links, relationships and supportive alliances with each other. This particularly includes people with physical and sensory impairments, people with learning disabilities and mental health service users/survivors. As has been seen, disability emancipatory research and survivor research have tended to develop as separate parallel activities. Closer contact and exchange, facilitated, for example, through international disability studies organisations and events, are likely to be helpful in strengthening the position of user controlled research overall.

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. NIHR 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 to explore the need for such a resource and what form it could most usefully take.

The issue of control and liberating research relationships

Mike Oliver (2009), one of the founders of emancipatory disability/user controlled research, has highlighted that what is key in such research is not so much that it gives voice to service users/disabled people, but that it is essentially controlled by them:

> My own view is that the crucial issue in developing more useful and less alienating research is that of control, not that of experience. Not all research based on experience accurately reflects that experience and not all 'objective' research fails to accurately capture experience even if the general criticism has some validity. This is not to deny the value of research that gives voice to those previously denied it, but to question whether, by itself, giving voice can ever be enough (p. 114).

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For Oliver (1992) it is ensuring such control that is at the heart of the changed social relations of research which he and other disability activists are committed to. We have already outlined the complex meaning of control in this context of such research. Oliver helps extend our understanding of the meaning of control and how great its ramifications may be, not just for this research approach, but also more generally for the relations between researchers and those they research:

> If such research is ever to be useful, it must not only faithfully capture the experience of the group being researched, but also be available and accessible to them in their struggle to improve the conditions of their existence. This isn't just about making researchers more accountable but about giving over ultimate control to the research subjects. Elsewhere I have referred to this as the 'changing of the social relations of research production (p.101).

This does not mean that researchers have to give up researching but that they have to put their knowledge and skills in the hands of research subjects themselves. It also implies that we need to develop a language (or discourse) that does not continue to maintain the artificial distinction between researcher and researched (Oliver 2009).

This emphasis on breaking down boundaries between service users and researchers clearly has long term importance. It should be said that it has not only been between service users and non-service user researchers that there have been tensions. Tensions have long been identified between researchers and others regardless of whether the researchers are also service users or disabled people (Oliver 2009; Straughan 2009). Campbell and Oliver (1996), for example, have reported that many disabled people are suspicious of research. This extends to other groups of service users, who can be no less suspicious of service users who are researchers. Finding ways of superseding these tensions and divisions seems important for the future of user controlled and indeed all research. This also reminds us that in the NIHR INVOLVE review what was important to service users was that research was controlled by service users, not necessarily undertaken by them.

Concluding a review of emancipatory disability research in 2009, Mike Oliver identified the key challenge for the future as being:

> …how to build an enterprise that exposes the real oppression and discrimination that people experience in their everyday lives without merely contributing to the classification and control of marginalized groups who seek nothing more than their full inclusion into the societies in which they live (p. 118).

Acknowledging and challenging structural constraints

A major feature of user controlled research has been its refusal to conceive of research in isolation. It has sought to make explicit the broader structural constraint operating both on people and on research itself and to challenge both. These structural constraints need to be acknowledged if they are to be effectively addressed. Two such key constraints are:

Globalisation: There has been a growing trend for prevailing Western models and

understandings of health, welfare and social care issues to be exported internationally. Such dominant models have had an increasing influence globally, affecting and replacing local approaches in the developing/majority world. This has certainly happened in relation to disability and mental health issues where dominant medicalised understandings and responses have gained increasing acceptance (Pilgrim and Rogers 1999). This in turn has reinforced the dominance in research of traditional medicalised approaches and methodologies, to the disadvantage of alternatives like user controlled research (Holden and Beresford 2002; Stone 1999; Barnes and Mercer 2005).

The international pharmaceutical industry: Related to this is the powerful influence of the international pharmaceutical industry (Beresford 2005b). This is particularly associated with psychiatric policy and practice, but it is influential across a much wider range of policies and service users relating to social care, from people at end of life, to frail older people and young people with behaviour problems. This helped inspire and perpetuate the dominance of drug-related responses across policies, although this is particularly evident in the context of mental health. The pharmaceutical industry is the largest funder of psychiatric research and has had a significant influence in shaping the agenda of that research and its reliance on a narrow range of methods which tend to focus on the individual (Wallcraft *et al.* 2009). The preoccupations of the industry seriously limit opportunities for user controlled research to adhere to its principles of being led by service users' priorities and concerns and maintaining an holistic approach to their rights and needs.

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