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Partnership Research: A review of approaches and
challenges in conducting research in partnership with
service users

Dr Jo Frankham
Visiting Senior Research Fellow
Education and Social Research Institute
Manchester Metropolitan University
j.frankham@mmu.ac.uk

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Abstract

This paper is aimed at policy makers, research funders, research supervisors and others interested in, but not conversant with, issues in service user involvement in research. The paper also outlines challenges in the execution of this work and raises some philosophical questions about its enactments. The first section of the paper outlines the historical context and the perceived benefits of service user involvement in research, drawing largely on authors who work within that field and wish to promote greater service user involvement. The primary advantages of service user involvement are seen as: learning from the first hand direct experience of service users; using the distinctive 'way of knowing' of service users to inform the design and execution of research; that engagement in research can be empowering to the service users involved; and that the outcomes of the work will be different and, as it is perceived by advocates in the field, more relevant to both service users and providers. The second section of the paper summarises some key issues in the practical conduct of research with service users, emphasising the complexities involved at a number of levels. Four key issues are highlighted: recruitment of service users; communication; research training; and ethical issues. Section three aims to 'trouble' the field of service user involvement in research by engaging in debate about three key issues in the field: The privileging of personal experience in knowing and understanding; issues around what and how we learn in research partnerships; and the notion that service users will or can be empowered through participating in research. The paper ends with three, more general, points. First the author highlights a dilemma in engaging with issues in service user involvement in research associated with the political nature of the endeavour. Anyone entering the field will, it is argued, also have to work through the ideological issues involved. Second, the 'closed' nature of the field is referred to, and it is suggested that this is connected to the political nature of the endeavour. Third, the author suggests there will be many calls in the future for further research/evaluation about service user engagement in research but that meaningful work in this area will be both costly and complex because of the necessity for ethnographic work.

1 INTRODUCTION

This discussion paper is aimed at policy makers, research funders, research supervisors and others interested in, but not conversant with, issues in service user involvement in research. The paper also outlines challenges in the execution of this work and raises some philosophical questions about its enactments. The first section of the paper outlines the historical context and the perceived benefits of service user involvement in research, drawing largely on authors who work within that field and wish to promote greater service user involvement. The second section summarises some key issues in the practical conduct of research with service users, emphasising the complexities involved at a number of levels. Section three aims to 'trouble' the field of service user involvement in research by engaging in debate about three key issues in the field: The privileging of personal experience in knowing and understanding; issues around what and how we learn in research partnerships; and the notion that service users will or can be empowered through participating in research. As many other authors have remarked (e.g. Evans et al, 2008; Nolan et al, 2007; Frankham et al 2006a; Seddon et al, 2004; Daykin et al, 2004; Beresford, 2002; Carrick et al, 2001) the details of such endeavours continue to be underdebated. "The issues involved are complex and opinions often polarized, for user participation in research is still in its infancy, with many practical, ethical, moral, methodological and philosophical questions unanswered" (Nolan et al, 2007).

2 HISTORICAL CONTEXT AND PERCEIVED BENEFITS OF 'USER INVOLVEMENT' IN RESEARCH

Since the 1970s, across a wide number of fields, there have been increasing pressures for more collaborative forms of service planning/delivery, research, development and evaluation. In the more recent past this has extended to participatory forms of training and theory development (e.g. in social care). This 'movement' was fed by more general social and cultural shifts such as feminism and the civil rights movement which "shaped a generation's consciousness of the role that gender, race, ethnicity and class play in constructing knowledge and legitimating 'knowers'" (Brisolara, 1998:26). The field of International Development was one of the first in which participatory approaches became "widely acknowledged as a basic operational principle of development programming" (Ackermann et al, 2003:7). Rural and community development initiatives funded during the 1970's and 80's (Ross and Coleman, 2000; Packham, 2001) reflected this principle, which has since been extended into a growing recognition that monitoring and evaluation of development initiatives should also be collaborative. In the more recent past, this has been extended to participation in research in development issues evident in the growth of methods such as Participatory Rural Appraisal (PRA), Community Based Participatory Research (CBPR) and Participatory Action Research (PAR).

The late 1960s and early 1970s also saw the "politicisation of disability by disabled activists throughout the world" (Barnes, 2003). As Barnes describes, of particular significance was the redefinition of disability by Britain's Union of the Physically Impaired Against Segregation (UPIAS) (1976). This new definition included the crucial shift "away from an emphasis on individual impairments towards the ways in which physical, cultural and social environments

exclude or disadvantage people labelled disabled" (Barnes, 2003:5). This is known as 'the social model of disability'. The emphasis on the socio-political context in the 'social model' links arguments for change amongst minority or subordinated groups; they all (in one shape or form) argue that their status in society results in particular understandings that have grown from that experience. It is not so much their gender, sexuality, ethnicity, disability, per se, which dominates their experience, then, rather it is how others respond to them, and how social policy impacts upon them (Lewis, 2004), that should be the focus of attention and where the emphasis for change should lie. As Oliver (1996) argues, "what should be researched is not the disabled people of the positivist and interpretative research paradigms but the 'disablism' ingrained in the individualistic consciousness and institutionalised practices of what is, ultimately, a disablist society" (14). This shift in emphasis helps to explain how the impetus for service-user involvement in research has also been driven by "the movements of disabled people, psychiatric system survivors, social care service users, community and citizens' organisations, their allies and supportive researchers" (Beresford, 1999: 672).

Similar trends in research in the humanities (education, sociology, gender studies) were evident in the development of 'critical social research' during the 1980's and 90's. This specifically allied itself with marginalised groups (e.g. Truman et al, 2000). Action research, particularly in the field of education, also burgeoned during this time. The general growth in understanding of the contribution of qualitative methodologies (particularly ethnography) can be seen as a parallel move inasmuch as such methods hold the potential for shared control of the focus/direction of the work. As Carrick et al (2001) describe, "The advantage of these methods is that their ideology matches that of the researcher committed to user involvement; ethnographic approaches to data collection and Grounded Theory are by their nature discovery based" (222). Key in this respect is that the methods of data collection and analysis allow for understandings *outside* the researcher's original frame of reference to be generated. Of course there is no guarantee that qualitative methods, per se, will be used in an emancipatory way and Bennett (2004) cautions against seeing participatory approaches as synonymous with qualitative research. In addition, the notion of 'discovery' does suggest the pre-existence of truths to be uncovered, as compared to the idea that 'truths', at least to an extent, are constructed *in the process* of research. Nevertheless, positivism, and methods typically described as quantitative, have an even greater reputation for separating the knower and the known and for ignoring the situatedness of knowledge. That is, the methods that are employed tend to ignore the idea that knowledge is socially constructed. This helps to explain Hartsock's (1997) comment that positivist knowledge is "discovered from nowhere in particular" (369).

In the late 1980's and early nineties, there grew a more insistent voice for sharing control over research practices from disabled people, from feminists and from critical race theorists. From this point, there was rapid growth in what has been called emancipatory and participatory research, with many commentators describing the importance of sharing and/or giving up control to those who are most implicated by research. This trend was most obvious in the field of disability research but was also evident in the study of poverty by some groups (Bennett, 2004), in gender studies, and in aspects of educational research. Barnes (2003) and others (e.g. British Council of Disabled People, 2004), regard 1992 as a

key moment in the development of emancipatory research, following the Joseph Rowntree Foundation funded seminars on 'Researching Physical Disability' held in 1991. In addition to foregrounding the 'voice' of disabled people, it was argued that 'traditional' forms of research had done little to improve their lives (Oliver, 1992) and that emancipatory and participatory research was more likely to achieve this aim. Some have gone further (e.g. Wilson and Beresford, 2000; Barnes and Mercer, 1997) and suggested that research carried out by 'dominant groups' can be oppressive both in terms of its processes and outcomes.

Since that time there has been considerable debate about definitions of emancipatory and participatory research, and their potential (or otherwise) to achieve what they set out to achieve (e.g Clough et al, 2006; Bennett, 2004; Taylor et al, 2002; National Disability Authority, 2002; Pratt and Loizos, 1992) and to put them in a hierarchy in respect of their potential for empowerment of service users (Beresford, 2002; Swain, 2001 in Beresford). Emancipatory research has been widely taken to mean only that sort of research which is controlled by those who are implicated by it, with the aim of the empowerment of those participants through the research process and outcomes¹. This is closely related to what is known as user-controlled research (Boxall et al, 2007). Participatory research is taken to mean research which includes research participants in the design and processes of research but where overall control remains with academic researchers (Bennett, 2004)². In the more recent past another term has entered the debate: Partnership Research. This approach has been most widely advocated by those working in the field of learning disability studies and with mental health service users. In these fields, as Carrick et al (2001) describe, "outsider allies" in the form of researchers can be seen as an asset, and perhaps essential, to the endeavour of collaborative work 'getting off the ground'. Here the emphasis is on shared control of ideas, processes and outcomes.

These forms of research are often presented as if they are on a continuum (McLaughlin, 2006), ranging from relatively limited forms of consultation, to collaboration through to full control by service users. Beresford (2002) makes an important distinction here; he wants to take 'user-controlled' or emancipatory research out of such a continuum as it is quite distinct, he feels, in its aims and nature. It is related, he suggests, to a "broader ideology or philosophy" concerned with the redistribution of power. As all these forms of research have

¹ Barnes (2003) (p.6) "In essence, emancipatory disability research is about the empowerment of disabled people through the transformation of the material and social relations of research production. In contrast to traditional investigative approaches, the emancipatory disability research agenda warrants the generation and production of meaningful and accessible knowledge about the various structures – economic, political, cultural and environmental – that created and sustain the multiple deprivations encountered by the overwhelming majority of disabled people and their families. The integrating theme running through social model thinking and emancipatory disability research is its transformative aim: namely, barrier removal and the promotion of disabled people's individual and collective empowerment. From this perspective the role of the researcher is to help facilitate these goals through the research process."

² Bennett (2004) describes participatory research as that which gives participants appropriate respect for their particular knowledge and experience, some control over the research process and influence over the way the research is used. It puts into practice the belief that people "have a right to participate in analysing their own situation and how to tackle it" (6).

gained recognition by an increasing number of funders, including charities (e.g. Joseph Rowntree Foundation, Community Fund), research councils (e.g. ESRC, MRC) and other bodies (e.g. NHS, Consumers in NHS Research Support Unit, SCIE, etc) who have promoted and/or required service user involvement to a greater or lesser extent in their research.

The emphasis on user involvement can also be seen as part of a wider trend in social policy/practice in the UK (Howes and Frankham, 2008; Nolan et al, 2007). New Labour's enthusiasm for partnership working and networks permeates their policies and practices (Calder, 2003). This enthusiasm built on Conservative party rhetorics and policy moves (Newman, 2002; Williams, 2002; Clarence and Painter, 1998) and is part of what has been described as the "third spirit of capitalism" that emerged in the 1980s (Chiapello and Fairclough, 2002). As Newman (2002) describes: "Networks and partnerships, public participation and democratic renewal, are all symbols of what has been termed a new form of governance in the UK" (p.7). This is evident right across New Labour's social policy agenda: "The development of a more consultative process of policy formation, a focus on joined-up government and partnership and the extension of public participation and involvement in decision-making" (Newman, 2002:7). This policy context has helped to encourage and shape the wider participation of user groups in research, particularly in the NHS in the fields of cancer care and mental health. In the more recent past there have been a number of related developments including services such as Patient Advice and Liaison Services (PALS) (Evans et al, 2008) which has a key role in liaising between service users and the NHS. Now service user involvement is being mooted in areas of health as diverse as infection and microbiology (HCAI Research Network, 2008). Government policy has also helped to sanction and promote the employment of service users in academic research, with a number of universities now employing service users as researchers and in course development (e.g. the BA Learning Disability Studies at Manchester University), and others establishing service user research groups (e.g. at the Institute of Psychiatry) (Rose, 2003b). Increasingly charities (such as the Stroke Association) employ service users on their research committees and service users are being employed to help develop "best practice standards" (McLaughlin et al, 2007). It has also been proposed that a new role for social workers should be to support service users "to participate in emerging forms of active and inclusive citizenship" (Postle and Beresford, 2007: 143).

In the more recent past, there has also been increasing acknowledgement of the role that children and young people might play in decision making and in research (McLaughlin, 2006). The INVOLVE website (www.invo.org.uk) gives details of current work with children/young people in health and social care research (as well as useful background on service user involvement in research more generally). Educational developments include elements of the National Curriculum which require active engagement of pupils (e.g. Citizenship Education) and the 'Pupil Voice' movement which has contributed to widespread establishment of school councils in the primary sector and to the promotion of the idea that children themselves become researchers (Kellett, 2005). In legislative terms, the UN Convention on the Rights of the Child (1990) and The Children Act (2004), have both specified "the right for children to engage in decision-making". 'Every Child Matters' (DfES: 2004) also enshrines "listening to children, young people and their families when assessing

and planning service provision, as well as in face-to-face delivery" (4). This applies in respect of social care, education and health.

This brief overview of the development of collaborative approaches to research, has referred to what are seen as some of the advantages of this approach. In summary, these advantages are perceived as:

1. Learning from the "first hand direct experience" (Beresford, 2002) of those most closely affected by the issues being explored. It is argued that these experiences will be qualitatively different as a consequence of the relationship of users to the issues concerned and the context in which they are living, impacted as they are by social policy. This has variously been described as learning from 'local knowledge', or foregrounding the 'voice' of participants or accessing 'insider knowledge'.
2. The distinctive relationship of service users to the issues being explored results in more than simply 'insider knowledge'. It is argued that those on the 'inside' of an issue have a different epistemology (way of knowing, understanding, experiencing the world) and that this needs to be taken into account throughout the research process. Knorr Cetina (1999) describes these 'epistemic cultures' as "those amalgams of arrangements and mechanisms . . . which, in a given field, make up how we know what we know. Epistemic cultures are cultures that create and warrant knowledge" (1). This knowledge, then, is about more than contributing 'personal experience'; such knowledge has the potential to inform the foci for research, how such research should take place and with whom, and its outcomes (Lloyd et al, 2008).
3. That the process of engagement in research can itself be transformative to the individuals involved. It is claimed that participating in research can be empowering (Hanley et al, 2004; Beresford and Evans, 1999), and further, that this empowerment may help build towards further transformation in the social world. In this sense, user involvement is an enactment of participatory democracy and has the potential to "challenge the historic ascendancy of professional and management influences" on social policy (Callaghan and Wistow, 2006: 2299). (Clearly, the degree of involvement of service users will obviously affect the potential for this outcome to be realised.)
4. That the outcomes of the research are likely to be different than those produced by 'professional' researchers and, it is claimed, more relevant both to service providers and users (Faulkner, 2005). It has also been stated that the research will be of higher quality if service users are employed as researchers inasmuch as other service users are more likely to speak candidly to them (Allam et al, 2004). In addition, the audiences for the research may well be different, and therefore the forms in which it is published. Others have claimed that the knowledge produced is less likely to be oppressive than research that is controlled by 'dominant groups' (Wilson and Beresford, 2000; Barnes and Mercer, 1997). In addition, it is argued that if insiders are responsible for the research, or at least actively participating in it, they are more likely to take seriously its outcomes.

Before moving on to describe key issues and challenges in enacting partnership approaches to research, a further note in relation to the parameters of the debate may be helpful. As has already been suggested, the degree of participation by service users across approaches will vary along a wide continuum. It is impossible, in a paper of this scope to describe in detail the challenges associated with each different approach. Instead the paper concentrates on overlapping intentions in respect of service users becoming “active partners” (Hanley et al, 2004) in the research process. This paper, then, is organised around practical and philosophical issues raised by that notion in general, and tries, where possible, to point to important issues across the continuum of levels of participation.

It is also the case that partnerships with service users are highly context specific. As Callaghan and Wistow (2006: 2292) summarise: “The creation of a set of ‘complex relations of reciprocal interdependence’ (Jessop, 2003) . . . necessarily yields structures that emerge from historical and local factors and are, therefore, widely divergent”. The issues raised will also be highly dependent on the focus of the research, as Harrison et al (2002) describe. There is likely to be a distinction between those who have been directly affected by an issue, work which is *instigated* by service user groups, and the involvement of the ‘general public’. Similarly, there is a very broad range of activities described as research and different approaches themselves will precipitate different challenges. It is not possible in the space available, to interrogate the multiple complexities in such a matrix.

In relation to terminology, this review uses the label ‘service user’ although it is recognised this is problematic in some respects. The term foregrounds only one aspect of a person’s life and in that sense does not acknowledge the wider context of those lives. However, as Wilson and Beresford (2000) describe, it continues to provide a useful “umbrella term”.

3 PRACTICAL CONSIDERATIONS IN THE CONDUCT OF RESEARCH WITH SERVICE USERS

In respect of practical considerations in the conduct of research with service users, it should be said that any work undertaken in groups is an activity concerned with the considerable challenges of negotiation, collaboration and power sharing. It is likely in respect of carrying out research with service users that these issues are further exaggerated. At minimum, then, these complexities raise the issue of whether sufficient *time* has been allocated to research with service users and this, in turn, has resource implications.

This section of the report draws on insights from user involvement in areas others than research (e.g. evaluation and development of services) where these issues are likely to overlap with questions about user involvement in research. Given the scope of this paper the section does not include guidelines on the day to day conduct of research with service users. There are a series of ‘how to’ guides available which will be useful to anyone wanting to set out on such an endeavour. Faulkner (2005) and Hanley et al (2004) are comprehensive and helpful and point to many other resources. What this section does try to do is draw together insights from across a range of publications in the area, connect this with personal experience of carrying out research with service users, and draw out some general indications of the sort of practical challenges one may encounter in research with service users.

This section begins with key issues in relation to the recruitment of service users. This issue is foregrounded here given that who is recruited, and to what, is interconnected with many practical and philosophical issues in the conduct of research with service users. This is followed by brief sections on: Communication; Understanding research procedures/processes; and Ethics and accountability.

3.1 Recruitment of Service Users

Evidence on who gets recruited to participate in service user research and the impact of this involvement is difficult to ascertain. This is partly because of the “elusive nature of the networks from which individuals are drawn” (Newman, 2002: 8) and the many difficulties associated with researching partnerships (Frankham, 2006b; Riles, 2000). This is connected to difficulties associated with evaluating the *outcomes* of collaborative research with many authors also calling for more systematic evaluation in this area (Evans et al, 2008; Faulkner, 2005; McLaughlin, 2006; Beresford, 2005; Carr, 2004; Ball, 2004).

Clearly, the notion of ‘recruitment’ is itself worthy of interrogation given that it implies a given ‘body’ setting out to find others who will participate in a particular piece of work. This construction immediately belies (or at least calls into question) the notion of ‘shared control’ over research as it begs the question recruit *to what?* As Fisher (2002) describes, much ‘partnership’ work still involves “users being asked to join a process where the research issue and the methods have largely been defined beforehand, and where the outcome remains under the control of researchers” (p.306). As Boxall et al (2007) describe, an on-going concern relates to “negative perceptions and stereotypes of service users . . . in passive, consumerist and stigmatising roles” (159) and this tendency may be reinforced by tokenistic approaches to their involvement in research.

It has been argued that guidance on the involvement of service users has “frequently conflated the roles of public, patient, consumer and citizen” (Callaghan and Wistow, 2006: 2294) and assumed that any ‘stakeholder’ will, in a general sense, contribute to the development and reinforcement of democracy in service user delivery, evaluation, research, etc. As Callaghan and Wistow go on to argue, clarity about who is involved and the perceived nature of their relationship to the issues to be explored is central to the nature of their participation and the outcomes of the work. As Williams (2000) describes, this is exemplified in New Labour’s requirement that local service providers are “responsive” to local needs. “Sometimes it takes responsiveness to mean state agencies acknowledging the viewpoint of the public (DoH, 1999: 25-26), i.e. ‘we have heard what you have said.’ Other times responsiveness is used to mean acknowledging what the public have said *and* agreeing to act in accordance with it” (1).

In some cases, those recruiting service users have attempted to address the dilemma of representativeness by recruiting groups of service users which “reflect the proportions of different groups (men and women, young people and the elderly, particular ethnic groups and so on) in the population as a whole” (Newman, 2002: 10) or what Daykin et al (2004) describe as a “cross-section” of the public. Although this may be preferable to taking no account of such differences, it could be said to proliferate the problem. (Is there anyone in the group who is lesbian or gay? Disabled *and* Black? And so on.) In addition, this

approach conflates the issue of identity with holding a particular position or as Newman (2002) puts it “. . . a bioessentialist assumption of a homogeneity of interests and identities . . . ” (12). In other words it is implicit that a woman will hold a ‘woman’s view’, or that a particular role (e.g. single parent) is seen as synonymous with other attributes (e.g. poor, isolated, ‘struggling’). As suggested above, the objective to find a group that is representative of the whole population is often connected to service users having a very tightly and narrowly defined role within a pre-defined agenda. The job of the participants then becomes giving evidence that speaks for the ‘whole population’ and attempts at collating or summarising those views becomes the priority. Structures which allow for highly divergent and contradictory views to emerge may allow for a greater ‘representativeness’ in the sense of approximating the complexities of real lives. At the same time, however, this is likely to present multiple challenges in how these views are taken into account, and responded to, given that they may be incompatible. As others have argued, it may be that opinions and priorities are so divergent as to dissipate any drive for sustained change (Chambers, 1992).

Even if those recruiting service users are clear about their own intentions it should not be assumed that participants have the same perception of their expected role, or necessarily agree this is an appropriate role for them. In part, this may be because any one individual is likely to have multiple subject positions, relationships to services, and current preoccupations/priorities in life. Others may not regard their experiences as relevant, for example in the study of poverty (Bennett, 2004), or wish to be associated with a particular issue. Others see participation exercises as ‘phoney’ (Commission on Poverty, Participation and Power, 2000). McLaughlin (2004) describes how the fluid nature of research with young people means repeated re-evaluations of roles and relationships and the reconfiguring of research in the process.

There are also a series of barriers to participation which need to be taken into account when recruiting service users and which may necessitate on-going support (McLaughlin, 2006; Beresford, 2000; 2005). Daykin et al (2004) highlight how those living in poverty will face greater barriers to participation, as will those with mental health issues and people with learning disabilities. Those directly affected by an issue such as cancer, or other serious illness/condition, face related challenges: “These may arise from feelings of isolation and responses to living with uncertainty, such as focussing on the present and a reluctance to anticipate longer term needs” (Daykin et al, 2004: 279). Further dilemmas may arise as a consequence of how ‘users’ are defined as described by Daykin et al (2004): “. . . users are defined in various ways, most often as patients and carers, although it has been reported that the needs of ill people and their carers can sometimes conflict” (278). In other cases, long-term service users may object to being put in the same category as a ‘casual’ user of services (Boxall et al, 2007). And, of course, there is not necessarily a straightforward distinction between service user and researcher as exemplified by Peter Beresford, a professor at Brunel university who is an “‘out’ ‘mental health service user” (Boxall et al, 2007). It is also the case that some approaches to recruitment may compound service users’ isolation as argued by Cornwall (2000). She highlights the myths associated with ‘community’ and that recruitment within any one area can deepen the exclusion of those with less power, often women.

The notion of representativeness is also contentious in another respect. Daykin et al (2004) point to a number of reasons why service providers might be dismissive of service users' accounts on the basis that they are seen as "unrepresentative of the broader group" (287). And Carr (2004) has described how some accounts are dismissed on the basis that a service user, through sustained immersion in research, comes to be seen as a 'professional user' and therefore unrepresentative. However, as Carrick et al (2001) argue, there is always likely to be "compromise" in terms of the constituency involved. Further, data will always be 'filtered' as a consequence of the experiences of the person re/representing it and it may be that debates about representativeness are sometimes a diversion. This is exemplified in work by Harrison and Mort (1998) in which they describe managers' willingness to take on service users' ideas when they accord with their own but to dismiss them, sometimes on the grounds of lack of 'representativeness', when they do not.

Rather than setting out to recruit particular individuals to participate in a piece of research, an alternative is to work with groups who already represent a general set of interests (e.g. People First³). These groups are likely, already, to have debated the tensions associated with representing others and have agendas for action based on their on-going work. It has been argued (Newman, 2002; Callaghan and Wistow, 2006) that this allows for a more dialogic relationship to develop, where all parties are more likely to listen and learn from each other's prior knowledge and experience. In that sense, these arrangements are perhaps more likely to result in shared agendas for action.

A third broad approach to recruitment can be described, although this is likely only to be taken up by academic researchers at this stage. This relates to researchers engaging in what Barnes (2003) describes as a "protracted process of engagement" with service users/service user researchers. This sort of arrangement may begin with a researcher actively setting out to recruit people to a particular piece of work (or it may be that a researcher is already part of a particular network in which she can generate collaborations). This initial work, however, then affords opportunities for further developments to take place, which are gradually more shared in focus and orientation. Indeed it could be argued that it is only through such sustained engagement with individuals that genuine dialogue can develop and only in this way can genuine participation be achieved. Certainly, 'user groups' who have been consulted on this subject felt the need to strengthen service user networking at individual and organisational levels and call for more sustained forms of involvement, if they are to help effect change (Branfield and Beresford, 2006).

As with other approaches to recruitment, this 'strategy' raises its own problems. Such processes are time-consuming and not generally regarded as part of an academic researcher's job specification. In addition, the agenda for research which is drawn up may be important, relevant and desirable but ultimately not fundable. In an increasingly market driven academic culture this is likely to be problematic to the researchers concerned. As far as 'user groups' involved in such processes, it may be they invest huge amounts of time and

³ "People First is an organisation run by and for people with learning difficulties to raise awareness of and campaign for the rights of people with learning difficulties and to support self advocacy groups across the country" www.peoplefirstltd.com

energy in an endeavour which comes to nothing because of the vagaries of funding. At the same time, there is increasing evidence of 'user research' emerging as compared to user involvement in research with service user groups setting the agenda, applying for funding and so on (Boxall et al, 2007).

3.2 Communication

It will be clear that the 'who' of service user involvement is interconnected with questions of the conduct of research and how this is achieved. A narrowly and tightly defined role will prompt relatively minor challenges associated with communication as the terms on which service users are expected to participate will have been previously defined. It is likely that the more extensive the degree of involvement that is aspired to, the greater the attention will need to be paid to *genuine* participation beyond token gestures.

Many authors describe how 'negotiation' between researchers and service users is one of the most challenging aspects of the work (Faulkner, 2005; Daykin et al, 2004; Trivedi and Wykes, 2002; Carrick et al, 2001; Ferguson, 1997). There is little detail, however, on the specific nature of those challenges. Instead, the literature tends to generalised statements such as the need to attend to "negotiating power relations" (Ramon, 2003) or that "parties with power must cede some of it in order for research to be collaborative" (Carrick, 2001; 219). This absence of detail is partly, of course, a consequence of the highly context specific nature of such challenges. In addition, changing power relations is highly dependent on the individuals involved and their capacities and commitments to make such collaborative arrangements 'work' often through informal means. As Seddon et al (2004) describe, this is a process which "rests upon the active negotiation of expertise and authority, careful networking and opportunism in pursuit of local action through a variety of inter-linked and hybrid public-private spaces where debate and action is collectively determined by relevant members" (131). These processes, however, are enormously difficult to track or trace and there is little empirical work available on the detail of such endeavours. As a number of authors have pointed out, although training is often available to service users in relation to becoming involved in research, academic researchers are often assumed to understand what the implications of becoming involved in collaborative research will mean (Nolan et al, 2007). Further research on the complexities involved may be one of the ways in which they could become better informed.

It is also important to recognise that power resides in many forms and the researchers involved will not necessarily have all the power all the time. It would also be a mistake to homogenise different groups within a research partnership as all holding the same forms or degree of power. It is more likely that different forms of power will reside, change and develop as the research proceeds suggesting dynamic and, perhaps, challenging sets of relations developing over time. Callaghan and Wistow (2006) suggest 'heterarchy'⁴ (rather than hierarchy) is a useful way of conceptualising the power/relations evident in service user networks. The general point is that enormous flexibility and responsiveness is a prerequisite

⁴ "A heterarchy is a system of organization replete with overlap, multiplicity, mixed ascendancy, and/or divergent-but-coexistent patterns of relation." (Wikipedia)

to successful work in this area. The notion of heterarchy also helps to problematise under-theorised notions such as 'empowerment' through service user research. As McLaughlin et al (2004) outline: "power is not a commodity and . . . we need to avoid binary oppositional relationships. We need to make allowances for difference and contradictions whilst being aware of the potentially disempowering aspects of empowerment" (162).

One of the practical steps that is recommended by a number of authors in relation to the tensions associated with 'negotiating power relations' relates to the formalisation of service users' roles through a contract or written agreement (Faulkner, 2005; Carrick et al, 2001). This can include agreements on the respective roles of those involved, the degree of participation intended/aspired to, questions of payment or other remuneration and so on. It is unlikely that such a strategy will, itself, 'cure' problems associated with power differentials and how these play out in communication/negotiation and so on. However, it may be, as Wykes (2003) suggests, that the *process* of drawing up such an agreement can be as important as the agreement itself as it requires the articulation of much that may remain tacit, masking misunderstandings or assumptions.

Of course, questions of vocabulary, specialist registers, the use of acronyms, etc, are all important issues in 'communication' in general and the 'how to' guides previously referred to give specific advice in relation to such issues. An issue that is less discussed, but which is likely to become relevant if participation is beyond the token level, is how researchers respond to what Seddon et al (2004) describe as *inevitable* conflicts of interest. It would be ironic if, over time, service users did not change the terms of the debate and *disagree* with researchers (and each other) as it is precisely their different ways of knowing and understanding that drives their involvement. And as Edwards et al (2007) describe, if these differences of opinion and ways of knowing can be made explicit, these can "themselves become legitimate focuses of discussion" (650); they may well be essential to beginning to understand others' epistemic cultures (Knorr Cetina, 1999). However, it is also the case that disagreements can be undermining and detrimental to research and Seddon et al (2004) identify "persistent points of tension within partnership formation and maintenance" (123). This suggests, then, that a key part of the role of anyone hoping to co-ordinate or facilitate research with service users needs to closely attend to how differences, disagreements and conflict are addressed/resolved. Left unattended to, such tensions may jeopardise the work and possible future collaborations. How people talk 'across' differences is another area where there is minimal empirical research in relation to service user/researcher relations.

3.3 Research Training

Where service users are increasingly being included as researchers in the actual conduct of a project, it is important to raise questions about how people are prepared for this role. It is often implied when discussing the inclusion of service users in research processes that anyone can become a researcher. Another view would be that there is no intrinsic reason why service users (or anyone else) should not become good researchers, but neither is there an intrinsic reason why they should (McLaughlin, 2006). Further, a review of publications in this area (e.g. Faulkner, 2005; Lockey, 2004; Rose, 2003b) and observation of a number of partnership initiatives suggests that the processes of carrying out research are sometimes reduced to a series of skills that can be applied like a technology⁵. In a number of cases, then, it is evident that service users are sent on short courses designed to give them 'toolkits' in research without any understanding of the underlying philosophical or epistemological issues that underpin the production of knowledge. As others have described (e.g. Rowlands, 2003) this can result in "the problem of insufficiently skilled practitioners using participatory methods badly."

There are also, of course, much more 'serious' attempts at training and preparation of service users as researchers as documented by Allam et al (2004) who acknowledges, for example, that any 'training' in interviewing must take into account "active listening, reflection and exploring skills, managing one's own emotions, managing interviewees' emotions, responding to 'inappropriate' behaviour or unexpected responses from respondents" and so on. A study with service users who had been 'trained' in research (Lockey et al, 2004) themselves said that 'top down' approaches to being taught research skills was not what they wanted but, rather, "real involvement and exchange" with research issues and researchers. Nolan et al (2007) suggest that the status quo in relation to the needs of service users will prevail until they are "fully integrated" into the research community. Certainly some institutions seem to be taking this idea seriously, with the Faculty of Health, Sport and Science at the University of Glamorgan proposing the establishment of a 'User led research group' which is to have the same status as all other research groups in the department (University of Glamorgan, 2008) and the National Institute of Health Research proposing service user involvement in all research 'hubs' from 2009 (NIHR, 2008).

If service users are to be involved in the conduct of a project, an alternative to the provision of training courses is to support them in learning 'on the job'. To reiterate a point made at the beginning of this section, however, this is likely to mean that considerable extra time/resources will need to be allocated to a project, with many authors stressing the need for on-going formal and informal support as the research takes place (Faulkner, 2005; Beresford, 2005, 2000; Lockey et al, 2004; Thorne et al, 2001). This may initially look like a disadvantage as far as the production of research is concerned, but has other important potential outcomes. These include the empowerment of the participants in terms of their preparation for further involvement in research and the educational potential to researchers

⁵ Skill is defined here as a bounded activity that can be taught, and with practice, mastered.

of working alongside service users who will have different insights into elements of the research process and can genuinely influence its direction and outcomes. Of course, this, in turn, raises questions about the degree of flexibility that is possible within a research project.

One of the drivers to service users becoming more involved in the processes of research has been the impetus for their 'full' or 'true' participation and, of course, there are important arguments for involvement beyond the 'token gesture'. It has also been argued that embarking upon only limited forms of participation with already marginalised groups serves to reinforce their marginality (Frankham, 2009) as can the experience of being "researched on by others" (Hanley et al, 2004). However, as others have argued, there is increasing recognition that 'full' participation does not necessarily mean participation at all stages in the research (Nolan et al, 2007). In addition, of course, some service users do not *want* to be so fully involved. Bennett (2004) argues that making sense of data, rather than gathering that data, may be a "key part of the process." Allam et al (2004) reinforce this, suggesting that service users' interpretations of data are often a key element to 'true' understanding of service users' perspectives. As Bennett (2004) reports, however, this is often the stage at which researchers take control of the process, sometimes because it is argued that this will "ensure objective results." The paradox here is that the very 'insider expertise' that is used to validate participatory research is reframed at this stage as 'insider bias'. This is one issue which perhaps exemplifies what a number of authors have described as the necessity for a "cultural shift" in research environments (Boxall et al, 2007; Daykin et al, 2004) where 'user involvement' is paid lip service (and sometimes a bit more than that) but ultimately control continues to lie with researchers.

3.4 Ethical issues

Questions of ethics in service user involvement in research are wide-ranging, complex and highly context specific. This entire paper, in a sense, is addressed to a fundamental question of ethics in research. This relates to who should do research, on what and how. Faulkner and Thomas (2002) argue forcefully in this respect in relation to psychiatry: "Technological accounts of madness and the coercive role of psychiatry raise serious ethical issues for the rights of people whose freedom may be taken away and who may be forced to receive treatments they do not want. The potential for coercion renders the failure to engage psychiatric patients in influencing research agendas even more significant, and demonstrates the importance of an ethical stance on Evidence Based Medicine in psychiatry. We argue that the best way of achieving this is by involving service users in research" (1). The *extent* of service user involvement is another, general, ethical issue raised by a number of authors (e.g. Boxall et al, 2007). It has been argued that unless service users are engaged at an early stage in the research and can truly influence its outcomes that 'user involvement' is more to do with active management than active citizenship (Milewa et al, 1999). This issue is discussed at greater length in the final section of the paper.

Typically, concerns about ethics in research relate to protecting participants in a number of respects (e.g. confidentiality, anonymity, avoidance of harm, etc). Typical responses to these issues may need to be reviewed if the researchers are also service users. For example, service user participants being interviewed by a service user researcher may have

particular concerns about confidentiality and anonymity because they are members of the same social networks. It may also be that service user researchers will have different needs than professional researchers and require their own forms of 'protection from harm', for example in the form of on-going support/supervision.

Real involvement of service users in the processes of research also raises a series of different questions of ethics including ownership and authorship of the research and the related issues of accountability, and remuneration. (See McClimens, 2004, for a broader discussion of the issues.) Each of these is potentially very complex and will be highly dependent on the nature of the project, its expected outcomes, the degree of involvement and so on. The greater the extent and 'reality' of service user participation the more such issues will come into play. In respect of ownership who gets the credit for the work is clearly an issue and not just in respect of the naming of authors. As a series of service user researchers (Rose, 2003; Faulkner and Thomas, 2002) have remarked, 'ownership', or lack of it, is also evident in whether they are credentialised through the research, are ultimately employed (if that is what they wish), and that their status is recognised as more than a 'junior partner'. Such questions also relate to the broader question of the status of the work. There are, of course, many arguments for accessible, user-friendly publications arising from such work. However, if that work is not also published in peer-reviewed journals, it may never gain the sort of status that is required to facilitate employment in research. Currently, as Rose (2003a) describes, most user research is published in the 'grey literature'. It may be the case, as Boxall et al (2007) describe, that different forms of peer review would need to be instigated for it to become otherwise.

The more general ethical question related to the degree of involvement of service users relates to an issue that was touched upon in a previous section. Although research funding bodies may encourage the involvement of users, the processes of bidding for funds may be inaccessible to them. Some have argued that this means research can never fully reflect the interests of service users. Another potential barrier to the full participation of service users in funded research relates to the role of ethics committees. Increasingly, research proposals will be scrutinised by an ethics committee and sometimes more than one committee. The process can be very time-consuming and somewhat daunting, involving the completion of extensive forms, which typically require the applicant to pre-specify objectives, methods and suggested outcomes. This may be somewhat in tension with the uncertainties associated with forms of partnership working where roles, relationships and outcomes emerge in the conduct of the work. Carrick et al (2004) caution, however, that it would be wrong to assume that service users do not sometimes engage in research for altruistic reasons and some will not necessarily reject the need for "a longer term, more academic perspective" (220).

It has been argued that ethics committees can exert an unhelpful influence on research processes in general (Lai et al, 2006; Frankham et al, 2006a; Hemminki, 2005). Such committees may have very narrow definitions of what counts as knowledge and 'good' scientific method, and fail to recognise the value of small scale, qualitative or case study work. This may also have a negative effect on partnership work, as it is more likely to fit within the qualitative/interpretive paradigm. Carrick et al (2004) document considerable

problems associated with consent forms that were required by an ethics committee but that were inappropriate to the constituency of service users they were working with. In the recent past, service users' views have been canvassed by the National Research Ethics Service, in order to consider the issues raised by user involvement in research (INVOLVE, 2009).

A further dilemma relates to the payment of service users for participating in research. This relates not just to whether they should be paid, but to how much they should be paid, and to questions about whether other forms of income (e.g. benefits) will be jeopardised if they are paid. As previously discussed, a contract can be one way of formalising expectations, understandings and expected outcomes rather than assuming that all parties feel comfortable with the status quo. It is also the case that a contract can signal appropriate acknowledgement of the contribution of all parties. A contract may recognise (for example) that if people are not getting paid, there are other ways in which they can be rewarded for their contributions. In the ESRC project 'Partnership Research: Negotiating User Involvement in Research Design'⁶, for example, service user researchers requested assistance with a number of practical activities in lieu of some payments.

The final ethical issue raised here relates to accountability in research. This is about much more than making sure that language is accessible or trying to include people in decision-making and relates to the social model of disability (referred to in earlier sections of this paper). The social model sets out to avoid the 'individual-blaming philosophy' of the individual or medical models. Instead, the emphasis is on understanding the "ways in which physical, cultural and social environments exclude or disadvantage people" (Barnes, 2003:5). Of course, one of the institutions that excludes and disadvantages people who are labelled disabled is the academy (or universities/other places of learning). Research conducted within the social model may raise tensions, then, for researchers who critique the academy of which they are a part. The social model also suggests that accountability for research lies with researchers who have a responsibility to ensure that research processes and outcomes put the participants/service users first. Most researchers are subject to the "regulatory influence" (Barnes, 2003) of the academy and may find it difficult to fulfil responsibilities both to the academy and to non-academic audiences. Again, this issue is debated further in the final section of this paper.

Dissemination, here regarded as an important element of accountability, is an area where participation by service users may be central to the process. Service users are much more likely to be members of networks of service users than researchers are. They may also be aware of key publications and other outlets for the publication of research and ideally will play a key role in presenting the outcomes of the research in ways which are accessible to other service users. McLaughlin (2006) outlines the benefits of young people playing a key role in dissemination to other young people. There is always a danger, however, that it is assumed that young people (for example) will know what other young people will respond to – this suggests a homogenised view of a highly diverse group (Frankham, 1998). At the

⁶ ESRC Ref: RES-333-25-0002. See Frankham et al (2006a).

same time, it could be argued that professional researchers can bring the research to an academic and policy maker audience although it may be, as previously suggested, that with limited time equal attention is not paid to both avenues. This issue is also connected to issues of ownership of research inasmuch as there may be greater status attached to academic publications.

4 TROUBLING THE FIELD OF PARTNERSHIP RESEARCH

In this section some widely accepted ideas in respect of service-user involvement in research are debated. As others have described (Nolan et al, 2007; Seddon et al, 2004; Daykin et al, 2004; Carrick et al, 2001), there is a tendency in this field to over-claim the benefits of partnership working and to avoid acknowledging the complexities of the field (Beresford, 2002). In this section, then, I set out to “counter the tendencies to celebratory narrative and premature closure about the implications, meaning and significance of social partnerships” (Seddon et al, 2004). It is not intended through this discussion to undermine the idea or the ideal of carrying out research with service users. Rather, it is regarded as an important part of the development of the field that questions and uncertainties be raised. As Nolan et al (2007) describe, the field is somewhat “resistant to criticism” (2) and this is unhelpful in a context where continuing developments need to take place. This section, then, takes seriously Lather’s (1991) encouragement to trouble notions of service user involvement from a concern that: “narratives of salvage and redemptive agendas can be ever deeper places for privilege to hide.” Questions are raised here in relation to three main themes: The privileging of personal experience in knowing and understanding; issues around what and how we learn in research partnerships; and the notion that service users will or can be empowered through research.

4.1 Speaking from ‘personal experience’

As previously described, the importance of ‘insider’ experience is central to the move for greater user involvement in research. I pose here some questions in relation to the privileging of personal experience in the business of knowing and understanding. As described, drawing on the personal experiences of service users is seen as one way of trying to ‘rewrite’ some of the wrongs of previous research in which service users’ personal knowledge was insufficiently taken into account. As Beresford (1999) describes: “It values people’s first-hand direct experience as a basis for knowledge” (673). However, there is a danger that in privileging the personal experience of individuals that new essentialisms will proliferate; in suggesting that one person ‘knows’ what it means to live with a learning disability, for example, that individual is taken to be representative of a group who share that characteristic. These accounts, then, can act as a new form of ventriloquism – one person speaking *for* others – and to the homogenisation of groups of people, as accepted accounts of what this experience means are repeated and reified. “The overall effect is to impose a single drastically simplified group identity which denies the complexity of people’s lives, the multiplicity of their identifications and the cross pulls of their various affiliations” (Nancy Fraser, 1995: 112).

Secondly, if personal experience is foregrounded it may be that rather than service users’ knowledge being privileged, *they* become privileged as an (assumed) knower. That is,

because they have had a particular experience they are assumed to *understand* that experience (not just be able to describe it). This may lead to an unfortunate 'taking at face value' everything that a service user describes. In addition, this unfortunate 'tying' of individuals to particular domains of knowledge may, in turn, make it harder for service users to make contributions in respect of issues *not* obviously concerned with their personal experience. In turn, then, this may lead to very limited forms of participation and to missing out on significant opportunities for learning.

Thirdly, and related to the previous issue, there is perhaps a tendency to avoid trying to unpick or unpack service users' stories, because this would be to somehow deny the realities of an individual's experience. This leaves out, as Joan Scott (1992) describes, many of the social processes evident in the construction of accounts: "Questions about the constructed nature of experience, about how subjects are constituted in the first place, about how one's vision is structured – about language (or discourse) and history – are left aside." (25) Connected to this, the process of storying a life is, as Somers (1994) describes it "an ontological condition of social life." He says: "people make sense of what has happened and is happening to them by attempting to assemble or in some way to integrate these happenings within one or more narratives; and that people are guided to act in certain ways, and not others, on the basis of the projections, expectations, and memories derived from a multiple and ultimately limited repertoire of available social, public and cultural narratives" (639). In this sense, experience is 'made' partly at least through the storying of that experience. The integration of these understandings about personal narratives into research with service users is another neglected area.

Of course, this relates to a previous point in respect of service users having a different epistemology (way of knowing, understanding, experiencing the world) to those, for example, who provide services (when such clear distinctions are possible). The juxtaposition of these two issues, however, brings us to a key dilemma in the field. Asking questions about the accounts that are given (which is not to suggest questioning the *veracity* of those accounts) may be taken to imply doubt and scepticism and to ignore the idea of service users' epistemology. Denying the social, cultural and political issues evident in the development of people's accounts, on the other hand, may be to miss out on highly important contextual issues and broader understandings of the ideas being explored.

4.2 Learning within research partnerships

A question that is neglected in the literature on research partnerships relates to the forms of knowledge that will be produced within these partnerships. Knowing and learning in research partnerships is typically characterised by the discourse of 'building blocks' – knowledge production as a process of accretion (Nolan et al, 2007). A combination of bits of knowledge coming together is assumed, with each person having particular and unique knowledge to contribute to the 'bigger picture'. These metaphors of learning share some qualities with the development of scientific and technological 'truths' as described by Latour and Woolgar (1979) where a multiplicity of 'traces' come together to define a reality. As Law and Hassard (1999) and others (e.g. Ward, 1996) describe, this process may *suggest* homogeneity, when the ideas in circulation are actually heterogeneous and incompatible. The language employed (collaboration, partnership, co-operation, sharing, etc) suggests the

connections between ideas will seem obvious and that they simply need to be 'assembled' to occupy a coherent and consistent space. Ward (1996) regrets that in the process the idea of complex thinking – "thinking that is not strategically ordered, tellable in a simple way, thinking that is lumpy or heterogeneous" is elided in the desire for simple, clear and transparent understandings of a situation or a way forward. This, of course, is connected to an issue raised in the first section of this paper. If forms of collaboration are relatively limited, the questions to be debated are formulated in advance, and if participants do not question their own or others' roles, there may well be little that is contentious or problematic in the process of apparent learning. On the other hand, it could be argued that such a degree of participation is barely worth the effort, as existing texts are likely to give as much insight.

That we *will* learn in these research partnerships is also assumed, both in a general sense and in the 'model' of knowledge construction that is outlined above. It may be that the paucity of empirical work in this area relates to the fact that, sometimes at least, there is little or no new knowledge generated. Of course, it may be that other benefits accrue (personal/social networks, opportunities for future collaborations and so on). However, it is regarded as necessary, here, both to raise the question that we may *not* learn much in such research partnerships *and* consider why such questions are rarely raised. I have suggested elsewhere (Frankham 2006b) that this is connected to new forms of governmentality in western industrialised nations.

Peters (2003), drawing on Deleuze, describes changes in forms of social organisation from 'societies of sovereignty' in the eighteenth century, to 'disciplinary societies' in the early twentieth century, to 'societies of control' in the early twenty-first century. Disciplinary societies are distinguished by the establishment of various forms of 'enclosure' (the family, schools, hospital, prisons, etc). Peters (2003) goes on to say: "One is in a period of generalised crisis in relation to all environments of enclosure. Institutions built on the model of enclosed spaces, that is the institutions of modernity . . . are finished, despite all efforts to reform them. The closed system, the enclosed space, and institutions built on its processes of concentration and distribution are being replaced by the open system based on the control model of the network. These networks are both more malleable and more flexible" (126).

'The network' is taken, here, to be connected to collaborative forms of working such as service user involvement in research. And Seddon et al (2004) give examples of how 'networks' can be seen as forms of control in the sphere of education, at least: "the state has to represent generalised neo-liberal market failure as localized issues (e.g. failing schools, deficit communities) which are addressed through localized responses to crisis. Such 'local states of emergency' include interventions that allow failing students to choose an alternative to school, the proliferation of individualized case management to realize education and employment outcomes, provision of localized supports to patch up the safety net of existing (or failing) institutions and targeted initiatives to address supposedly deficit communities or regions. From this perspective, social partnerships can be seen to be an intervention which show that governments are doing something locally in response to the general problem of market failure and legitimacy within neo-liberalism" (132/3). Such

responses also set 'the community' up as the legitimate locus for attention and action. If that 'community' fails to participate, however, they may also become the convenient scapegoat in relation to action not being taken.

In addition, in such a context, it would be counterproductive to suggest that these 'open' models of control *may not* result in new understandings and new developments ('progress' in the general sense) as that would be to beg questions about the very purpose (or otherwise) of the collaboration. This is also connected to the relatively impoverished discourse about learning in literature about research partnerships. The 'building blocks' metaphor that I referred to, above, can 'stand for' progress, gain, growth whereas other metaphors of learning (such as entanglement or estrangement or other terms which do not suggest a trajectory or 'journey' with a clear destination) might suggest overwhelming complexity, or 'dead-ends' or any of the other possible outcomes of collaborative work. As others (e.g. Lyotard, 1984) have described, Habermasian (1984) notions of 'ideal speech communities' where people come together to 'share' knowledge with 'partners' in an atmosphere of mutual respect presuppose equality, shared goals, and a degree of altruism which empirical research does not support. However, for as long as the discourse of service user involvement in research continues to 'speak the language' of equality, partnership, community and so on, such challenges are rarely seriously debated. Where problems of 'equality' are raised, the tendency is to stress the need to ensure that everyone can contribute on "equal terms" (Beresford, 2005), as compared to working with an understanding that such a thing is probably not possible.

These developments are connected to wider issues in the commodification of knowledge where knowledge is conceptualised as transportable and transposable (the key metaphor is flow), where structures are 'inclusive' (everyone is welcome to participate) and the complexities of power/relations are elided in a discourse which emphasises 'community'. This is a system where everyone 'gets on', in the co-operative sense, but also 'gets on', in the sense of a situation improving or progressing, as everyone gains from the exchange of ideas. In these respects knowledge is conceptualised as a commodity, with an endlessly expanding forum for its consumption, and potential for mutual gain. As Parker (1998:15) describes: "The commodity metaphor supports and is reinforced by a network of other metaphors which picture knowledge as something that can be assembled and acquired in a purely linear, additive manner."

This 'vision' of knowledge production is also evident in the largely unquestioned notion that there is a clear 'endpoint' and purpose for service user involvement in research – the improvement of services (Nolan et al, 2007; Beresford, 2005). It is difficult to argue against such a notion because the inference is that all existing services are at least adequate, if not perfect, and this is clearly not the case. However, to uncritically privilege this as an outcome may be to deny others' legitimate concerns, the demands upon them, the wider policy context and so on. However, for as long as service users' knowledge is privileged in this debate the complex matrix of questions, issues and the *possible* multiple outcomes of research which includes service users, remain under-debated. The implication is that if service user research is carried out in the 'right way' the knowledge generated will make clear what needs to change and why. However, an alternative view would be that in a

complex matrix of questions and issues, service providers and service users who are implicated in a variety of interconnected ways, *and* a dynamic policy context, that the focus for action or whose interests might come first should be open to question.

4.3 Research with 'service users': An opportunity for empowerment?

Many authors have raised questions about the "official sanctioning of the user voice" (Mort et al, 1996) and how much it has been "perhaps more influenced by consumerism and the ethos of markets than ideas concerning the rights of citizens to participation" (Truman and Raine, 2002). It is worth reiterating at this point, that Beresford (2002) has drawn attention to a critical issue in respect of such debates. He wants to make a distinction between 'consumerist' approaches to user involvement as exemplified in New Labour policy and practice and the 'democratic' approach to user involvement. Hence the latter – known either as emancipatory or user-led research – should be evaluated in different terms (in respect of empowerment potential) inasmuch as it is centrally concerned with power and the redistribution of power. This is quite different, then, from 'consumerist' approaches which, to varying degrees, allow for external input while the initiating agencies maintain control. Having said that, Beresford suggests that empowerment is possible through these consumerist approaches. The issues raised here are of a more general nature in relation to the wider policy context in which collaborative forms of working are developing.

An important study by Harrison and Mort (1998) describes health service managers' perspectives on 'user involvement'. Although they were overwhelmingly in favour of user involvement 'on paper', their practice suggested greater ambivalence. Firstly, these managers found it useful to 'play the user card' when it helped them win an argument against a colleague or the institution but were happy to overrule users' views when they did not coincide with their own. They also stressed that service users were only one of a number of stakeholder groups and that their views needed to be 'balanced' against the views of others. They were also frequently critical of the representativeness of the service users involved. It is little wonder in such a context that service users consider there have been 'limited gains' when engaging in such processes. As Milewa et al (1999) summarise, these managers "admit and exclude data, interpret and prioritise diverse strategic and policy imperatives, and attach different degrees of significance to the opinions and preferences they judge to be legitimate" (462). Some, however, would want to ask, how could it be otherwise? An irony of the current enthusiasm for service user involvement (and other forms of collaborative working outlined in the first section of this paper) is that many concurrent policy moves are concerned with increasing *centralised* control while simultaneously talking of decentralisation and public participation. This is exemplified in the multiple forms of audit in the public sector that have proliferated in the last decade and the accompanying tying of payment to 'results'. This helps to put Milewa et al's (1999) observation that those assigned the responsibility for service user engagement are negotiating forms of 'active citizenship' in ways that look more like 'active management'.

This general point relates to the forms of participation generally employed in collaborative group working. These forms can be seen as examples of the technologisation of conversation moving into the public sphere - what Fairclough (1992) calls "conversational discourse". As he describes, the associated informality helps to obscure "overt power

markers" and raises questions about whether the "power-holders and gatekeepers of various sorts are merely substituting covert mechanisms of control for overt ones" (204). Certainly the language that tends to be used in respect of service user involvement in research (partnership, collaboration, community) suggests unproblematic notions of equality within groups, obscuring the inevitable power/relations that exist. Sarangi and Slembrouk (1996) describe "conversationalism" as a strategy adopted specifically to "simulate equality." They describe how the bureaucratic rules and procedures which can accompany meetings diminish the likelihood of productive debate "burying the dialogue that would allow real problems to emerge" (188). And Riles' (2000) work with members of Non Governmental Organisations coming together in networks to learn from one another, exposed similar problems associated with the "aura of inclusiveness" and the "sound bite atmosphere" of meetings where "everyone gets a chance, and nothing more than a chance, at self-expression" (181).

However, as Milbourne (2002) describes, it would be a mistake to scapegoat the managers or local authorities or individual workers involved. "Remedies would then seem to lie with recruitment of appropriate staff, staff training or with local policy development. However, this ignores the wider structure within which individual officers and local authorities work, the reduction in their local autonomy and the increasing pressure and controls exerted through nationally imposed targets and performance standards embedded in a pervasive managerialist ideology. This context poses conflicting demands for officers, which result in compromise and constraints on responses to local needs. Thus, the actions of local officers both reflect and re-create barriers to local autonomy" (301/2). This perspective helps to foreground the complexities of any analysis of research partnerships, in respect of issues such as empowerment, and in respect of many other unresolved questions. In respect of the meaning and claims made for empowerment through research such insights would need to be taken into account in context specific, probably ethnographic, studies of research partnerships. Although over a decade old, McLaren and Giarelli's statement is still apposite (1995:301): "In many cases little or no attempt is made to theorise empowerment. Indeed, it is often left undefined. Mere invocation is, seemingly, thought to suffice." Others have described this process as "theoretical painting by numbers" (Dale, 1991) where the invocation of the idea seems to "preclude the need for more theoretical work" when, in fact, such work is sorely needed.

5 ENDPOINTS

This paper has tried to both present the arguments *for* service user involvement in research (as claimed by those who work and lobby within that field) and raise questions about that involvement. As Nolan et al (2007) describe, opinions about service user involvement are often polarized. Those who work within the field and wish to promote greater service user involvement in research make ambitious claims for the work and its positive effects on service users (see Section 1 of this paper). In such a context, critique can appear tantamount to undermining the notion itself, although it is here regarded as important in terms of contributing to debate about the field. The experience of writing this paper, then, has felt at times somewhat like 'walking a tightrope'. This issue is raised here as it is partly a consequence of the political nature of the drive for greater service user involvement in

research and anyone else entering the field will, I believe, have to work through the ideological issues involved.

Writing this paper has also raised questions about the parameters of the field and the value in the future of drawing on understandings from other areas, for example from educational research, anthropology, discourse studies or conflict resolution studies. It is also interesting to ask why the subject of service user involvement in research is such a 'closed' field, rarely taking in such insights. I believe this may be connected to the felt necessity to promote and defend the activity for motives somewhat extrinsic (as I would perceive it) to whether the research is 'good research'. As suggested above, this is another ideological issue, however, and there are no 'neutral' criteria available for making such judgements.

It is clear that there continue to be many 'drivers' for greater service user involvement in research and there are many practical examples currently underway. As previously mentioned, there are accompanying calls for more research/evaluation about this research (e.g. Evans et al, 2008; Faulkner, 2005; McLaughlin, 2006; Beresford, 2005; Carr, 2004; Ball, 2004) and as service user involvement becomes more 'mainstream' it is likely that greater resources will be devoted to this activity. It is also the case, however, that significant, high quality research in this area would be particularly complex (and costly) as the processes involved, I believe, would require ethnographic work in order to identify and trace the intricate webs of issues raised, over time. In addition, forms of cost/benefit analysis of service user involvement will provide only a surface understanding of the outcomes and effects of the work, underlain as it is by political motives of both the consumerist and emancipatory variations.

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