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'The Research Involvement Continuum'

I've put something about the background to INVOLVE at the end of this document because I don't want to spend a lot of time explaining who we are if you already know. I'm going to give a personal overview of some of the barriers and opportunities for Service User Research based on my experience talking with a whole range of people involved in research in different ways, including people who use services, user researchers, academics, health and social care 'career' researchers, and research commissioners.

INVOLVE advise on public involvement across a very wide range of types of research. So I can't claim to be an 'expert' on Emancipatory Research, any more than I can claim to be an expert on Randomised Controlled Trials. In fact, until I came to work for INVOLVE over three and a half years ago, I had been involved in community development in the voluntary sector and had no research background at all, although I had a little experience of being researched. One of the things I still find striking about coming into the research world from one in community development are the different values placed on knowledge depending on who generated it and how.

INVOLVE has always acknowledged that there is range of types of involvement on a continuum, from 'consultation' at one end to 'collaboration' and then 'user control' at the opposite end. But it is only in the last 2 years that we have begun to do serious work on the user-controlled end, following feedback from social care service users. We recently commissioned some work on the definitions of user-controlled research, and the project is currently about halfway through to completion. It is being undertaken by a collaboration involving Shaping Our Lives, and Folk.us. Hopefully, this will help us to overcome some of the barriers that this type of research faces when research commissioners don't understand or recognise what it is.

I think what we call 'evidence', or rather what counts as evidence, is a key issue when looking at the barriers to some types of research. For example, when presented to traditional commissioners, somehow 'Emancipatory' Research – research that principally aims at, and actually improves the lives of those involved, does not necessarily equate with the idea of 'unbiased' scientific 'evidence' and therefore does not merit funding, resources, or even consideration. Ask a health or social researcher why they are doing research they'd say to gain new knowledge to improve services and technologies that will improve people lives. Yet as we know, for a long time it was traditional not to actually consult, let alone involve, those very people whose lives were supposedly to be improved by the research. It would have helped immensely to have at least checked that the research question was relevant from their point of view. Not surprisingly the evidence from this research was often sound from the point of view of scientific methodology, but fundamentally

useless to most people. This problem has not gone away today, and there is still a worrying trend towards the idea that 'scientific' method is the only way of providing valid evidence without due attention to the proper context in which it sits. In other words, the belief seems to be that science as a 'view from nowhere' will somehow pin things down as they 'really' are. In health and social research it can therefore end up by denying the value of people's experience - the 'view from somewhere'. I don't think this is because science is fundamentally unhelpful – far from it, it's just that on its own it is so often seems to miss the point. Perhaps this is because science is often used without sufficient awareness of the political, social, and culturally frame of reference in which it is operating. Indeed it is often seen as an end in itself, and the construction of a frame of reference for everything else.

But there are signs of change which seem to me to be in the right direction. For example it's good to know that the Social Care Institute for Excellence has started to look at the problem of different types of knowledge and how they might be evaluated side by side¹. I hope this kind of work gets shared across knowledge developing institutions.

I have heard many different views from many different people about different types of research. Randomised Controlled Trials (RCT's), we are told are the 'gold standard' of research. I can't agree - but then I'm not an 'expert'. I sometimes hear the view that Emancipatory research is the only valid involvement for service users in research. I can't agree – but then I'm not a current service user. What I do see is that many people who use medical services in particular getting actively involved RCT's. They believe firmly that their influence will help, if not themselves, then their peers – now or in future generations. In some areas such as Cancer research, they are getting rather good at it. The benefits of Emancipatory research are self-evident as far as I'm concerned, and there are the various shades of research in between this and hard 'science' lab based research to consider too. What matters is their worth to people who use the services and technologies the research is addressing. What I don't agree with is that one type of research is inherently more worthy than the other in terms of the type of knowledge it generates, and therefore the resources it should attract.

The work of INVOLVE is to promote the involvement of people who use services in health and social care research. We have been at the coalface in different forms since 1996. Things have changed in that time, but there is still a long way to go. I think one thing is that there is now an increasing dialogue across the whole field of research as a result of promoting involvement. Commissioners now meet real service users, for example, and researchers who have never even heard of Emancipatory research can find themselves having to think about it. This dialogue has enormous value. Anyone who is invested with powers can go on introducing one 'system' or policy after another as a result of 'evidence' (or not), but I firmly believe that real long-term cultural change comes from dialogue and new experience.

¹ Pawson, R. Boaz, A. Grayson, L. Long, A. Barnes, C. (2003) **Types and Quality of Knowledge in Social Care**. SCIE

As one famous scientist, Albert Einstein said: “The problems we face cannot be solved with the same level of thinking that created them.”

Roger Steel
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Background to INVOLVE
Promoting public involvement in NHS, public health and social care research
(formerly Consumers in NHS Research)

INVOLVE are an advisory group on public involvement in research and development (R&D) in the Department of Health. We met for the first time in 1996, as ‘Consumers in NHS Research.’ For the next five years we offered advice to the Director of R&D for the NHS on involving members of the public in NHS Research.

In 2001 we also began to cover R&D commissioned in other areas of the Department of Health through it’s ‘Policy Research Programme’.’ This includes R&D in the areas of public health and social care. In 2003 we changed our name to INVOLVE to reflect this wider remit.

The group meets four times a year. We have about 20 members, a broad mix of people including: users of health and social care services, carers, representatives of voluntary organisations, health and social services managers, and researchers. They are appointed by the Director of R&D at the Department of Health. We believe that involving members of the public leads to research that is:

- more relevant to people’s needs and concerns
- more reliable
- more likely to be used.

What do we mean by ‘the public’?

When talking about the public we mean people who are:

- patients and potential patients
- informal (unpaid) carers
- people who use health and social services

As well as:

- members of the public who may be targeted by health promotion programmes
- organisations that represent the interests of people who use health and social care services
- groups asking for research because they believe they have been exposed to potentially harmful substances or products e.g. asbestos or pesticides.

What do we mean by 'involvement'?

By public involvement in research we mean active involvement, where the people are not the 'subjects' of research but are active participants e.g. on a research steering committee.

Active involvement is where research is carried out 'with' or 'by members of the public rather than 'to', 'about' or 'for' them.

What are our aims?

We aim to ensure that public involvement improves the way that:

- decisions are made about what should be a priority for research
- research is commissioned (chosen and funded)
- research is carried out
- research findings are communicated

What are our objectives?

- To develop key alliances and partnerships which can promote greater public involvement in research
- To support members of the public to play an active role in research
- To monitor and assess the effects of public involvement in NHS, public health and social care research.

The INVOLVE Support Unit

INVOLVE has a support unit to carry out its work. The Support Unit is based in Eastleigh, Hampshire. There are 8 core members of staff (5 of whom work part-time) to carry out and support the work of INVOLVE. The Support Unit:

- builds links with and provides information, advice and support to members of the public and researchers
- gives talks and workshops and organises conferences on public involvement in research
- has its own website, and keeps a database of research projects that have actively involved the public

INVOLVE publications

We have produced a range of publications, including:

- Involving the Public in NHS, public health and social care research: Briefing notes for researchers (2003)
- Getting Involved in Research: A Guide for Consumers (2001)
- A Guide to Paying Members of the Public Actively Involved in Research
- Various conference and workshop reports

We also produce a free quarterly newsletter. If you would like to receive this, please contact us by telephone or email and we will add your details to our mailing list.

All our publications can be downloaded from our website www.invo.org.uk or you can order a free copy from us.

How to contact us

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