

## Where Participatory Approaches Meet Pragmatism in Funded (Health) Research: The Challenge of Finding Meaningful Spaces

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**Abstract:** The term participatory research is now widely used as a way of categorising research that has moved beyond researching "on" to researching "with" participants. This paper draws attention to some confusions that lie behind such categorisation and the potential impact of those confusions on qualitative participatory research in practice. It illuminates some of the negative effects of "fitting in" to spaces devised by other types of research and highlights the importance of forging spaces for presenting participatory research designs that suit a discursive approach and that allow the quality and impact of such research to be recognised. The main contention is that the adoption of a variety of approaches and purposes is part of the strength of participatory research but that to date the paradigm has not been sufficiently articulated. Clarifying the unifying features of the participatory paradigm and shaping appropriate ways for critique could support the embedding of participatory research into research environments, funding schemes and administration in a way that better reflects the nature and purpose of authentic involvement.

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## 1. Introduction

In recent years an approach to research that embeds active participation by those with experience of the focus of that research has been championed both from the human rights perspective, that people should not be excluded from research that describes and affects their lives, and from a methodological perspective in terms of rigorous research: "... knowledge constructed without the active participation of practitioners can only be partial knowledge" (SOMEKH, 2002, p.90). [1]

As a researcher in the UK committed to researching "with" people rather than "on", the re-positioning of people from being the subjects of research to having an active involvement in that research comes as a welcome policy shift. There is, however, a range of language and practices relating to such research that is widely accepted but not well understood. Naming is a convention, not a definition. It is easy, as Elliot EISNER (1998, p.17) suggests to "substitute concept for precept, the name of the thing for the thing itself". The sharing of common terminology builds illusionary consensus, ie people use the same words to mean different things. This can lead to different expectations for action. Research that involves people in a wide variety of shapes and forms tends to be termed participatory. Whilst it is not possible to say that involving people in research "will, or should, always be undertaken in the same way to achieve the same benefits" (SMITH et al., 2008, p.309) defining what is meant by "participation" and "involvement" is vital to delineating the participatory research paradigm and what legitimate expectations of this might be. [2]

## 2. Participatory Research: Terminology and Illusory Consensus

In January 2006 the goals for health research and development in England for the next five years were set out in a Department of Health (DoH) publication entitled Best Research for Best Health: A New National Health Research Strategy (DoH 2006). The Strategy included the recognition that members of the public and patients/users of services can play an important part in the research process and make research "more relevant to people's needs and concerns, more reliable and more likely to be put into practice" (p.34). The policy on public and patient involvement (PPI) in research was founded on the principle that people who are affected by research have a right to have a say in what and how research is undertaken (STALEY, 2009). [3]

Whilst there is this policy focus, PPI in practice is not well understood. Considerable confusion remains about what it might look like and of what it might be capable. The label PPI, by putting patients and public together, tends to overshadow uncritical homogenising of people with distinctly different experiences and skills. Those with direct experience of what is being researched (for example people with the disease being researched) are likely to have different knowledge to those who have an interest but no "insider knowledge" (for example the public who volunteer to support patient groups). In addition terms such as "service user" "patient" and even "consumer" are used almost interchangeably yet "users of services" might include both patient and family members who do not necessarily

hold the same perspectives on service provision. There appears to be little differentiation between the types of knowing held by people with different experiences, nor is there overt recognition of the impact such homogenisation can have on research outcomes. [4]

The ways in which people are involved in research covers a wide spectrum of types of engagement. PPI and "user involvement in research" have become used almost synonymously in the UK as umbrella terms for all types of user involvement. The UK National Institute of Health Research (NIHR) defines three categories of user involvement with consultation<sup>1</sup> at one end of the continuum, user led<sup>2</sup> at the other and collaboration wedged in the middle<sup>3</sup> (see <http://www.nihr.ac.uk/research/Pages/default.aspx>). It is left to each researcher to categorise their own research according to these labels. Tina COOK and Anna JONES (2009), investigating how PPI is understood and implemented in health research networks in the North East of England, found that understandings across the networks varied radically. This contributed to a lack of clarity in relation to possible impacts of such research, what it can offer and what it cannot do. Significantly, whilst there was a small minority of researchers in the region engaged in collaborative research, the predominant presentation of PPI in practice was of consultation. This finding was replicated nationally by Kristina STALEY (2009, p.12) who reported that consultation, the more marginal involvement, is the most common form of PPI being funded and user led the least common. [5]

If consultation has become an identifying marker for PPI it can eclipse the paucity of user led research taking place. The definition of PPI used by INVOLVE (the UK NIHR organisation that promotes public involvement in NHS, public health and social care research), whilst stressing the "... active partnership between consumers and researchers in research" (HANLEY et al., 2003, p.2) also includes "public involvement in advising on a research project" (STALEY, 2009, p.13). Peter BERESFORD and Michael TURNER (2005, p.vi) articulate the radical difference between giving advice and user controlled research, "... the former is seen to embody inequalities of power which work to the disadvantage of service users". They argue that user involvement in research can be an add-on to traditional research<sup>4</sup> with no real challenge to the prevailing conceptualisation. User controlled research on the other hand goes beyond the NIHR term user-led. It has "links with "new paradigm" research, like feminist, black and educational research" (BERESFORD & TURNER, 2005, p.v). Mike OLIVER (1997, p.17) suggests that there are three key fundamentals on which an emancipatory

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1 Researchers ask members of the public about the research e.g. through individual contacts, one-off meetings.

2 Members of the public lead the research and are in control of the research. This is often, through a community or voluntary organisation led by service users.

3 This includes active, on-going partnerships between researchers and members of the public e.g. involvement of members of the public on the project steering group, or as research partners on a project.

4 Traditional research is characterised as research that is designed, led, carried out and disseminated by external researchers. People with lived experience may be respondents in that research, but have no power to shape it.

paradigm must be based; reciprocity, gain and empowerment. Proportionately little research takes forward this more radical research (BERESFORD & TURNER, 2005, p.x). Kristina STALEY and Virginia MINOGUE (2006, p.2) found that "service users and carers have mostly been involved in research by being integrated into the traditional research process". Whilst PPI in research might sometimes be a collaborative process the term PPI cannot be used as shorthand for participatory research. [6]

Participatory research is connected to a bewildering array of labels such as "participatory health research", "action research" and "community-based participatory research" (USA) to name but a few. Behind such overarching labels, dramatic differences exist between participatory researchers at the theoretical and operational levels. [7]

"Various approaches such as pragmatism, critical theory, feminism and constructivism are applied to varying degrees in the conduct of participatory research, impacting data production and interpretation as well as questions of internal and external validity in different ways" (WRIGHT, ROCHE, VON UNGER, BLOCK & GARDNER, 2010a, p.116). [8]

At the heart of the debate is what participation might involve, why it can be a vital part of some research processes and how this shapes expectations for such research in terms of impact. [9]

### **3. Participatory Research: A Distinctly Different Set of Research Practices**

Michael WRIGHT et al. (2010a, p.117) suggest that two core elements characterise participatory research. Firstly there is a "specific quality of interaction between those conducting research and those whose lives are the focus of the research" and secondly there is "an inherent and often explicit connection between research and social action, the former designed to support the latter". The participatory approaches fore-grounded in this paper draw on a notion of "authentic participation", used by Robin McTAGGART (1997, p.28) to mean "ownership, that is responsible agency in the production of knowledge and improvement in practice ... Mere involvement implies none of this and creates the risk of cooption and exploitation in the realisation of the plans of others". [10]

Participatory research does not merely ask patients/ the public to comment on what "is", but challenges people to work together to design what "could be". Meanings are forged through critical discussion rather than captured using single-event data collection methods. It involves participants in co-labouring to forge new approaches, methods and outcomes for the research. Co-labouring, described by Denis SUMARA and Rebecca LUCE-KAPLER (1993, p.393) as an activity that involves "... toil, distress, trouble: exertions of the faculties of the body or mind", goes beyond consultation where patients/the public act as referees, reviewers or panel members, where they sit on committees or are invited to comment on drafted proposals. It seeks to build, through what Etienne WENGER

(1998) calls "communities of practice"<sup>5</sup>, positive working relationships and productive communication to harness a dynamic interchange of knowledge and understandings. What is important in participatory research is not existing "hierarchies of credibility" (WINTER, 1998, p.57) but mutual learning and emergent knowledge. It seeks to break down the barriers between "scientist" and "subject" found in traditional forms of data collection and interpretation (WRIGHT et al., 2010a) and work towards creating knowledge through bringing together contextualised understanding, practical experience, wisdom, and reasoning. This dynamic and democratic approach is designed to challenge and disturb current understandings for practice. Change in how practice is conceptualised and carried out is an expected impact. [11]

The engagement of patients and public in participatory research is not an "add-on" to advance current systems and dominant discourses, nor is it a "managerialist/consumerist" approach "concerned with including the perspectives and data of service users within existing structures and arrangements of research" (BERESFORD & TURNER, 2005, p.14). The notion of participatory research as discussed in this paper holds the possibility of having a direct effect on:

- participants by shaping their thoughts, knowledge and practices;
- researchers, by affecting the theories they draw from the research for practice;
- the design, rigour and trustworthiness of the research process
- knowledge about practice;
- policy and practice. [12]

These aspects of participatory research, core to making it worthwhile and powerful, are likely to be lost if consultation is seen as the watch word for participatory. This is not denying the important role that consultation and other forms of involvement play but participatory research is generally conceptualised as more radical than this. [13]

#### **4. In Practice: Two Studies**

In practice, the participatory paradigm has found itself having to work hard to gain legitimisation in the eyes of research funders (and indeed publishers of research). To illuminate some of the issues relating to carrying out qualitative participatory health research funded through competitive, standardised bidding structures, I draw on my own experience of leading two studies in the UK. Whilst they took place in the North East of England, the studies highlight issues likely to have relevance, both national and international, for researchers who are embracing participatory research methodologies and struggling with supporting its translation into effective practice. [14]

Both studies took a participatory approach but people were involved in distinctly different ways. [15]

5 Communities of practice: groups of people that share concerns and passions about a topic.

#### 4.1 Study one: "Understanding Research"

This study, "Understanding Research, Consent and Ethics: A Participatory Research Methodology in a Medium Secure Unit for Men with a Learning Disability"<sup>6</sup> (COOK & INGLIS, 2008) was funded through the DoH National Forensic Mental Health Research and Development Programme. People with learning disability have historically been the subjects or recipients of research, rather than participants or contributors (NORTHWAY, 2000; WALMSLEY, 2001) but recent participatory research studies demonstrated that they have a valuable contribution to make and are increasingly being involved in, and taking control of, research (DoH, 2006; WALMSLEY, 2004; FAULKNER & LAYZNEILL, 2000; MARCH, STEINGOLD, JUSTICE & MITCHELL, 1997). As little is known about what people with learning disability understand about research and the rationale behind research practices, the aim of the "Understanding Research" study was to work with people with learning disability to identify effective ways of making it possible for them to participate in an informed and meaningful way. [16]

The study took place within a hospital setting in a medium secure unit (MSU) for men with offending behaviours. 93% of the total population have a criminal record. They also have a range of diagnoses additional to their learning disability, for example, schizophrenia/paranoia, depression/post traumatic stress disorder and alcohol/substance abuse. Seven men, all deemed able to consent, participated in the study. They were supported by two academic researchers. The main vehicle for building a shared understanding of how the research process would take place, what kind of data we would generate and how we would make meaning of that data was a set of eight workshops. The workshops used dialogic inquiry as a way of challenging and changing understandings. During the study the men worked together with the academic researchers to co-construct understandings about research and to identify the most effective ways for reaching new understandings (learning). The philosophical underpinning for this approach was HABERMAS' notion of rational critical theory (1970; KEMMIS, 2001) that argues for the possibilities of rational and critical communication. This approach works at the boundaries of what can be known by engaging all participants in critical discourse to co-construct new meanings. As one man in the project explained, when you were discussing things together "... if you couldn't get the information there were people to back you up ... and then we had a discussion and in the discussion you often came up with more than you started with" (David<sup>7</sup>, original data from research transcript: COOK & INGLIS, 2008). [17]

The research design, funding bid and proposal for ethical scrutiny were carried out prior to the involvement of the men. Given that the purpose of the study was to investigate ways in which people with learning disability develop their understanding of research, the study would not have been viable if the men had

6 "Disability" and "difficulty" are sometimes used interchangeable in this article. This mirrors the way in which the terms were used by participants themselves.

7 David, Keith, Alf and Peter are pseudonyms for the men involved in the "Understanding Research" study.

developed their knowledge about research prior to taking part. This was a collaborative study but not user-controlled or user-led. The men were active in shaping and re-designing the process of the research, determining meaning making, specifying outcomes and challenging perceptions of where knowledge might lie, who can know and how we might learn new things. The excerpt below, taken from the recorded workshops, illuminates working towards understanding the notion of collaborative research, although the topic under discussion was how to find out the provenance of a coin found using a metal detector.

"David: ... if you work in a group you tend to find out more information than you actually need ... you can split up if you work in a group, so say your job is to find a bit of history on the coin, I would go out and find information about where it was located but because that's all I'm looking up I've got more chance to find out and get as much information as I can . I might be looking at who made it, you might be looking at the century it came from and what went on at the time. Because we are all looking up a specific thing and we haven't got 3 or 5 things to look up, we can get as much information as we possibly can find.

Keith: You are asking one person to do one part of the question and one to do another part but then they all come back together to work in a team and see what they have got.

David: What you fail to realise though is that sometimes when you are doing research, sometimes [*the ideas*] they end up connecting together.

Alf: It's like search and research all together isn't it?

Facilitator: It is. But I am a bit worried now because we have so much information, how do we decide what is important about what we have?

David: Yes, and what happens if our questions and answers clash?

Alf: But all our questions might be related and linked somewhere along the lines on what we are aiming from. We are aiming for the centre of it ... this is like a Roman Coin, who made it? Was it Julius Caesar's team who made it? And then we ask what was the year it was made in? Someone might ask 'which tribe was it?' And when you have the year, and the tribe and where it was found, you are going to point the finger at it straight way. Rome. The Romans.

David: It's like we are a group of people in this room at this time and we have all gave views and ideas of research and the people in this room are coming up with things other people might not even of thought of, or even have known, and we are putting it together, we have started the jigsaw, and it coming on pretty canny<sup>8</sup>" (Original data from research transcript: COOK & INGLIS, 2008). [18]

#### 4.2 Study two: "Towards Inclusive Living"

The second study "Towards Inclusive Living: A Case Study of Inclusive Practice in Neuro-Rehabilitation/Neuro-Psychiatry Services Using A Collaborative Action Research Approach" (COOK, 2008-2011) was instigated by a group of people, mainly service users, who thought there might be a link between the way people with neurological impairments are included in the NHS community and their

8 "Canny": colloquial for very well.

motivation to use knowledge from treatment to develop their own skills and independence in the wider community. The group who became the core researchers in the study consisted of: three people who used, or had used, the services of a regional neuro-rehabilitation service in the North East of England ; one unpaid carer/family members of a service user; people who worked with voluntary agencies, e.g. the MS Society (three people); a members of staff (one person) and myself as the academic researcher<sup>9</sup>. This group of prospective researchers worked for two years to transform the original thought/idea into a research proposal. The guiding principles for the work were that it would be collaborative and that it would make a difference. People were clear that they only wanted to be involved if it made a difference to practice. Alison FAULKNER and Brigid MORRIS (2003, p.33), in their writing about user involvement in forensic mental health research remind participatory researchers that: "one of the main reasons for service users/survivors wishing to be involved in research is to make a difference". Maryrose TARPEY (2006) also found that some users refused to become involved unless subsequent changes could be guaranteed. [19]

The process for designing the study took a democratic, participatory approach framed by the concept of symbolic interactionism, i.e., that the understandings people attach to their situations are socially constructed and that people create shared meanings through a critical interpretative process (BLUMER, 1969). [20]

In order to shape the design the core researchers had to learn about asking researchable questions and about methodological approaches that might enable them to find and address the issues they wished to research. It meant learning about how to phrase questions, how to share and critique ideas, ways of generating and analysing data, writing for an audience and supporting each other during difficult times. It meant building sufficient rapport and trust between the members of the group to enable them to work productively at the very boundaries of their current understandings, to deal with uncertainty, disappointment (and even bereavement) and to celebrate successes. [21]

The methods chosen by the group for their research included interviews and focus groups, but also incorporated a questionnaire, photography projects, blogs, diaries and mapping processes as ways of generating data. Crucially the project used a cyclical design where research participants were invited back to revisit, in collaboration with others, their original issues, to develop and critique their dialogue and to contribute to deciding on the fundamental issues yielded by the research (data analysis). [22]

These two projects, both successfully gained funding but illuminate some of the tensions participatory research raises between researchers, organisations that host research and those who judge the quality of research for funding and publication purposes. [23]

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9 I had also previously worked in the organisation supporting research and development and had previous working connections with a number of people in the project.

## 5. Ideals and Actualities: Pragmatism in Practice

Participatory research is set against an historical backdrop where beliefs have been undervalued as components of people's actions: "... real knowledge, (as opposed to mere beliefs) was limited to what could be deduced from theory, operationally measured and empirically replicated" (PATTON, 2002, p.92). My own experience is that popular expectations of research include that it will "prove something", find a "fixed truth", that it will be "objective" (i.e. the researcher will not interfere) and the use of "replication" and "controls" will be key indicators of "good science". In addition, my experience of funding systems for research, even where qualitative research is called for by funders, is that it tends to be overly populated by quantitative frameworks. These frameworks start from the positivist notion of finding the measurable features of a situation from a process of following a fixed set of research activities. Believing that your research proposal is going to be judged in this environment gives researchers, including myself, the dilemma of how to present participatory research in a way that is recognisable to august bodies without affecting the quality of our research. [24]

### 5.1 Space for collaborative learning: Before gaining funding

"[U]ser involvement in the development of a research bid provides a key opportunity for shaping a project around the perspective of users, at a point where aims and methods may not be decided and so involvement can have most impact" (INVOLVE, 2006, p.6).

Participatory research demands a set of spaces and resources that differ from approaches where participants are subjects or consultation may be the main form of engagement. In the case of "Towards Inclusive Living", as the research question came from grass roots discussion, people were actively involved in the development of the study. They were keen to do this on the basis that we would work on all aspects of the research together, including developing the research design for a viable bid. Most people in this core group had experience of research that involved questionnaires, interviews and market research rather than qualitative participatory research. Finding out about and debating different types of research purposes and practice was crucial to enabling these prospective researchers to debate the means by which new knowledge might be developed. People needed time to understand the research process, in particular how data might be generated, their contribution to that, how data might be analysed and what might be done with their contribution once the research is complete. This participatory approach shaped the research design in unexpected ways. For instance, the inclusion of a questionnaire as a method for data collection was entirely down to the voice of one service user. Writing about the study, HUTCHINSON et al. (2010, p.8) explain the importance of this collaborative approach.

"Everyone had different knowledge and skills that they brought to the table. We then began the process of working together to find a clear focus for our research that we all thought was important enough to commit a considerable amount of time to and

held the possibility of improving practice. The discussions were about the difference between integration and inclusion, what we meant by the NHS 'community' and the way that we would go about doing the research. The process of doing this, of listening to others, debating and then finding a clear focus, has been lengthy but necessary. We all learnt a lot from the process itself". [25]

Support from an experienced researcher was needed, however, to:

1. introduce the group to a variety of ways and purposes of different research approaches;
2. support the writing of a robust research proposal;
3. write a bid to funding bodies in the language recognised by funding bodies;
4. organise the financial aspects for the study;
5. complete the administrative requirements and use my knowledge and experience to steer the research through the ethical procedures of the University, the NHS Trust and the [National Research Ethics Service](#). [26]

In addition, it was requirement of the funders that the chief researcher had a track record in research and publication. [27]

Time needed for developing a bid in a collaborative manner, especially when working with people who are new to research (and who may also have learning or cognitive difficulties) can be lengthy. Maurice MITTLEMARK, HUNT, HEATH and SCHMID (1998, p.192) found that no less than and sometimes more than one year was needed to carry out successful planning for participatory research. For the "Towards Inclusive Living" study the preparation time for numbers 1-3 above was over two years. The long development time for this study was only possible due to the goodwill of all participants, including the academic researcher who had no time allocation for this. I would suggest this is a fairly typical experience for participatory research with authentic involvement at its centre. The need for a considerable allocation of time before research is funded has implications, however, for the viability of participatory research if it has to depend on so much on goodwill. INVOLVE (2008, p15) highlights the importance of funding "for a range of activities from building relationships between patients and the public and research organisations, to facilitating patient involvement in research projects through resources and training". [28]

Without this funding participatory research is in danger of replicating the historical reliance on goodwill and charity that has marked the lives of many marginalised people, and limiting their access to change mechanisms. [29]

Being able to devote so much time to developing a research bid is only possible if you are not responding to funding calls with a short time frame between announcement and submission date. Short time frames continue to be the norm, even when the call has an explicit focus on user involvement. This disadvantages participatory research, especially research with people who might find it harder to get involved, such as those with learning difficulties, cognitive impairment, mental

health issues, communication needs etc., as the time scales for contact, organising meaningful meetings, educating and development are all necessarily longer: "If people with learning difficulties are involved in this project, as a researcher, more time is needed to develop their skills even more as a researcher" (Peter, original data from his research diary: COOK & INGLIS, 2008). [30]

If the possibility to be involved in research relating to their own lives is governed by time frames set for other types of research, and this short time frame leads to the exclusion of their voices, this becomes a social justice issue. [31]

## **5.2 Space for collaborative activity: During the research process**

If authentic involvement is to take place considerable time and effort needs to be allocated during the research process to "just talking". In both studies "just talking" involved repeated questioning of meanings we were developing so that we could "... go beyond the already "expert" understandings which defined [our] starting points" (WINTER, 2002 p.36). Talking was fundamental to moving beyond general conceptualisations of practice to deeper understandings. Some of the men in the "Understanding Research" study had originally been a little disparaging of "all that talking" but they came to recognise its worth.

"... there was so much information to go through and so many angles and so much to discuss and talk about and come up with ideas to think about. And you came to points where you were having to go away one week, come back next week and just a bit more information and then go away again. And by the time you had finished it you had, like, a mile long list. And it was just incredible. And I did it and enjoyed it so much" (David, original data from research transcript: COOK & INGLIS, 2008). [32]

Michael WRIGHT et al. (2010a) point out the quality of interaction between participants is key to knowledge development and change i.e. to effective research. This necessitates time to build trust, trust that contributions will be valued and used appropriately; trust to allow critique to be positive, enlightening and illuminating; trust so that critique is not seen as disparaging criticism. [33]

"Talking" is often considered the poor relation to action. To be seen to be "doing" is important; "talking" is seen as vacillation. Seeking funding for talking can be difficult as it is hard to articulate the necessity for such activity given that it rarely provides outputs measurable against pre-determined standards. [34]

## **5.3 Organisational space: Complexity in practice**

Time consuming aspects, mainly peculiar to participatory studies but also of relevance to other studies that involve different forms of engagement, were experienced at the interface between the host organisations and research in practice. Working with non-traditional researchers tested bureaucratic and support systems. Examples where extra time was needed in both projects to put the research into practice include:

- time for discussing, explaining and planning meetings if the notion of a meeting is an alien concept to core researchers and participants;
- providing practical help and support for people to attend meetings or research activities;
- the necessity of sending out information in a variety of formats when not all people had e-mail, could read or could concentrate on written information;
- practical help to enable people to remember what they had to do, and in some cases, help and support to carry out their responsibilities;
- communication to keep everyone involved over the length of a study when there might be long gaps between engagements;
- gaining ethical approval;
- conferring honorary contracts. [35]

For the host organisations, the notion of services users (patients and carers/family members) and volunteers as researchers severely challenged local systems for supporting research. For instance, all researchers in the "Towards Inclusive Living" study needed honorary contracts with the NHS Trust. This necessitated police and occupational health checks. Many hours were spent on this process which tested the systems in place in the NHS and the patience of some of the core researchers. The unwieldy (and sometimes unnecessarily intrusive) nature of the rigid application of practices not designed for purpose meant some of the core researchers considered leaving the project after we had received funding but before the practical research started. In addition, support services in the NHS and University, such as IT and finance, were designed for other purposes. This led to significant barriers to effective communication between researchers and participants and adversely affective responsive remuneration to volunteer core researchers and participants, some of whom were on very low incomes. [36]

In the "Understanding Research" study working with people in an MSU resulted in the need for complicated and careful planning around their work and treatment schedules. Men in the MSU are not allowed to be alone with external researchers. The need for escorts required, and was afforded, considerable commitment from the hospital to enable it to take place. This went well beyond what was funded by research monies and was supported by the amazing generosity of staff, some of whom came in on their day off to support the men. Despite this however, a number of workshop meetings had to be cancelled, sometimes at short notice, which left us with considerable time pressures in meeting our research deadlines. [37]

Despite my past experiences I repeatedly underestimate the time scale and personal effort for organising participatory research. I am aware that my inability to believe it will require this much input is reflected in my own under-costing of bids. A recent bid for funding for participatory research has, nevertheless, received criticism from reviewers due to what they perceive as the high cost for research support time. This leaves a tension between deliberately underplaying the costs to gain funding (not being transparent about the time scales for

collaborative processes and their importance) or stating the full costing so that time is recognised but risking losing the opportunity to do the research. [38]

#### **5.4 Space for dissemination: Beyond the research**

"The long time involved in conducting community-based research presents challenges not only in working with funding agencies, but also with the shorter term expectations typical of ... universities" (ISRAEL, SCHULZ, PARKER & BECKER, 1998, p.192).

In the UK the formal recognition of the expertise of academic researchers, the [Research Excellence Framework](#) (REF) is directly connected to their contribution to academic journals. The judging of their contribution is set within a time frame for scrutiny and based upon a set of criteria such as the number of articles published, how often articles have been cited by other interested researchers and the academic standing of the journals in which the articles are published. For participatory researchers, committed to working with communities, and particularly those working with more marginalised communities, this raises a number of dilemmas. [39]

Firstly, given the iterative and collaborative approach fundamental to participatory writing, time before the possibility of publishing is necessarily lengthy. BAXTER, THORNE and MITCHELL (2001) in their report on "Lay involvement in health research: lessons from other fields", noted that whilst approximately a third of research considered in their case studies had been either user-commissioned or user-led, very few appeared to have involved users in the dissemination of research findings. To make an impact on practice research findings need to be disseminated in a range of ways, using a range of methods, and to meet a range of audiences. This includes "Easy read" versions, theatre presentations, papers in professional practice (rather than research) journals and articles written for journals and magazines that reach service users. This is absolutely key to making sure participatory research has reached beyond those who have taken part but this multifaceted approach is time consuming and not always sufficiently recognised by research commissioning agencies. For the academic researcher in the UK publications in non-refereed journals are not recognised in the output for the REF (or indeed for many of us, in our workload allocations). This can create a tension for academic researchers supporting participatory approaches. They are pulled between competing imperatives and this can reduce opportunities for collaborative approaches to dissemination. [40]

Secondly, when working with marginalised communities, whilst the impact of participatory research on those communities might be high given their direct involvement in the study, papers written about this are less likely to command a high numerical level of citations than those published in fields with a wider linkage to the whole population. [41]

Thirdly, there is a tension between where and how participatory researchers might want to publish. There are "only a small number of journals willing to

publish this more descriptive science" (VISWANATHAN et al., 2004, p.5). Whilst this has grown in recent years, given the relatively new history of such research, the number of journals that have established international credentials remains small. This makes them less attractive for academic researchers in terms of the REF. [42]

## **6. Space for Different Ways of Conceptualising and Judging**

The elevation to the "gold standard" of the type of research where "the presumed objectivity of scientific knowledge" is raised above "subjective or experiential knowledge" (ISRAEL et al., 1998, p.176) has left participatory researchers in a position of having to justify the very notion of participatory research as well as the detailed contextualised approach each time they bid for resources, apply for ethical approval or disseminate their knowledge. They have to explain, at each juncture, how the rationale and trustworthiness of participatory research can be found in almost the opposite spaces from more traditional research. [43]

Not having a clear articulation of participatory research has "implications for the advancement of PHR [participatory health research] as a whole and for the uptake of the findings produced by way of participatory methods" (WRIGHT et al., 2010a, p.118). They suggest that an important reason why it is generally more difficult to secure funding for participatory health research is "that each proposal needs to be argued on its own terms." It is not the complexity of the approach that is the problem, but rather that its complexity has not been confidently articulated in a way that serves as a basis for recognising its legitimation. [44]

### **6.1 Conceptualising: Recognising the paradigm**

Historically research has been seen as a search for observable, objective, static, outcomes that can be replicated through the application of method. Its positivist underpinnings tend towards reducing complexity, controlling variables and collecting data from the observable or measurable. Its epistemology elevates, as a desirable quality, objectivity, an approach that distances the researcher from subject, separates the knowers from the known (BLUMER 1969; ISRAEL et al., 1998). Bias was understood as something found in subjects, not in researchers and research processes. Being distanced from participants, not drawn into the complexity of their discussions, their perceptions and formulations, has been seen as a way of ensuring that researchers' understandings are less likely to be distorted towards those of the participants. Research aimed to leave the research arena undisturbed by the process of that research. Collecting data in a detached manner, where contexts can be controlled and replicated, and outcomes measured, is seen as a mark of validity. This type of research, seemingly devoid of political purpose, has been known as science. [45]

The word scientific has been somewhat of a hurdle for participatory research as it suggests a framework for research that finds merit in distance and replicability. Two questions commonly asked of me when doing participatory health research are "how can this be reliable evidence if you engage with the respondents, won't

you become biased towards their point of view?" and "how can this be reliable evidence if it is given by the participants who will be biased to their own particular point of view?". If we are committed to understanding how and why a particular policy, programme or activity functions, how can our work be seen as reliable if participants, who hold a unique knowledge set relating to personal experience of that situation are not involved in that process? Herbert BLUMER (1969, p.86) warned that remaining aloof as a so-called "objective" observer, refusing to take the role of the acting unit is "to risk the worst kind of subjectivism—the objective observer is likely to fill in the process of interpretation with his own surmises in place of catching the process as it occurs in the experience of the acting unit which uses it." [46]

Or, as David, from the "Understanding Research" study so aptly articulates, without the authentic participation of people with learning disability, this study would have lacked its most valuable dimension.

"It's no good putting a group of people into a room that have not got learning difficulties because you can't be certain that by the time that you came up with your booklet that you're going to give to a person with learning disabilities ... [they'll say] 'Oh, that's very good, that' but they'll probably not even understand it ... Without us [the men] it would have been a waste of time doing it because by the time you've finished it you would have got to the point where you showed it to, like, 100 people with learning difficulties and they all went "Eh<sup>10</sup>?" " (David, original data from research transcript: COOK & INGLIS, 2008). [47]

The impact of not asking disabled people for their views, or not taking them seriously, has meant that policies and services have been built and delivered in inappropriate ways (HUNT, 1966; BARNES & MERCER, 1997). As subjects, not active participants in shaping the research, they were less able to influence the research to enable it to reflect the issues that they felt most constrained or eradicated their potential. As Keith, one of the participants the "Understanding Research" study, wrote in his diary

"... for many years research was done by people who had lots of power to say what life experiences they were researching about. ... And their researchers were called 'experts' and they made their careers by researching people who were called 'subjects' " (Keith, original data from his research diary: COOK & INGLIS, 2008) [48]

In participatory research the "fundamental source of legitimacy is the collective judgement of the people" (GUTMANN & THOMPSON, 2004, p.9). The involvement of people with learning difficulties (and other marginalised people) in research has been seen to not only support their own development in terms of knowledge, confidence and interest, but to contribute to the research in a way that takes research in important new directions. Participatory research holds potential to allow "marginalized voices to be heard, to challenge dominant

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10 "Eh": colloquial for "what does that all mean?"

discourses and to open up alternative perspectives and courses of action" (LATHER, 1986, p.272). [49]

Participatory researchers judge their research as effective if the engagement does change a situation, if it is transformational, if it has, what Patti LATHER (1991, p.68) calls "catalytic validity" i.e. "the degree to which the research process re-orient, focuses and energizes participants toward knowing reality in order to transform it". Where positivist research looks for stability and fit, participatory research looks for change and difference. Participatory research is designed to affect the situation being researched (CHO & TRENT, 2006), to agitate, disturb and to enhance the lives of the people it affects (STALEY, 2009; WALMSLEY, 2004). As such it can be seen as overtly political. The interweaving of the personal and political challenges how we perceive research and the power of human interactions in the research processes. This runs counter to, and disturbs, common notions of scientific research. Recognition of its fundamental difference in relation to more traditional conceptualisations of trustworthy research is vital to demonstrating its possible impact of, achieving that impact and having it valued. Participatory research calls upon a particular set of indicators of trustworthiness and legitimisation that need to be articulated. If the intention to challenge and change is not explicitly framed as an expected/desirable outcome of participatory research due to historic conceptualisations of rigour, then we struggle to truly represent what makes this research worthwhile. [50]

The purpose of outlining differences in research approaches is not to privilege one paradigm above another, but to take a Kuhnian approach and recognise that they are different paradigms (KUHN, 1962), with different approaches and designs, differing organisational practices, different spaces for meaning making and different ways of knowing. [51]

## **6.2 Being judged: Colliding paradigms**

Having set out the case for recognising that participatory research inhabits different spaces and offers different ways of seeing, then it follows that there are also different ways of recognising validity and rigour for this paradigm. If funding bodies remain rooted in particular frameworks for judging they may struggle to recognise the essence of participatory research and its impact. Reviewers expecting evidence of validity, rigour and output that are not part of a participatory paradigm may not know how to look for and value those that are. It is important that those judging participatory research have a clear understanding of the primary purposes, processes and expectations for such research: "The reviewer with education, skills and experience in quantitative research may not even recognize qualitative proposals as research at all, and some qualitative purists may view quantitative research proposals as mere bean counting and hardly scholarly endeavour" (MITTELMARK, 2007, p.83). [52]

To be scrutinised by those with expertise in different forms of research can result in the rejection of perfectly sound research and indeed the commissioning/funding of research that is not sufficiently formed. This leads to

confusions between reviewers and researchers about what is being looked for and how to articulate the participatory process. [53]

The experience of looking for funding for the "Towards Inclusive Living" study illustrates some of the inconsistency currently faced by participatory researchers. The first bid for funding from a large and well-appointed UK funder was rejected at the initial stage due to questions about its design and methodology. Given the work and energy that had been put into this bid, and given that it was all done on a voluntary basis without any supportive funding, keeping the participants sufficiently encouraged to both think it was possible to gain funding, and to try again, was an important task. Shortly after this disappointment the UK NIHR announced a call for bids to research the impact of the National Service Framework for Long Term Conditions (DoH, 2007). The priorities outlined dovetailed with the work we wished to do so we submitted our largely unchanged bid. Our submission was successful and we were awarded funding with special commendation in relation to our methodological approach. [54]

One aspect of bidding for funding that may have an effect on the ability of participatory researchers to demonstrate the qualities of their proposal is the more standardised form for funding bids. In the UK, almost all major funding calls (and indeed the process of ethical review for research) have become web based. Whilst improved somewhat in recent years, the forms for the larger funding bodies here in the UK tend to be shaped by a positivist conceptualisation of research that involves problem definition, time lines and expectations of measureable outcome. If the commissioning of research is governed by rigid frameworks that predetermine what kind of validities and impacts should be articulated this may well bury the quality of a participatory proposal. Taking action research as an example, the need to articulate a research question, required on many standardised forms, is problematic. In action research, researching the question in a participatory manner is a key element of practice and can be seen as an indicator of the quality of that research. Bridget SOMEKH and Ken ZEICHNER (2009, p.7) note that, writing as far back as 1949, Stephen COREY suggested that:

"[i]n a program of action research, it is impossible to know definitely in advance the exact nature of the inquiry that will develop. If initial designs, important as they are for action research, are treated with too much respect, the investigators may not be sufficiently sensitive to their developing irrelevance to the ongoing situation". [55]

Conforming to the dictates of those who have shaped ways of judging can result in the compromising of designs and hiding original motivations. If the dynamic part of the research, where participants shape the processes of knowing, is not brought to the fore, this at best devalues participatory research design and at worst renders it ineffective. [56]

## 7. Where Are We Now?

There has been an observable shift towards participatory research as an important form of inquiry. What seems to be lagging somewhat behind is an accompanying clarification of terminology and reform in judging processes and procedures. This makes it particularly difficult to firstly, fit participatory research into spaces designed to articulate the validity of other research paradigms with fixed standards for design and expected observable/measurable outcomes and secondly, to enable it to reveal its full potential and maximise its transformational impact. If participatory research continues to be judged by a set of standards from other paradigms then our opportunities for doing this research (getting funding), effecting change (impact) and being published (being heard) are reduced. [57]

Participatory research is driven by a variety of practices and purposes which include improving understandings and meaning making, knowledge building, improving/changing practice and contributing to greater democratic processes for social justice. Whilst there may be a plurality of motivations and ideological commitments there is, however, an underlying "participatory research paradigm" which unites all (MINKLER & WALLERSTEIN, 2003). Participatory researchers need to be able to link to an accepted paradigmatic understanding and so avoid repeated individual justification of the participatory approach. This paper adds its voice to others who suggests that the underlying paradigm for participatory research needs to be more clearly articulated. (WRIGHT, GARDNER, ROCHE, VON UNGER & AINLAY, 2010b; ROCHE, 2009; MINKLER & WALLERSTEIN, 2003). It is not that there are no standards for such research, "the library shelves are stacked with epistemological discussion and methodological advice about the full range of qualitative approaches available" (TORRENCE, 2008, p.70) but that, like other qualitative approaches, "the discursive nature is not resolvable in terms of written standards" (p.71). [58]

This paper is not a call for a set of fixed orthodoxies for participatory research. It is a call for greater transparency in the processes that allow and enable participatory researchers to forefront the purposes, strengths, trustworthiness and impacts of our work and to have those recognised and valued. It raises the importance of articulating the paradigm and expressing the diversity of research approaches that might be found within it, the elements that unify these approaches and the places to look for evidence of effective research design. To support the translation of research bids into funding and practice participatory research needs to be clear about what it can do and how it achieves this. It is therefore incumbent upon participatory researchers to articulate the nature and purpose of our work, to make the different types of legitimisation and impact transparent and to raise the status of engagement and participation as a means of knowing. We have to celebrate what participatory research is, what its purpose might be and to be confident in the processes we use. If participatory researchers continue, for pragmatic reasons, to try and adapt not only how we portray our research, but also to adjust how it is carried out, we run the risk of reducing its effectiveness and impact. Only if all aspects of our work are honestly revealed

can these be explored and collated to support the development of a body of knowledge in relation to participation. [59]

The responsibility for ensuring that participatory research is judged according to its own merits, and that it finds appropriate and powerful spaces to make a difference to current practice, lies in two courts, those of participatory researchers and those who review participatory research. If the first step is to be more explicit about the nature, purpose and potential of the paradigm within which we work, the ball is currently in our side of the court. Participatory research faces the challenge of establishing its credentials. [60]

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