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User involvement, research and health inequalities: Developing new directions

Introduction

The focus of this paper is service user involvement, research and health inequalities. There has so far been limited consideration of service user involvement in the context of research into health inequalities. To address this subject, this discussion explores and brings together two complex and disputed ideas and issues. The first is the involvement of 'service users' in research. The second is the matter of diversity and 'representativeness' in user involvement. This focus has been chosen first because it is felt here that participatory research approaches are likely to have particular benefits in developing new knowledge about health inequalities and ways of challenging them. Second, it will be argued that unless attention is paid to addressing diversity in user involvement in research, then it is likely to reinforce rather than cast light on existing exclusions and marginalization, to the detriment of any attempt understand and address health inequalities.

The pressure for participation in research

For a long time 'user involvement' in research meant that key stakeholders, like research commissioners and funders (frequently powerful institutions), for instance, government departments and charitable foundations, should be engaged in the research process and fed back to. This is the way in which this term has long been understood by key statutory funding bodies like the ESRC. More recently a different interpretation has been placed on user involvement. The emphasis has been on 'public, patient and *service* user' involvement in research – that is to say the involvement of potential end users, beneficiaries and 'taxpayers'.

There is now strong and increasing pressure for such 'user involvement' in research and evaluation from government, research funders and health and social care service users. NHS R&D established Involve (formerly Consumers in NHS Research) to take forward such involvement in health, public health and social care. New statutory research networks, like the Cancer Research Network and Mental Health Research Network, have provisions for such involvement in their own process and require evidence of it in research applications. Funders like the Joseph Rowntree Foundation and Big Lottery have taken a lead in supporting such 'user involvement research'. There is now a large and growing literature about public/patient/user involvement in research, it is offered as a component of many research studies, and discussions about it and findings from it have been begun to find their way into high status international peer review journals.

Resistance to user involvement in research

It would be a mistake, however, to assume that there is any consensus about the merits and gains to be got from such research, or that it is widely seen to produce knowledge of equal status to more traditional research approaches. A recent example of this is provided by 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 is itself of some interest and 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 (which I gave (Beresford, 2005a)) and another one focusing on 'some perils and pitfalls of participatory research (given by Martin Bulmer). The Time Higher Education Supplement covered the conference and reported it under the negative headline 'Research by public could be "unreliable"'. (McCall, 2005). This was followed by a flurry of correspondence attacking and defending user involvement in research.

Clearly the involvement of non-researchers in research can be problematic, for example the undue influence sometimes exerted by politicians and pharmaceuticals on the focus of research, research priorities and even research findings and publications. I raised this in my contribution to the conference, but the issue of concern that the THES and many delegates raised was 'public and user involvement' as though this democratic impulse was the most important obstacle currently in the way of rigorous and reliable research.

This example highlights in microcosm the extent to which user involvement in research is a contested idea and development, although this is frequently not made explicit in formal academic and research debate. This point is highlighted here because it is an important undercurrent affecting attitudes and responses to participatory research approaches, which should not be under-estimated. At the same time such user involvement, as has been said, is increasingly a requirement in health and social research. There is a significant tension here.

The nature of user involvement in research

While the discussion about participatory research tends currently to be framed in terms of public, patient and user research, in this discussion, the term service user involvement will generally be used. A broad and inclusive definition of service user is adopted here, including people eligible for but not necessarily receiving services. (see, Beresford, 2005b) A range of degrees of user involvement in research along a number of dimensions has begun to emerge. Service users/research participants may be involved in any of these dimensions. They include:

- ? Identifying the purpose and potential benefits of research
- ? Identifying the focus of research and research question(s)
- ? Commissioning research
- ? Seeking, obtaining and controlling research funding
- ? Designing the research
- ? Undertaking the research (as researcher, interviewer, etc)
- ? Managing/controlling the research
- ? Collating and analyzing data
- ? Producing findings
- ? Writing up and producing publications/outputs
- ? Developing and carrying out dissemination policies
- ? Deciding and undertaking follow up action (Beresford and Evans, 1999)

Service users may be involved in all, some or none of these aspects of the research process. Their involvement may range from none, to some or full involvement. For example, in relation to designing the research, they may have no involvement; be consulted over the process, design it jointly with others, or determine its design themselves.

From user involvement to user research

Service users may also be involved in the broader processes and structures of research. There are examples of all the following expressions of such involvement, which can include being involved in;

- ? identifying and setting research agendas
- ? research institutions/organizations
- ? purchasing research
- ? the development of research methods and methodology
- ? selection of research projects for funding
- ? the recruitment and promotion of researchers
- ? research training and education
- ? peer reviewing for and on editorial boards of journals and other publications

Thus user involvement in research can mean a little or a lot. Its sweep may be considerable or limited. At the same time as there has been official and research interest in user involvement in research, there has also been a growing interest among health and social care service users in 'user research'; that is research which service users initiate and develop themselves, rather than research they are involved in initiated by other people. Such research has a longer history than current interest in user involvement in research. Some of its expressions are user controlled research, emancipatory disability research and survivor research, all of which also have links with feminist, black and educational/development research. (Turner and Beresford, 2005; Lowes and Hulatt, 2005, Barnes and Mercer, 1997)

Crucially this research is concerned with changing the roles and relations of research and research production. The aim is to shift from increasing professional knowledge, power and control to the liberation and emancipation of service users/research participants. Also to replace unequal relations of dominant researcher and subordinate research subject with equalized relationships and much greater overlap between the two. Thus research is concerned primarily with bringing about change in line with the rights and wants of service users rather than solely the production of knowledge, supporting the personal empowerment of service users as well as broader social and political change. (Barnes and Mercer, 1997)

Such user research highlights the value of experiential knowledge – what service users know from direct experience - and is explicit about its inherently political nature. Because of this it clearly comes into collision with positivist values of ‘objectivity’, ‘neutrality’ and ‘distance’ traditionally associated with so-called scientific research.

Competing ideologies

Ideological differences can be detected between user research and mainstream user involvement in research. This reflects broader ideological differences underpinning different approaches to participation more generally. User research, with its commitment to equality and change reflects the democratic model of participation that has developed from grassroots movements, while mainstream support for user involvement in research has many parallels with managerialist/consumerist approaches to participation, with their emphasis on seeking the views of service users as customers for the purpose of market research and information gathering. (Beresford and Croft, 1993) It is helpful to be explicit about such different approaches to involvement (in research as in other areas), not to privilege one or the other, but to be clear about their different origins, intentions and value base.

The benefits of user involvement in research

A reflection of the ‘newness’ and controversial nature of user involvement in research and user research is that so far it has been subjected to only limited evaluation. Certainly an urgent priority is for such systematic evaluation to be undertaken. It also needs to be undertaken in an open minded manner to explore the strengths and weaknesses of such research rather than to highlight presumed inadequacies. This raises its own questions about the role of service users in such evaluation, which in my view needs to be central. Service users and user researchers have already raised concerns about poor quality initiatives where involvement is merely tokenistic or a ‘tick-box exercise’.

However, service users and others supportive of user involvement in research

are also increasingly arguing that such involvement can make for better research. They highlight the gains to be got from it, if it is undertaken properly. They argue that it makes for research that is better informed by the concerns and needs of public and patients; research which is based on methods which are more sensitive to and better enable the effective engagement of research participants; which are likely to elicit fuller and more open responses from them because people with similar experience have been involved in formulating them. As one user researcher put it:

We are more aware of issues around the quality of consent, we support a more empathic process of recruitment and interviewing, we push for a more open process. We also acknowledge, as we become more educated about research, the pressures experienced by professional researchers but can try and work with them to overcome some of the difficulties that can lead to some of the less palatable examples of bad practice around. (cited in Beresford 2005)

The disabled people's movement first developed its own distinct approach to research, emancipatory disability research, because disabled people frequently experienced conventional disability research as oppressive and tied to dominant regressive understandings of and responses to disability. It thus established a research approach consistent with the achievement of disabled people's rights rather than one which could be part of a process undermining them. (Barnes and Mercer, 1997)

Service users concern with equalizing research not only makes more possible the truly informed consent of research participants, but also keeps them properly and reliably informed about the research throughout the course of the research process, feeding back developments, being sensitive to ideas and suggestions participants themselves offer, thus acknowledging them fully as human beings.

Finally, there is the issue of accountability. Recently, as a result of medical and related research scandals, new systems of so-called governance and ethical procedure have begun to be established in UK research. Service user organizations have already raised concerns that these may in practice serve as much to exclude as to include the perspectives and views of service users and public. But the effective involvement of service users, patients and other members of the public offers for the first time a basis for something far beyond such bureaucratic accountability. It offers the possibility of enabling effective accountability in research. It makes possible a shift from the procedural representative democracy that has been the best that state sponsored research has so far offered, to a real possibility of the true democratization of research. This is not going to be an easy or straightforward process and claims for user involvement in research need to be treated cautiously, but this is an argument for their careful evaluation, not devaluation.

The benefits for research on health inequalities

Health inequalities, with its concerns with disadvantage, social justice, social inclusion and equality seems a particularly suitable area to research in a participatory way, involving service users/participants and/or supporting and encouraging them to undertake their own research. User involvement and user research have developed particularly in the context of long term users of health and social care services. There are many overlaps between the population included in these categories and people identified as liable to and/or experiencing health inequalities (for example, older people, disabled people, people who use mental health services, people with learning difficulties, people with chronic conditions, etc)

The importance of addressing diversity in involvement

This both highlights the need to address diversity and the barriers that can be in the way of it. If these not addressed, then participation is likely to be partial and reflect broader social divisions and exclusions. It is not difficult to see how with health inequalities particularly affecting people who face exclusions, it may be more difficult to involve them, creating a vicious circle. Thus participatory research must make specific provision to engage and include groups facing particular oppression, disempowerment and exclusion. Groups which have been regularly identified in social care in participatory initiatives as particularly susceptible to such exclusions include:

- ? People with learning difficulties;
- ? People identified as having multiple or 'profound' impairments;
- ? People who do not communicate verbally;
- ? Older people with impairments (particularly those who do not identify as disabled people);
- ? Black and minority ethnic service users and refugees.

This is far from a comprehensive list. In his discussion of actively involved excluded groups in research, Roger Steel identified a much longer list, including, for example:

- ? Travellers
- ? Homeless people
- ? People with addiction problems
- ? Single parents
- ? People in poverty
- ? People in receipt of mental health services
- ? Prisoners.
- ? People with chronic and life limiting illnesses and conditions. (Steel, 2005, p19)

All these are people who are overrepresented among groups experiencing health difficulties and where health inequalities may have a bearing on their situation.

‘Representativeness’

This issue of addressing diversity in user involvement (in research and in other areas too), has sometimes been confused with that of achieving ‘representativeness’. This issue is sometimes raised as an argument against user involvement. It is suggested either that it is not possible to engage all perspectives, therefore such involvement will in the nature of things tend to be discriminatory, or alternatively, that service users who are involved can claim no real mandate, so that the basis on which they are involved is likely to be questionable. These are important points which are frequently made. Service users often feel that this is particularly the case where they do not say what is wanted of them! Service users in response to these arguments suggest that other stakeholders are not expected to be ‘representative’ and that generally they have no special mandate, so why raise this particular argument in relation to the constituency that is likely to be most liable to exclusion. They argue instead for the importance of seeking to be inclusive and to address diversity in user involvement. (Beresford and Campbell, 1994)

Ensuring inclusion

Roger Steele, like others before him, identifies a range of ways in which marginalised groups can be more effectively included in research. These include:

- ? Offering time and resources to support their involvement;
- ? Providing choice about getting involved;
- ? Structuring research meetings to be inclusive;
- ? Providing advocacy
- ? Reaching out proactively to marginalised groups
- ? Recognising the importance of language in ensuring inclusion and developing appropriate language policy and practice. (Steel, 2005; Beresford and Croft, 1993; Morris, 1998; Ward, 1997; Wilkinson, 2002)

Another way of framing the need to address diversity is in terms of developing policy and practice for access – broadly defined. Access is often thought of narrowly in terms of physical access, for example, for wheelchair users. User controlled organisations like Shaping Our Lives, however, argue for much more developed understanding of access which addresses access in terms of:

- ? Environmental access
- ? Cultural access
- ? Communication access
- ? Access through resources to ensure that involvement is a zero cost activity

Shaping Our Lives see these as coming within an umbrella concern to be *respectful* to potential participants, providing whatever support is needed to make possible their involvement and contribution on as equal terms as possible.

Conclusion

A recent review of user controlled research found that service users felt that user involvement research, particularly user research was particularly helpful in addressing inequalities and diversity in practice, reinforcing the argument which is raised here that research with such user involvement is likely to have a helpful contribution to make to exploring health inequalities and to developing helpful new knowledge in the field.

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