Values and methodologies for social research in mental health

Jerry Tew, Nick Gould, Deian Abankwa, Helen Barnes, Peter Beresford, Sarah Carr, Jeanette Copperman, Shula Ramon, Diana Rose, Angela Sweeney and Louise Woodward

Editorial support: Jerry Tew and Nick Gould

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Although social research in the field of mental health is still a relatively underdeveloped area, its importance is becoming increasingly recognised for the delivery of an effective recovery-oriented mental health service in line with the National Service Framework for Mental Health. However, many service users, carers and practitioners feel that they have not been properly involved in influencing or participating in research. They have found that it has not always asked the right questions, or asked them in the right way, so as to produce findings that actually helped to make a difference for them. Our aim is to address this by developing a foundation for social research that ensures that it fits better with their values, aspirations and concerns.

Care Services Improvement Partnership CSIP

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Authorship

This paper was written collectively by a diverse group of authors who are actively involved in social research and are based in academic, policy or practice settings. The majority of the authors also have experience as mental health practitioners and/or as service users.

The process of writing revealed substantial common ground, but also significant differences between the authors. The dialogue around these points has been illuminating and productive. Thus, while the final paper reflects the broad agreement that emerged, there is a need to acknowledge and respect some continuing differences of language and orientation.

Summary

Although social research in the field of mental health is still a relatively underdeveloped area, its importance is becoming increasingly recognised for the delivery of an effective recovery-oriented mental health service in line with the *National Service Framework for Mental Health*. However, many service users, carers and practitioners feel that they have not been properly involved in influencing or participating in research. They have found that it has not always asked the right questions, or asked them in the right way, so as to produce findings that actually helped to make a difference for them. Our aim is to address this by developing a foundation for social research that ensures that it fits better with their values, aspirations and concerns.

Mapping out the value base for social research in mental health

Five themes are proposed that start to clarify a value base for social research in mental health. These may be seen to link with current developments in service values:

1. **Partnership** – how relevant stakeholders, such as service users, carers and practitioners, can be meaningfully involved as partners in key aspects of the research process.
2. **Standpoints and distance** – good research needs to combine the 'insider' (experientially based) knowledge and insights of service users and carers with frameworks that give space for rigorous analysis, so that a clear and authoritative picture can emerge.
3. **Holism not reductionism** – looking at a person's experience as part of their wider social context. This leads to a focus on social change (attitudes, opportunities…) as well as individual recovery.
4. **Recognition of social diversity** – acknowledging the impact of social divisions on people's experience and opportunities, and being cautious about applying research findings from one social or cultural group to another.
5. **Emancipatory purpose** – how will research produce evidence and theory that can enable service users and carers to:
   - have a greater **awareness** of their situation so that they can make informed decisions and choices
   - have more **control** over the direction of their lives
   - **participate** more in social, economic and political life and can enable them, in conjunction with practitioners and members of the wider community, to:
   - **challenge** stigma, injustice and social exclusion?

Ethical permission

Existing processes for granting ethical approval for social research are currently being reviewed by the Department of Health. Service users and carers have conventionally been excluded from membership of ethics committees (although this is starting to change), and decisions may currently be made by committees with little expertise within the field of social research.

Social perspectives and methodological issues

The value base may be seen to have implications in terms of how methodologies are implemented in practice and, to some extent, on the choice of methodology. In advancing an emancipatory agenda, there is a need to acknowledge the potential value of both qualitative and quantitative approaches. It is proposed that choice of methodology needs to be on the basis of what best fits the research question, rather than by reference to any predetermined 'hierarchy of evidence' as, for example, randomised controlled trials (RCTs) may only be of limited applicability in social care research. Given the complexity of the causes of mental distress, and of the needs of service users and their carers, research strategies may be required that can capture the interactions between social structures and individual agency; often this suggests multi-method studies.

Service user and carer involvement

Service user and carer involvement is not only a moral issue, but involvement at all stages of the research process can be crucial in strengthening the relevance, utility and methodological adequacy of research. These include:

- identifying priority topics for research
- commissioning/funding research
- specifying research questions
- selecting appropriate methodologies
- identifying appropriate outcome measures
- vetting the ethics of research proposals
- interviewing and data collection
- analysis of results
- writing up
- presenting and disseminating results.

As well as broadening the scope of involvement, it is important to work towards a greater degree of involvement in relation to each stage of the process – moving from models of consultation towards partnership or user control.

Assessing the quality of research

Peer review remains the normal process for the quality control of research, both in relation to the acceptance of proposals for funding, and the publication of research findings. However, as with ethical approval, service users, carers and other stakeholders have tended to be excluded from this process of judging research.

Conventionally, the main criterion of quality that has been applied has been that of methodological rigour – with little concern for the potential relevance, usefulness or emancipatory potential of research. The Social Care Institute for Excellence (SCIE) has proposed a set of more inclusive criteria: Transparency, Accuracy, Purposivity, Utility, Propriety and Accessibility (TAPUPA). With appropriate clarification and development, these are seen as providing a useful framework for assessing the quality of social research in mental health.

Notes on the authors

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1 Introduction

Despite some important and pioneering work, social research in the field of mental health remains a relatively underdeveloped area. However, with the implementation of the *National Service Framework* and associated strategies, it is becoming increasingly recognised that social aspects are significant, both in contributing to mental distress or breakdown, and in relation to recovery (Duggan et al, 2002; DH, 2003 a, b and c; Social Exclusion Unit, 2004; Tew, 2005) – and hence there is a need to develop a more effective research and evidence base in this area.

The particular focus of this paper is on establishing a foundation for social research in terms of underpinning values and preferred methodologies. These would need to be congruent with the emerging value base of modern mental health services (see, for example, DH, 2004), and able to engage with the complexities of people's social relationships, identities and experiences.

Many service users, carers and practitioners have been critical of existing mental health research – finding that it has not always asked the right questions, or asked them in the right way, so as to give them the effective tools that they needed in order to work towards empowerment and recovery. This paper seeks to address these concerns. It aims to clarify and build on good research practice in order to encourage social research that is both ethical and practically useful. In addition, although the paper explicitly addresses the domain of *research*, we see the analysis it contains as applying equally to the fields of evaluation and economic analysis of mental health services.

By highlighting some of the theoretical, practical and ethical issues which may need to be thought through before embarking on social research, it is hoped to make the task of the researcher somewhat easier, and to ensure that the research enterprise is more effectively 'joined up' with the interests and participation of other stakeholders such as service users, carers and practitioners.

This paper also starts to explore what may be helpful and relevant criteria by which to evaluate research proposals – criteria which take account of wider considerations than just the soundness (or otherwise) of their internal logic. To this end, the paper has been written collectively so as to build on a breadth of interest, experience and standpoint.

This paper is intended to be useful to all stakeholders involved in the process of research, including:

- commissioners of research and funding bodies
- the academic research community
- service user and carer researchers
- social care and health practitioners
- those involved in research governance.

It seeks to promote an approach to the process of social research which is inclusive and emancipatory. It is important that the research process is not seen as one in which academic and professional elites control research in a way that furthers their interests, rather than necessarily the best interests of those who experience mental distress, or those who support them in either a personal or professional capacity.

All research in this field needs to recognise that mental health is a contested domain, and that there will need to be space for working through what may be quite profound differences of perspective between stakeholders – both within and between professional disciplines, and between service users, carers and practitioners. Some of these differences are reflected in questions of language and definition. The medical paradigm of research is centred around concepts of 'mental illness' or 'psychiatric disorder', subdivided by diagnostic categories which are defined in terms of specified symptomatologies. There is a need for social research to find language(s) and definition(s) that are appropriate to its own perspectives. For example, it may be appropriate for definitions to be based on levels of need or social functioning, or subjective levels of distress, or the meanings that people attach to their experiences – none of which may correlate particularly strongly with medical diagnostic categories. Furthermore, many medical terms – whatever their value in relation to medical treatment – have come to be seen as socially stigmatising labels and are deeply unpopular with many service users. For the purposes of this paper, we have chosen to use generic terms, such as 'mental distress' or 'mental health difficulties', which are more acceptable to the majority of service users and neither presume nor rule out the presence of any biological illness process.

2 Values and ethics

Before starting any social research in mental health, a number of fundamental questions need to be asked, such as:

* Who has been involved in deciding what needs to be researched?
* Who has relevant knowledge and expertise that may be used to guide the research?
* Who is going to be participating in the research and how do they give informed consent?
* Who is it hoped will benefit from the research and in what way?
* How will research findings be used and who will have access to them?
* Do all stakeholders in the research process have equal power and influence, or are some privileged with respect to others?

At one level, these are pragmatic and practical questions. However, people's answers will be indicative of the values that underpin their approach to research. Within the field of mental health, much of existing research and 'evidence-based' practice has been based on positivist biomedical methodologies, whose value base tends to assume that:

1. People are passive objects that are *done to* by the technologies and practices of expert professionals.
2. In order for research to be rigorous, it is better if people are ignorant of what is being done to them and why.
3. Questions of meaning, categorisation and significance are to be determined by the researchers and not the researched.
4. It is the individual, rather than their social/economic/political context that is problematic and needing to change.

Such assumptions – and the value base from which they stem – may be seen to be inappropriate for the practice of social research in mental health. Furthermore, such a value base may be seen to be out of step with the orientation of modern mental health service delivery in which principles of recovery, partnership and social inclusion are becoming increasingly central (DH, 2004). An alternative value base for mental health research has been proposed by the Social Perspectives Network (2003):

1. People are active participants or partners in their own recovery.
2. People are experts *on* their own experience and *by* their own experience.
3. The research agenda must be as much about promoting social change (attitudes, opportunities...) as it is about individual recovery.
4. Service users, carers and practitioners who consent to participate in research must be fully informed about the purposes of the research and, if they wish, be given the findings of the research in a form that is accessible to them.

If service users and carers are to be treated as experts by experience within therapeutic relationships, then it is vital that they are accorded a similar status with regard to the research process – and social research has the potential to be at the

forefront of such developments. Similarly, positions around other current issues in mental health, such as empowerment and valuing diversity, also need to be reflected in the value base of research – if research is to deliver evidence and findings that are actually going to be relevant to the diverse social and cultural contexts in which people are living.

2.1 Ethical permission

Traditional approaches to research ethics have emphasised, quite rightly, that the process of research should not harm those who are being researched. The Research Governance Framework for Health and Social Care stipulates that primary consideration should be given to the dignity, rights, safety and well-being of research participants (DH, 2001). A second guiding principle is that research should be of potential benefit to those researched – or to others in similar situations. However, the very people on whose behalf such judgements are being made have conventionally been excluded from decision making – which raises the question of who is allowed to have ownership of ethical debates. The great majority of ethical permission committees in the UK do not have, among their members, service users of health and social care who could offer such a committee valuable advice on how research activity might be perceived by those on the receiving end – which "*can* result in overly protective or paternalistic committees" (Faulkner, 2004, p 31). However, it is encouraging to note that some ethics committees have been giving this issue active consideration and there are already examples of good practice in which service users have been co-opted as full committee members.

There are a range of ethical codes in the public domain that are potentially relevant to social research in mental health – for example those put forward by the Social Research Association (2003), British Psychological Society (2000), British Association of Social Workers (2003) and the British Sociological Association (2003). However, as these tend to be discipline specific, the resulting fragmentation is not conducive to a 'joined-up' approach to ethical approval and is particularly unhelpful in providing clear guidelines for ethics committees who are seeking to decide on research proposals which are increasingly likely to be coming from research groups that cross disciplinary affiliations and include service user and carer researchers.

It has not so far been the practice of most ethics committees to address questions of service user and carer participation in the research process – or giving such people an effective say in how results are used and disseminated. In such respects, the value base underlying mental health research may be seen to lag behind developments in values based practice and service delivery (Repper and Perkins, 2003; DH, 2004; Woodbridge and Fulford, 2004).

Beyond this, the current composition and modus operandi of ethics committees can tend to favour more traditional 'clinical trial' type approaches to mental health research, so that "even when emancipatory research is funded, ethics committees may be resistant to approving that it can take place, as they often do not understand the importance of emancipatory and user-controlled research" (Hanley, 2005). Thus, under the guise of 'ethical protection', research may be being stopped where its explicit purpose would be to provide a knowledge base that would enable service

users to live more fulfilling lives and make more informed choices about the services they receive.

The routes for ethical approval for social research have been under review by the DH (Pahl, 2004), and it is recognised that there have been particular difficulties in relation to obtaining approval for social research via Health Research Ethics Committees whose composition has meant that they may not have fully understood proposals and have given inappropriate responses (Lewis et al, 2003). As yet, it is unclear as to what will be the best way forward, but there is a broad consensus that current arrangements are unsatisfactory.

2.2 Mapping out the value base for social research in mental health

This paper explores five overlapping themes that may help to define the value base of social research in mental health:

1. **Partnership** – how relevant stakeholders, such as service users, carers and practitioners, can be meaningfully involved as partners in key aspects of the research process.
2. **Standpoints and distance** – good research needs to combine the 'insider' (experientially based) knowledge and insights of service users and carers with frameworks that give space for rigorous analysis, so that a clear and authoritative picture can emerge.
3. **Holism not reductionism** – looking at a person's experience as part of their wider social context.
4. **Recognition of social diversity** – acknowledging the impact of social divisions on people's experience and opportunities, and being cautious about applying research findings from one social or cultural group to another.
5. **Emancipatory purpose** – how will research outputs enable people to attain fuller social and economic participation and exercise more informed choice in relation to the services they receive.

2.3 Partnership

Social research in mental health takes place within a policy and practice context in which there is an increasing expectation of partnership with the major players, who usually would be service users, their significant others (some of whom will be carers), practitioners, service commissioners, policy makers, politicians and the general public. In this section we will consider more specifically the involvement of users, carers and practitioners in contributing to the research enterprise alongside academic researchers.

Genuine partnership among stakeholders in any social research is based on ensuring equality within the research context. This should be manifested in terms of involvement in the different phases of research, inclusive of:

* the choice of research question
* selecting appropriate methodologies that fit the research question
* identifying appropriate outcome measures

- vetting the ethics of research proposals to ensure that they are respectful of the interests of those to be researched
- data collection
- analysis, including negotiating questions of meaning, categorisation and significance
- writing up
- presenting and disseminating results.

The justification for such an involvement comes from a fresh look at the relative value attached to different types of knowledge, and an appreciation of how the varied expertise of service users and carers may be crucial in delivering good quality research. It makes excellent sense to involve non-professional stakeholders, because evidence and understanding around social aspects of mental health experiences must primarily be based on learning from the lives of these stakeholders, and it is only of value if it is useful in improving their lives. Similarly, practitioners possess valuable expertise based on their experience of what may, or may not, make a difference to the lives of the people with whom they work – and they should therefore also be full partners within the research process. Such wider involvement in the research process may also be seen to promote interest in, and a shared sense of ownership of, whatever new evidence is generated. In turn, this could have a big impact in terms of promoting the implementation of research findings into everyday practice.

Many traditional approaches to research have colluded with more medicalised approaches to psychiatry in invalidating experiential knowledge accumulated by users, carers and practitioners, as this was labelled 'subjective' and hence not good enough for those who viewed as knowledge only objectively verifiable evidence. With the advance of interpretative (qualitative) social science understanding and methodology we have come to accept intersubjective and subjective knowledge as valid too within the search for social and personal meaning.

Contested understandings as to the very nature of mental health difficulties provide a further incentive for involving service users, carers and practitioners from different disciplines in the research process, as a way of achieving greater comprehensiveness and clarification than has been the case up to now. The scientific and lay critique of medicine, embedded in disciplines such as medical sociology, and the promotion of participatory research outside of mental health, have provided further legitimation for such an involvement.

How possible is it to obtain equality within the research context when each partner comes with different knowledge and different expertise? This implies moving beyond a model of equality in which each partner duplicates what the other is doing, to participation which is based on the unique contribution of each, in a similar way to the pooling of expertise in any shared enterprise.

However, we would argue that for those unused to research it is important to provide real opportunities to understand what research is about – for example through seminars or training events. However, the most powerful way is to be engaged together in actually doing research, and participating as much as possible in each

stage. Such participation highlights the potential of shared research to *empower* non-researchers (Ramon, 2003; Glynn, 2004).

The meaningful involvement of research respondents, called 'subjects' in traditional research, brings to the fore a number of related, yet different, issues from those of engaging non-professional stakeholders as researchers.

For far too long respondents were indeed treated as subjects, who were there only to provide the information the researchers were looking for, who had no say as to whether the questions put to them were acceptable to them or not, or whether they wanted to participate in the study or not. In certain traditions of research there has grown up an orthodoxy which rules out any prior consultation with research subjects for fear of introducing 'interviewer bias'.

However, feedback suggests that people who are not involved or consulted with regard to the research process, or are reluctant to participate but do not feel empowered to say 'no', may tend to provide evidence that is of lesser quality or reliability. People may respond to please the researcher or professional by saying 'the right thing' – that is, what they think the researcher will want to hear. Or they may omit evidence which may be highly relevant, perhaps because they are not sure whether it would be considered important, or because it is not something that they would feel comfortable revealing if they felt they had no clear understanding of the purposes for which it might be used.

More recently, those social scientists who are ready to accept that respondents should be respected as full social actors or participants in the research encounter have started to create opportunities for a more open discourse, and some of them see the involvement of users as researchers as an attempt to enable a more equal and truthful research encounter. A more participative approach may engage the research subject more actively in a quest for the (subjective and/or objective) truth of the specific situation or context. Evidence suggests that service user respondents are much more confident to 'tell it as it is' if they know that other service users have been involved in designing and carrying out the research (Tew et al, 2000; Rose, 2001). In a number of research projects in which users were the researchers, the respondents' feedback has indicated how much better this was as an experience than being interviewed by non-user researchers.

Ethically, it is hard to defend the concealment of the research purpose from respondents. Most ethically agreed research protocols today would explain to the respondents the aim of the research from the researchers' perspective, and will outline to them what their rights are as respondents, including the right to withdraw from participation at any stage, as well as what will happen to the data collected from them. However, the considerable inequality between a respondent and a researcher, who comes with their pre-prepared research instrument, is not easy to overcome, and the measures mentioned above may require further thinking through in specific situations. Returning to respondents the transcript of what they have said in the research encounter, asking for their feedback on accuracy and verification of meaning, providing them with a summary of the research findings at the end, are some of the ways of introducing a more meaningful and less exploitative relationship.

2.4 Standpoints and distance

In recent decades, within the world of social science, there have been ever more complex debates as to how to generate knowledge of the social world (epistemology). Historically, a dominant position within social science has been a concern only in those aspects of social phenomena that seemed to be objective and predictable – amenable to the ways of producing knowledge that had been developed in natural science. More recently, there has been an increasing interest in subjective and intersubjective realities: what people experience and the meanings and significance they give to these experiences. Within the field of mental health, it may be argued that a failure to engage with subjective and intersubjective realities may result in a very skewed, superficial and erroneous account of processes of breakdown and recovery.

2.4.1 Standpoint epistemology

The idea of 'standpoint epistemology' started with feminist writers who suggested that science had been dominated by men, or at least by discourses characterised by the attributes of men (Rose, 1994; Hartsock, 1998; Harding, 2004). The exclusion of women from science was a matter of power as their own discourses and knowledges were undermined and denigrated. It was then argued that women's knowledge, stemming as it does from a different position in society, needs to be re-instated as valid and powerful.

Put simply, standpoint epistemology asserts that life experience of subordination or exclusion (as a woman, a Black person, a mental health service user, etc) can give people greater knowledge about certain realities that those in positions of relative power and privilege cannot easily know about in the same way, because they lack that life experience. This can be knowledge of 'what is' and also knowledge of 'what is important': both of which may be crucial to harness within the research process.

Since the Enlightenment, just as the notion of 'reason' has been used by those in positions of power and privilege to discount the capacity of women and Black people to be involved in the production of useful knowledge, so too it may be used against mental health service users – and, to some extent, carers and practitioners – who may be seen as too 'involved' to be 'objective'. Issues to do with responsibilities towards others (for example, children) traditionally had not been seen as important as they were assumed to be 'natural' to women. The word 'natural' is important as it implies that women are closer than men to 'nature' and so emotional and less characterised by reason – assumed to be the province of men. But service users' knowledge is invalidated on similar grounds to that of women. One could argue even more so. The idea of 'reason', with its birth in Enlightenment thought, has silenced the voice of madness on the grounds of its 'unreason' (Foucault, 1967).

Sandra Harding argues that standpoint understandings do not come 'naturally' to women, but constitute a level of awareness and knowledge that is achieved through a process of struggle against external and internalised forms of oppression. Such a logic may be seen to apply equally to mental health service users who may, through their process of recovery, arrive at insights and meanings in relation to their mental

distress, and also first-hand knowledge of what may have been empowering and what may have been oppressive within their experience of psychiatric services. However, this argument should not be taken too far. There is a need to respect people's own understandings even when they seem to some to be an example of 'internalised oppression'.

Research by service users seeks to describe and explicate the *experiences* of those deemed mentally ill and to show that these do indeed make sense. Because of this, a social perspective on mental illness can demonstrate how the life conditions of service users are the context in which difficulties arise, and that the very services offered (or compelled) may themselves compound difficulties. It may be seen that the silencing of the perspectives of service users is an act of power, and that the experiences of those with a diagnosis can constitute a valid and coherent standpoint.

If service users were to develop their own knowledges of madness, would these be seen as valid as the currently dominant discourses of psychiatry? There is reason to believe that the knowledge thus generated could be more valid. For example, the standpoint knowledge of service users may be seen to have challenged conventional understandings of voice hearing and self-harming experiences – insights which may be seen to have profound implications for service users, carers, practitioners and policy makers (Pembroke, 1994; Lefevre, 1996; Coleman, 1999).

The second reason why service users' knowledge may be seen as especially valid is that they have access to both the dominant discourse and their own experiential knowledge. Service users cannot escape the dominant discourse of psychiatry – it surrounds them. But they also have access to their own knowledges, often collectively produced. Being able to 'speak two languages' means that service users can have a more complex understanding of mental health and mental health services than those speaking from only one position.

Whether such standpoints may be articulated only by service users themselves is a difficult question – and it is important that standpoint knowledges are not appropriated by (powerful) others who may lack the necessary empathy and understanding and who may seek, however unconsciously, to use such knowledges to further their own agendas.

2.4.2 Learning from the work of disability researchers

Service users in their quest to develop more empowering and inclusive approaches to research have not only sought to build on other contributions, like that of feminist research. They have also sought to develop their own research approaches. It may be helpful to see mental health service users'/survivors' research as part of a broader project which includes the pioneering work of other groups of health and social care service users, notably that of disabled people (Oliver, 1992, 1996; Lindow, 2001; Mercer, 2002).

Such emancipatory and user-controlled research rejects positivist assumptions of 'objectivity'. Researchers not only acknowledge the subjectivity of their own (and other research) approaches, they have also begun to challenge positivist assumptions

about the helpfulness of being distanced from their subject. Thus, they not only challenge traditional assumptions of the deficiencies of service users designing questions and interviewing research participants. They also identify *gains* in doing this, for instance, in terms of these making more sense to the participants and eliciting different, fuller responses (Rose, 2001). Now, both implicitly and explicitly, the advocates of such research approaches are questioning both the possibility of 'neutrality' and 'distance' in research, and whether what have been seen as their merits may actually be deficiencies (Beresford, 2003).

2.4.3 Distance in research and its problems

The problem of being 'distant' from the experience being interpreted has particularly been highlighted. This can lead to the distortion and misunderstanding of such experience, for example, as a result of:

- unequal power relationships between researcher and research participant, resulting in either hostile or paternalistic understandings
- inadequate awareness on the part of 'distanced' interpreters of their own position in relation to other people's experience, cultures and perspectives
- where people or groups are separated by discriminations relating to class, 'race', gender and other forms of difference
- commitments to ideologies, agendas and values which pull people away from valuing or being able to appreciate the other person and their experience
- socialisation into and reliance on models of understanding which subordinate and pathologise people (for example, medical models of mental health (Beresford, 2004).

A historically significant example of the problems inherent in such 'distance' was the 1970s Miller and Gwynne study of institutionalised disabled people. Disabled people's reaction against this research played a key part in the development of emancipatory disability research. This study rejected the experiential knowledge of disabled research participants, who said that they wanted to and could live, with appropriate support, independently in their own homes. It asserted instead that this was 'unrealistic' and that they were inherently 'parasitic' (Miller and Gwynne, 1972). Subsequent changes in thinking, policy and practice, based on the experiential knowledge of disabled people, have fundamentally disproved this argument.

More recently, a range of gains from researchers being closer to the issue under study have been identified and the benefits of researchers getting closer to the experience with which they are concerned have been explored (Beresford, 2005). A number of ways in which researchers (without shared experience with research participants) can do this, have been suggested. Ways of moving from individual experiential knowledge to collective knowledge have also been highlighted (Mercer, 2002; Beresford, 2003, 2004). In this way, service user involvement in research may go beyond the nuts and bolts of doing research, and service users may begin to develop their own theories and arguments about what underpins research. In mental health user/survivor research such developments are already nascent.

2.4.4 Maintaining rigour

Within a positivist paradigm, it is the expert researcher whose pre-existing knowledge guides the research, and informs the interpretation of results; the quality of research (defined in terms of reliability and validity) is seen as dependent on an experimental design that distances the researcher from any meaningful interaction with their research subjects. As has been argued above, this form of distance can lead to research that 'misses the point' – potentially quite disastrously – through disenfranchising the knowledge of those with the most direct experience of the issues being studied.

However, some framework that allows space for thinking and reflection is essential in research. Raw experience does not immediately turn itself into useful knowledge: there is a need to stand back in order to analyse and interpret. There can be value in seeking out alternative sources of evidence to corroborate (or challenge) the knowledge that emerges from individual and collective experience. There may be benefit from collaborative working between those who come from different standpoints – such as academic researchers and service users, carers and practitioners. Such approaches to engaging with, and triangulating between, different sources of evidence may not be conducted on the basis of any assumptions of 'neutrality' or 'objectivity'; questions of evaluation and significance can only be worked through on the basis of standpoints that are declared and out in the open. In many instances, rigour may perhaps best be judged by how faithful the outputs of the research process are in their representation and conceptualisation of people's lived experience – and service users will tend to be the best judges of this.

The dynamics of maintaining closeness (so as not to lose sight of the situations and experiences being researched) and giving space (for analysis, interpretation and discussion of the evidence) would need to be dealt with carefully. Such tensions may only be managed successfully if all standpoints are valued, and there is no use of power to sway the process in any particular direction. Collaborative approaches would have access to more positions and standpoints than more traditional approaches to research, and are likely to produce findings that could be more incisive in terms of getting to the core of those issues that are of greatest concern to service users, carers and practitioners. There are already successful examples of putting such approaches into practice where service user research groups are working collaboratively with university-based research teams. However, it must be emphasised that, given the history of supposed professional superiority that is still embedded within much research practice, achieving equality within such collaborations takes considerable hard work, honest reflection and mutual challenge.

2.5 Holism not reductionism: looking at the person in their social context

Within the dominant biomedical approach to mental health research, there is an inherent tendency towards reductionism: the unit of study is usually a cluster of symptoms or a diagnosis. However, it is now recognised that this model is not always adequate to explain many forms of illness. Although it has traditionally been assumed that "all illness has a single underlying cause, and removal or attenuation of

the disease will result in a return to health", evidence is increasingly emerging which suggests that these "assumptions are wrong" (Wade and Halligan, 2004, p 1398). The World Health Organization (WHO) has recently recognised the shortcomings of biologically dependent accounts of illness. A proposed expanded model of illness emphasises that physical disease is one factor alongside social/cultural and personal contexts (WHO, 2001).

Under the biomedical model of research and treatment in mental health the question has not been what will help a whole person, with their particular strengths and vulnerabilities, on the road towards recovery, or what may have been the particular social and personal stresses that may have contributed to a person's distress or breakdown. There has often been very little attempt to understand a person's experience in relation to their social context, in terms of family, community, culture, gender, sexual orientation, employment history and so on. Reductionist research has its place – but it can only answer certain limited sorts of questions. "Traditional biomedical models of illness focus attention on discovering the pathology rather than understanding the illness" (Wade and Halligan, 2004, p 1401). It will typically be the task of social research to grapple with broader 'whole systems' questions and the effects of social, cultural and personal context on mental health and recovery.

It is now widely agreed that social circumstance, economic and environmental factors and life events can affect mental health (Ostler et al, 2001; Wilkinson and Marmot, 2003). Conventional biomedical approaches to research may not be sufficient to address or measure social and cultural factors, as they can be based on a limited understanding of the complexity of mental distress. A considerable critique of traditional clinical experimental methodologies in mental health research is emerging (Gould, 2006). As a study design which requires standardised and often artificial experimental situations, the randomised controlled trial (RCT) has been found wanting when investigating 'complex interventions' and systems, such as those in mental health (Hawe et al, 2004).

While recognising the value of much clinical research, service users/survivors have said that "it does not adequately address the wider range of key issues that are critical to mental health, especially social issues..." (Mental Health Foundation, 2003, p 1). Now that the majority of mental health care is delivered in community, rather than hospital settings, the need for research to recognise the complex interplay of social, psychological, economic, political and environmental factors on an individual's mental well-being is ever more vital. And if they are to be relevant to practice and outcomes, mental health research methodologies that account for the personal and social context need to be further developed and implemented.

Service users are very clear that there should be a holistic approach to, and understanding of, their lives. They advocate "a 'whole systems' approach taking in [social care], healthcare, benefits, transport and support with training and employment" (Turner et al, 2003, p 25). But further to this "the social model is meant to imply more than just the practical issues that impact on a person's life... Contexts – social, political and cultural – are central to the understanding of mental health problems" (Double, 2002, p 26). For example, compelling bodies of research

now demonstrate that those who experience social or political prejudice and exclusion can be at risk of poorer mental health. However, it is often these people who receive inadequate mental health services (Sainsbury Centre for Mental Health, 2002; King et al, 2003; King and McKeown, 2003; Social Exclusion Unit, 2004), partly because they are historically based on a medical model that does not account for the influence of social or cultural factors.

The unique insight of service users/survivors into the social consequences of stigma, and how identities can be 'spoiled' as a result (Goffman, 1968), introduces an additional dimension to the social context. It has been noted that "some sociological studies of labelling and stigmatisation suggest that diagnosis, in effect an imposed biomedical model, has costs in reduced self-esteem and lower social status for the afflicted individual" (Saravanan et al, 2004, p 107). It is likely that these elements would also remain unconsidered in an exclusively biological reductionist or clinical approach to mental health research and research methods.

There has been a tendency for mental health research to focus on biomedical outcomes, such as the remission of symptoms. Such outcomes may be important but only tell part of the story. From the perspective of service users and their families, what may matter most is the degree to which they can participate in family and community life, whether they are able to obtain and hold down a job, and whether they feel valued as a worthwhile member of society. Some service users may prefer to continue to have some symptoms if the costs of treatment – such as unbearable side-effects of medications – outweigh aspects of their difficulties. These concerns connect with a wider political agenda around social inclusion (Social Exclusion Unit, 2004), and suggest the need to frame social research in such a way as to capture such findings.

2.6 Recognition of social diversity

Much of mental health research undertaken within a positivist tradition has tended to assume a homogeneous population, who would suffer the same sorts of mental health difficulties, brought on by the same causes, and for whom standardised treatments and service responses would have universal applicability. However, in other contexts, the realities of diversity are increasingly being recognised in academic and policy discourses, and there is a growing mass of research evidence which indicates that experiences of mental distress (and levels or prevalence) may differ very significantly across (and within) social and cultural groups (Rogers and Pilgrim, 2003). Interestingly, a recognition of human diversity is increasingly becoming part of medical research, with the aim of tailoring medical treatment to the individual – so this may become an area of some convergence between medical and social research methodologies.

What may be seen as relevant research questions – and the very meanings attached to experiences of mental distress – may differ as between social groups and communities because of our different social, historical experiences and relations to power. For African and African-Caribbean communities, there may need to be an interrogation of the history and legacies of slavery for example – racism, internalised racism and colonisation – in an attempt to confront and heal the far-

reaching impact this history has had on African communities. A particular focus of this interrogation is an attempt to unravel the relationships between this historical legacy and current mental ill health issues that impact particularly severely on Black communities in Britain, such as their apparently higher levels of mental illness, and their disproportionate subjection to compulsion in relation to mental health services (Ferns, 2005). Equally, it is important to recognise how other specific forms of oppression may link with particular mental health experiences for other communities (such as those originating from South Asia or Ireland).

Not only are ethnic and cultural differences crucial in relation to mental health: prevalence and types of distress, and the social meanings attached to them, may be mediated by other factors such as sexuality, disability, age and gender. Considering the particularities of each collective experience adds dimensions to our understanding of how questions of disempowerment, marginalisation and oppression may interlink with people's mental distress. Researching and addressing these issues may have major implications in terms of mental health promotion and opening up the possibilities of sustained recovery and enhanced quality of life. A consideration of such issues may provide opportunities to develop specific strategies that address the uniqueness of these experiences, while, at the same time, identifying common themes, such as social exclusion or inequalities of opportunity, that may affect many different social groups and communities.

As has been discussed earlier, questions of meaning and significance may be important in understanding mental distress and its impact on people's social lives and opportunities. Such meanings only exist within specific social and cultural contexts, and can easily be misread if the normative understandings of dominant social groups are applied. Hence research constructs (such as diagnostic categories) cannot be generalised without regard to questions of culture, gender or other dimensions of diversity. For example, particular patterns of behaviour, such as emotional expressivity, may be misread as signs of mental disorder.

If it is to be effective, social research in mental health needs to locate the individual in their social, historical, economic and community context. The knowledge that communities and groups hold in relation to identities is integral to formulating an emancipatory agenda, to arriving at relevant research questions and to unpicking assumptions. For example, Linda McFarlane's research on mental health *with* the gay and lesbian community involved that community in formulating the research agenda and was carried out by an organisation that had knowledge of gay and lesbian cultures and experience and credibility in that area (McFarlane, 1998). By utilising such standpoint knowledges, her research findings may be seen to contrast sharply with other research which has been done *on* the lesbian and gay community.

Both the specificity and communality of experience need to be recognised. For example, women's experience has been traditionally pathologised or ignored within mental health research – the lack of routine inquiry into women's previous experiences of violence or abuse in mental health services is well established, despite evidence about the relationship of violence to mental distress (Williams, 2005). At the same time it is important to acknowledge that not all women have the same experience or view it in the same way, and that women hold a multiplicity

of identities. Relevant and effective social research within a complex and diverse field may be seen to require both cultural knowledge and, more specifically, the standpoint knowledges that have arisen out of the struggles and the awareness of those with less power within society. Just as it is important to explore the complexity and diversity of women's experiences, so too there is a need to explore the interplay between masculinities and mental health. Over recent years, certain groups of men have become particularly pathologised as they are seen as more dangerous, aggressive and violent, and therefore more likely to need social control by the mental health system.

If we recognise that much about mental distress is not just culture-bound, but is intimately interlinked with other social differences with their attendant power implications, then we must become cautious about applying research findings from one social or cultural group to another. It cannot be assumed, a priori, that results can be generalised regardless of gender, sexuality, 'race', class and personal circumstances. The applicability of findings must be argued on an instance-by-instance basis. Where theoretical understanding and empirical evidence indicates a commonality of experience, then it may be appropriate to explore, through further research, whether findings are indeed applicable to other social or cultural groups. But this must not be assumed without checking it out first.

2.7 Emancipatory purpose

Drawing on wider traditions of political and social action, service user movements have proposed that the purpose of social research should be explicitly emancipatory. The production of knowledge 'as an end in itself' may be seen as an insufficient justification for research from the perspective of those who may currently experience social exclusion or oppression in relation to factors such as 'race', gender, sexuality, disability or use of mental health services; research must aim to bring about change (see Humphries et al, 2000; Hanley, 2005). As one service user put it:

> Participation is affected if people don't see a prospect of change. Especially for black service users, who start off with issues about engagement with services anyway. The issue of change is one reason why black people can be reluctant to get involved in research. (quoted in Faulkner, 2004, p 5)

Emancipatory research prioritises the achievement of people's human and civil rights and their increased say and choices over their lives and the services they receive. This value base is reflected in its commitment to priorities of:

- more equal social relations of research production
- the empowerment of service users
- the making of broader social and political change.

Carers and other family members may also experience marginalisation or powerlessness in their own right, both in their interactions with mental health services and, more generally, in their ability to participate fully in the economic and social life of their communities. In this way, they too may stand to benefit from a research paradigm that has an explicit emancipatory purpose.

Emancipatory research challenges the tendency within conventional approaches to both research and service delivery towards pathologising the individual suffering with mental distress, and assuming that the person's social environment, and prevailing models of service delivery, are unproblematic. It places change at the centre of the agenda, both in terms of empowering the service user and their immediate social networks, and in terms of challenging processes of discrimination, exclusion or abuse that may be impacting on them. Thus, it is argued that the research agenda must be as much about promoting social change (for example, in terms of social attitudes, opportunities) as it is about enabling individual recovery.

Research has traditionally come from an elite – for whom publication is a source of power, status and funding. Research subjects have been allowed to take little, if any, part in shaping the research process and in how the results of the research are disseminated and used. An emancipatory approach seeks to democratise research, placing knowledge, and the potential for power that goes with it, in the hands of those who may currently feel disenfranchised and powerless to take control over their lives. This may be seen to fit well with a service orientation towards recovery.

It has been noticeable that it has been much easier to gain funding for certain topics rather than others – for example, it has so far proved impossible to gain funding for a comprehensive survey of abuse within mental health services in the UK, despite the evidence from service users (especially women) that this is very much an issue for them. As part of moving to a more emancipatory research process, there is a need to democratise the funding context and make visible the power relations implicit in the research process:

> Most research commissioners seek to fund research that is perceived to be unbiased, objective and neutral. This has meant that existing research structures have prioritised and valued more traditional types of research over research that is seen to be emancipatory. Emancipatory research may not be seen as 'real' research because it focuses on people's experiences and making changes. (Hanley, 2005, p 41)

A shift towards a more emancipatory focus in research may be seen as both challenging and potentially empowering for practitioners. On the one hand, it moves away from the production of 'expert' knowledge that can only be placed in the hands of professionals, and which is designed to give them ever more powerful technologies whereby to 'do unto' service users. On the other, it seeks to provide research findings which can empower practitioners to work in new ways in assisting service users and carers to reclaim greater control over their lives.

An emancipatory agenda is equally challenging to academic researchers – especially those who do not have lived experience of service use. The recent Toronto Group seminars on user involvement in research adopted the position developed by disability researchers that emancipatory research should be "controlled by service users" throughout the entire research process, although "researchers who are not service users may be involved" (Hanley, 2005, p 40). Alongside user-controlled research, other collaborative or partnership approaches may also have the potential to achieve emancipatory outcomes, as long as service users and carers are able to

participate in research as full partners and not as implicit subordinates. Both user-controlled and collaborative approaches to research represent a major shift from the current domination of research by an academic research community and funding arrangements which are in no way accountable to service users or carers. They share a commitment to ensure that "research is driven by people's experiences, priorities and concerns, and draws more general conclusions based on these experiences" (Hanley, 2005, p 40).

As Foucault (1980) has argued, knowledge is power – so it is important to look at the practicalities of who will 'own' or have access to the fruits of research, and how they will use this power. Research will only make a difference if mechanisms are in place to ensure that it can empower service users, carers and practitioners to influence mental health policy and practice.

To summarise, the aim of emancipatory or collaborative research should be to produce evidence and theory that can enable service users and carers to:

- have a greater **awareness** of their situation so that they can make informed decisions and choices
- have more **control** over their lives in areas where this may have been taken from them
- **participate** in areas of social, economic and political life from which they may have been excluded.

and can enable them, in conjunction with practitioners and members of the wider community, to:

- **challenge** stigma, injustice and social exclusion (SPN, 2004, pp 24-25).

2.7.1 Putting it into practice

In seeking to put this agenda into practice, a number of issues may need to be considered:

1. *Formulating the research agenda: whose emancipation?*
   To what extent are service users and carers (whether potential researchers or research participants) involved in setting overall research agendas and in the formulation of more specific research questions? Do participants think that the research is potentially useful for them and would the research findings have the potential to give them more control over their lives?

   One cannot assume that the emancipation agenda will carry the same meaning to the different actors engaged in the research process. In view of this, it may be helpful to identify the different interests of those involved and seek to negotiate a research agenda that can be owned and controlled by all participants.

2. *Power relations*
   When engaging in research, how can researchers be sensitive to any power differentials involved in the research process – either within the research team,

or between members of the research team and research participants? It is likely that power differentials may be less of an issue if service users are conducting the research or have control over the research process. Where differentials do exist, recognising such issues may be seen as the first step in working to overcome them – and there needs to be space, and permission, for such issues to be discussed. Empowerment inevitably means that those situated in potentially oppressive positions of 'power over' may need to hold back from deploying it in order to allow the emergence of more effective forms of 'power together' between people with different backgrounds and experiences (Tew, 2002).

3. *Consequences and outcomes*

The potential social consequences of research need to be thought through – in particular being mindful that research has also been used as a tool to oppress and misrepresent the experiences of people it is supposed to be assisting. Therefore, some consideration may need to be given to how service users and carers may be able to influence or control how research findings are disseminated and used.

4. *Accessibility*

Research outputs have to be accessible in terms of language and context. In practice, research reports and publications may need to address different audiences if findings are to have influence on policy and practice – so different formats and summary versions may need to be produced. However, whatever format(s) are used, there needs to be a commitment to make the research accessible to those whose lives it reflects (Hanley, 2005).

3 Social perspectives and methodological issues

Seemingly technical (and dry) arguments about the methods that researchers select potentially become more understandable and significant when they are considered as symbolising differences in human thought about the nature of the world and how we can understand it (Oakley, 2000; Gough, 2004). One tradition (positivist) has attempted to develop social sciences in the way of natural sciences, seeking to understand the social behaviour as predictable and explicable in terms of general laws and principles. This is usually characterised by the use of experimental research designs and quantitative analysis. The other tradition (hermeneutic or interpretive) foregrounds people's own accounts and interpretations of their social world; from this perspective knowledge is considered to be provisional and contestable, reflecting local circumstances. This tradition is usually characterised by in-depth interviews, observation and the study of texts, undertaken through qualitative analysis.

There is a danger that disputes around the appropriateness of methodological choices in mental health research can descend into simplistic polarisation between these quantitative and qualitative approaches. This dualism is further often reinforced by unhelpful caricatures of one or the other being on the side of the angels, usually the protagonists of quantitative analysis claiming that only large or standardised studies can overcome problems of validity, while the champions of qualitative research claiming that only in-depth textually rich data can convey the lived experience of having a mental health problem and overcome problems of reliability. It is important to recognise that this polarisation is a misleading representation of what social science research is about. Both qualitative and quantitative methods, in social science and in other disciplines, have their respective purposes – one to explore the possible 'what's' of an issue or experience, and the other to explore who, where, when, how many etc. And while neither have an absolute claim to either reliability or validity, each have their own criteria in these respects – qualitative as well as quantitative – if they are to provide data which has some link to lived experiences in the areas researched.

Furthermore, as Miles and Huberman (1994) have argued, the mundane reality is that quantitative analysis (particularly using advanced multivariate statistical methods) often involves the exercise of qualitative judgement (for example, 'what label shall we use to describe this factor?'), whereas qualitative analysis usually incorporates some level of quantitative assessment (for example, 'how many times was this theme occurring in these interviews?'). Research has much to gain from combining the two approaches – invariably, qualitative studies can be used to generate hypotheses to be explored in more structured approaches and qualitative findings give understandings to aspects of statistical findings.

Within medical research, the dominant consensus has been in favour of a positivist quantitative paradigm, with almost iconic status having been given the RCT, although other quantitative approaches such as population-based and longitudinal studies have been seen as having their place. However, within the last 10 or so years, "qualitative methods have become more commonplace in areas such as health services research and health technology assessment, and there has been a corresponding rise in the reporting of qualitative research studies in medical and

related journals" (Mays and Pope, 2000, p 50). Even the Medical Research Council (usually thought of as a bastion of quantitative research) now strongly advocates the use of qualitative approaches in the theoretical and modelling phases of research, for complex interventions (MRC, 2000). In support of these approaches, there is now an increasing availability of guidelines on undertaking and assessing qualitative work (Boulton and Fitzpatrick, 1994; Secker et al, 1995; Blaxter, 1996; Dingwall et al, 1998).

In selecting appropriate methodologies for social research in mental health, there is a need to go beyond unnecessarily polarised representations of positivist and interpretive traditions to consider the wider logic of research, and the relationship between the needs of those who are researched, the research question and the selection of a research strategy (Gould, 2006; Glasby and Beresford, forthcoming). A more constructive approach would be to view methodological choices as informed by the nature of the questions being asked, rather than by some pre-determined hierarchy which may give a particular approach, such as the RCT, 'gold standard' status irrespective of its relevance or applicability to the research question (Upshur et al, 2001).

In researching social aspects of mental health and the impact of professional interventions on the whole person, the RCT, may often not, on its own, be the most appropriate methodology by which to investigate many sorts of research questions. However, certain other quantitative approaches that are familiar within medical research may transfer more straightforwardly to social research. For example, epidemiological or longitudinal studies of populations may be very effective ways of isolating the range of social, economic and interpersonal factors that may play a part in contributing to mental distress or breakdown, and in enabling people to make an effective recovery.

Thus, if we look at a range of possible research questions, we may see that different methodologies may have most to offer. For instance:

- How do users and carers experience their mental distress and the impact of the services they receive? Questions like this may be best informed by in-depth qualitative interviews.
- What are the causal relationships between social factors and the prevalence and distribution of social distress? This type of question can be researched productively by surveys and longitudinal panel studies (surveys that follow up the same individuals over a period of time).
- What priorities should be reflected in the development of policies and organizational structures? This might be informed by a mixed-method case study.
- What is the effectiveness of a specific psychosocial intervention? Here, valuable evidence might be gathered by an RCT that compares outcomes for people receiving the intervention, compared to those that do not – as long as the design of the study is sufficiently sophisticated to take account of issues of social diversity within both the sample and the wider population. However, even here, a qualitative component to a clinical trial may be helpful in terms of exploring what, within the delivery of the intervention, is perceived by a service as making a difference, and in guiding the selection of outcomes that are relevant to the needs of users.

'In-depth' approaches to understanding the social causation and resolution of mental distress are likely to require the application of both qualitative and quantitative research findings: together the qualitative and the quantitative can be employed to tell the story from perspectives characterised by the 'sociological imagination' (Wright Mills, 1970), and resonating with wider social action and emancipatory paradigms (Ward, 2000) such as that developed by Freire (1972) in his work in Latin America. Inherent to these approaches are understandings of social experiences and situations which are informed by both structure and subjectivity, inner and outer, constraint and creativity (Dominelli, 2002). Such understandings can engage with social model perspectives in which people as social actors rather than passive objects are "shaped by the world around them but ... are also creative beings" (Ward, 2000). In this they speak of the multiple interactions and processes involved in our social undertakings, which serve to underpin lived experiences – the processes hidden beneath our everyday perceptions and experiences of the world (Friere, 1972) by which people's 'private troubles', inner and outer, have emerged from 'public issues' (Becker and McPherson, 1997); thus, for example, we can trace the interactions of social meanings and social position in the generation of individual health concerns (Wilkinson, 1996).

As we have argued, there is an emerging recognition that both quantitative and qualitative research traditions play their part in deepening understanding of social phenomena, and consequently there are times when contrasting methods can be combined to strengthen the overall relevance of a research inquiry. For example, a qualitative exploration of an issue with a small number of people can illuminate the questions that can be researched through a larger-scale survey. Alternatively, quantitative analysis of survey findings can suggest which individuals or groups could be interviewed in depth to give qualitative understanding to aspects of the statistical findings. As a third possibility, some 'combined' studies run qualitative and quantitative elements in parallel so that findings from each inform the other on an ongoing basis.

3.1 Methodology and emancipatory purpose

The need to move beyond the stale dichotomies of objective versus subjective and quantitative versus qualitative connects with the perspectives of wider emancipatory paradigms in feminist, disability and anti-racism contexts. Understanding how processes involved in structural inequality, discrimination, social exclusion and stigmatisation impact on people's outer and inner worlds, and the monumental and devastating realities with which they struggle, provides people with their means of empowerment (Dominelli, 2002).

We cannot assume by any means that such a use of qualitative and quantitative social research will guarantee an emancipatory approach as proponents from feminist and disability movement standpoints have shown in relation to researchers from traditional social research perspectives seeking to approach their issues (Oliver, 1996; Hartsock, 1998). Some of these perspectives with their working assumptions about survivors can pathologise or render invisible their experiences as much as can a psychiatric diagnosis, and use of these assumptions in research generates interview questions, analyses and interpretations of findings which reproduce these

assumptions. What is important therefore is to develop understandings fully in tune with users' own experiences, respecting both their dignity as social actors and the profound impact of the social structures and processes they endure in social structures and social processes (Bhui, 2002; Double, 2002). Essential in developing this emancipatory paradigm are both increasing opportunities for user-led research, and processes of committed, lived partnership in the research enterprise between people who are survivors, practitioners and academic researchers.

In exploring the hidden depths of social experiences, the whole of the emancipatory enterprise is defeated if researchers are not wholly engaged with people's direct personal knowledge of those experiences. But how this can happen is only beginning to emerge from processes of dialogue and discussion, with survivors, carers, researchers and practitioners reflecting on experiences and assumptions, 'problematising' these reflections (Ward, 2000), and challenging each other (in the non-oppressive sense of raising awareness) (Dominelli, 2002) – all within a spirit of partnership. Much has to happen as a basis for this – researchers and workers need to engage with people from a position of changed assumptions and full commitment to take on and respond to whatever is learned about the monumental issues users and carers endure, their own part in this, and how in outer, practical terms as well as inwardly, the power they have can be genuinely shared in the course of the dialogue.

4 User and carer involvement

A key theme of this paper has been the relationship of service users and carers to social research in mental health, and in recent years there has been growing recognition that this is not only a moral issue, but involvement *at all stages of the research process* can be crucial in strengthening the methodological adequacy of the research (Pawson et al, 2003). It may be helpful to look in more detail at examples of the benefits that service user and carer involvement may bring at particular stages of the research process (Fisher, 2002):

- *Specifying the research problem.* Choosing the research question or issue is at the crux of the power relations between those who fund research, those who do it, and the people about whom the research reports. But defining the research question is not only a question of controlling the research agenda; without a user perspective, research may fail to articulate with sufficient precision or subtlety the question the research needs to address.
- *Defining outcome measures.* The distinction between research and evaluation is difficult to draw, and may be unhelpful, but broadly when we consider evaluation we usually refer to forms of inquiry designed to identify whether interventions produce better outcomes for people. The experimental tradition in social research has tended to seek to define outcomes in terms defined by experts and measured against scales that are standardised, that is, have equal validity when applied to categories of people. Advocates of user inclusion in research have argued that user-defined outcomes are particularly more likely to be sensitive to process aspects of an intervention, to the broader context within which the intervention takes place, and have a better chance of capturing the diversity of users' experiences. There is also of course no inherent reason why user-defined outcomes cannot be incorporated in standardised measures; we need a wider range of standardised measures that include social dimensions.
- *Analysis of qualitative data.* Analysing data collected through interviews, observation, reading documents and so on usually involves 'coding' or identifying the themes or categories that are most important in the data and assigning material to illustrate those themes. Although user involvement in data analysis is one of the less developed aspects of the literature, Fisher (2002) cites various projects that he has experienced where it was user researchers who were best able to identify the issues that 'counted' buried within the data, particularly where the content was about the experience of oppression.

Building on these ideas, it is possible to identify how service user and carer involvement can bring 'added value' to all stages of the research process. For example, what has often tended to be neglected in the past is the crucial importance of involving service users and carers right at the start of the processes of prioritising, commissioning and funding research – helping to ensure that limited resources are directed in the direction of research that has the potential to make a real difference to people's lives. This is an area of involvement that is now being taken much more seriously by key organisations such as the DH and the Mental Health Research Network.

As well as broadening the *scope* of service user and carer involvement to all stages of the research process, it is important to look at the *level* of their involvement – what is the degree of their influence and participation? Drawing on work on service user and carer involvement in service provision (Goss and Miller, 1995) and in mental health education (Tew et al, 2004), and on project work commissioned by the Empowerment Sub-Group of Consumers in the NHS (cited in Pawson et al, 2003, p 62), it may be helpful to conceive of a 'ladder' of involvement which starts from no involvement and progresses towards equal partnership or service user/carer control. In order to map progress in relation to the various stages of the research process, we can draw up a grid by which to record both the scope and the level of involvement within a research project:

Stage	Type of user or carer involvement			
	Consultation	Participation	Partnership	Control
Identifying priority areas for research				
Commissioning/funding research				
Specifying research question				
Identifying outcome measures				
Research design				
Ethical approval				
Data collection				
Analysis				
Writing up				
Dissemination				

Consultation may be seen as a helpful starting point which is likely to result in substantial improvements to the value and relevance of research undertaken. **Participation** takes this further with service users and/or carers making an active contribution. However, neither of these levels of involvement may be seen to shift the traditional imbalances of power between service users or carers and those commissioning or undertaking research – so there remains the danger that the research process may ultimately be reflective of established vested professional or academic interests. There is an ongoing debate as to whether full and equal **partnership** working, or **user/carer-controlled** research should be seen as best practice (Pawson et al, 2003, p 62). Both models have their proponents and have specific advantages. It can be argued that emancipatory outcomes may be more securely guaranteed if users or carers have control over the research process. It is also possible to achieve emancipatory outcomes through partnership working – and there may be other benefits to be gained from the different experience and expertise that other partners may bring.

There are also cautionary notes to be sounded. As Dominelli (1997, 2002) and Wilson and Beresford (2000) argue in emancipatory contexts, it is crucial to avoid 'dumping' on service users and carers. There is a critical need for researchers never to lose sight of service users' and carers' rights to serve their own interests and agendas – and their legitimate expectation of changes in service delivery and social opportunities as a consequence of their involvement in research. It is all too easy for service-based workers and researchers to 'colonise' users' skills, understandings and labour, giving them little back in return. Thus service users and carers may need to develop their own independent collectivities, essential in articulating their own perspectives, and in which they can decide where they wish to channel their energies. Practitioners and researchers have a major responsibility to develop awareness and practice in respect of service users' and carers' issues and perspectives. Equally service users and carers who choose an involvement in research have a right to all the training and support they need to be able to be fully involved.

Full-scale service user and carer involvement will lead to research that is different to what has gone before. If it is to engage with something of the lived realities that service users and carers face, it will need to demonstrate "a clear and open approach towards all of the people involved in the project" (Faulkner, 2004, p 3). This requires a degree of transparency in relation to people's positions, understandings and experiences which has not been common practice in existing practice or academic research, and involves a change of consciousness and strategy (Oliver, 1996; Beresford and Evans, 1999). This applies both to the theories and concepts underpinning the research, and to the details of the research questions developed, the questions designed, and the analysis and interpretation of data.

Stages in the development of a more emancipatory and inclusive approach to social research might include:

- academic researchers and practitioners listening to and learning from service users' and carers' views through setting up opportunities for dialogue
- service users and carers having opportunities to learn about research methods – including quantitative as well as qualitative approaches
- service users and carers developing their own research groups and support networks, theoretical and methodological perspectives, and negotiating the terms of their collaboration with other groups involved in the research process
- academic researchers and practitioners transforming their own practice – and not just abdicating the field to service user and carer researchers
- formation of new partnerships and collaborations – including academic researchers participating in service user or carer-controlled research projects.

If service users and carers are to be able to join the mainstream of social research as equal partners, their training, development and support needs must be recognised. They may face a variety of barriers to their involvement that researchers from more conventional academic backgrounds may not. These may include practical issues – for example, in relation to access to education or negotiating a way through the 'benefits trap'. They may also be dealing with other disabilities, such as lack of confidence or ability to concentrate for long periods at a time, which may result from the experiences that they have gone through and/or the (negative) ways in which

they have been treated by services. It is important that service users and carers feel *entitled* to the specific opportunities, adjustments and supports that they may need in order to become involved – and this may require major changes in the ways that social research is funded and practised, and the attitudes and values that underpin this.

5 Assessing the quality of research

The development of a social knowledge base is set within the changing context of mental health services in the UK. With the introduction of the National Institute for Mental Health in England together with the development of key policies, a shift has taken place within current thinking within health and social care – ranging from practitioners, academics, users of the service and carers, to policy makers. This has led to an increasing focus on the construction of a knowledge base relevant for socially oriented practice, and the development of criteria for assessing the quality of the research evidence that informs it.

Within medical research, systematic reviews and RCTs have often been the preferred method for generating evidence on which knowledge is based. However, as we have seen, such approaches are not always relevant or valid within the field of social research. The intention here is not to champion one paradigm over the other in entering the long-standing debate of quantitative versus qualitative methods, but to highlight that, within the field of social research, appropriate criteria need to be established to evaluate the quality of research evidence, whatever the methodology used.

While "the widespread use of hierarchies of evidence that grade research studies according to their quality has helped to raise awareness that some forms of evidence are more trust worthy than others" (Glasziou et al, 2004, p 39), current knowledge bases in mental health tend to be dominated by evidence that has been generated for the purpose of addressing clinical questions and service interventions. There has been relatively little attention given to the experiences and narratives of those affected by such interventions and using such evidence to inform knowledge. Consequently, although "a systematic review of randomised control trials would be appropriate for answering questions about the main effects of a treatment" (Glasziou et al, 2004, p 39), it may tell us little as to the effects this may have on the social functioning of an individual. For knowledge to be purposeful, it may need to draw on a variety of research approaches.

Given this, it is necessary to develop a framework in which 'quality' can be assessed and applied to a wide range of evidence, and one which makes clear what is meant by 'quality'. In general, there has been a consensus within the research community that one criterion of quality has to be that of methodological rigour within the research process – but what is meant by this is dependent on the methodology chosen. Quantitative research has conventionally been evaluated using criteria of *validity* (are the findings justifiable on the basis of how the data was obtained and how it was analysed?) and *reliability* (how confident can we be in generalising from conclusions and applying them elsewhere?). Such an approach underlies systematic reviews such as those undertaken by the Cochrane Collaboration in relation to medical research (www.cochrane.org). Interpretative and qualitative methodologies come with their own rules of *validity* and *reliability*: they bring their own rigour, albeit defined differently from how it is understood within traditional positivist social science (see for example, Guba and Lincoln, 1989; Secker et al, 1995; Blaxter, 1996; Dingwall et al, 1998).

While there are ongoing debates as to how criteria of validity and reliability should be defined and applied, more fundamental questions have been raised as to whether a focus just on methodological rigour may distract attention from other broader questions about the purposes and usefulness of research – particularly from the perspective of service users and carers (Hanley, 2005). For example, a conventional approach to the evaluation of research would not seek to interrogate the ideological or experiential standpoints of the researcher, or undertake any critical examination of the prior assumptions that the researcher may have made in formulating research questions, and in deciding on what is and is not significant within the array of data generated. As has been discussed earlier, methodologically 'pure' research can result in findings that 'miss the point' in terms of what matters to service users and carers, or by operating on the basis of certain implicit assumptions, or selectively attending to certain issues but not others, to produce findings that are fundamentally misleading or oppressive.

At both the stage of a research proposal, and at the stage of reporting research, the conventional academic process for ensuring quality has been through peer review by other academics in the field. This has been criticised for:

- concentrating exclusively on more narrow questions of methodological rigour
- being skewed by competitive rivalries between academic researchers
- being essentially conservative in the sense of tending to privilege 'conventional wisdom' and established approaches to research as against innovatory or emancipatory approaches
- reflecting academics' own perspectives or perceived priorities
- excluding service users, carers and other stakeholders.

Despite these concerns, this remains the dominant mode of quality assurance within research. However, through the adoption of more broad-ranging criteria, and through building on progress towards the inclusion of service users and others within the peer review process (Hanley, 2005), there is the potential for the peer review process to become a more effective arbiter of quality standards.

In response to concerns as to the narrowness of certain conventional ways of evaluating research-based evidence, the Social Care Institute for Excellence (SCIE) has proposed a broader framework for assessing the quality of knowledge within social care which may offer a potentially useful starting point for evaluating social research in mental health (Pawson et al, 2003). Unlike the more narrowly positivist tradition of 'evidence-based practice' (Trinder, 2000), the intention is not only to "attend to findings of rigorous empirical research", but also to take into account "the importance of first hand experience" (Pawson et al, 2003, p 3). It is seen as important not to "privilege the viewpoints of any particular stakeholder, or any one strategy of generating knowledge". However, it is suggested that not "all standpoints are of equal merit on all occasions, on all issues and for all purposes" (Pawson et al, 2003, p 3).

This is a point that merits further discussion. Traditionally, it has tended to be those in positions of superior power or status whose standpoints have been seen, explicitly or implicitly, as having greatest validity. (It is only 'expert opinion' which is included

within the Cochrane hierarchy of evidence.) However, from the earlier discussion, it may be argued that this hierarchy needs to be flattened out, and even reversed, so that for evidence to be seen as of 'good' quality, it must be seen as being grounded in, and accurately reflecting, the standpoint knowledges of service users and carers.

The proposed framework looks at establishing a wider range of criteria by which the quality of evidence could be judged. These criteria (collectively known as TAPUPA) are summarised below:

- **Transparency**
  The process of knowledge generation should be open to outside scrutiny – with clarification of aims, objectives and all the steps of the subsequent argument.

- **Accuracy**
  All knowledge claims should be supported by, and faithful to the events, experiences, informants and sources used in their production.

- **Purposivity**
  The approaches and methods used should be appropriate to the task in hand, or 'fit for purpose'.

- **Utility**
  Knowledge should be appropriate to the decision setting in which it is intended to be used or 'fit for use'.

- **Propriety**
  Knowledge should be created and managed legally, ethically and with due care to all stakeholders.

- **Accessibility**
  Knowledge should be presented in a way that meets the needs of the knowledge seeker. No potential user should be excluded by the presentational style used (Pawson et al, 2003, pp 38-40).

Although these criteria provide a very useful starting point, it may be helpful to expand and develop some of these further. Questions of **transparency** are crucial if we are to evaluate the quality of research evidence. In determining what would constitute good quality research, we might wish to consider:

- *Is it clear who was involved in identifying and prioritising the issues to be researched, developing the research question and selecting the most appropriate research design?*
- *What standpoints were or were not represented? When there were differences of opinion between stakeholders, how were these resolved?*
- *What was the rationale for decisions and judgements made during the research process?*
- *Is there a full and open discussion of the possible limitations of the research and the potential applicability of its findings?*

In relation to **accuracy**, it may be important to consider not only

* *Was the chosen methodology rigorous in terms of appropriate criteria of validity and reliability?*

but also

* *Were the findings and conclusions faithful to the concerns, issues and experiences of the service users and/or carers who were research participants? How was this checked out?*

The definitions of **purposivity** and **utility** suggest further criteria that contextualise research: not only must it be rigorous, but it must be explicit as to the purpose for undertaking the research (in terms of making a difference in the real world) and its findings must be delivered in a way that it is helpful to its end users. Where these definitions may need to be taken further is in terms of a more explicit examination of the perspectives of different stakeholders: who is involved in determining the purpose of a research project (and hence whether it is 'fit for purpose') and who is involved in judging its usefulness? This raises wider issues of accountability. In line with what has been argued above, there is an expectation that the purpose of the research should be emancipatory, both in terms of process and outcomes. From this perspective, there also needs to be an acknowledgement that "all knowledge production should be answerable to [service] users and their organisations" (Pawson et al, 2003, p 62). This would suggest the application of criteria such as:

* *Will the research enable the achievement of the human and civil rights of service users and/or carers?*
* *Will the research increase understanding of issues such as stigma, injustice and social exclusion?*
* *Does the research provide information or insights that would enable people to have more control over achieving and maintaining their 'wellness'?*
* *How will research outputs enable people to have more say and choices over the services they receive?*
* *In what specific ways may research findings be useful to service users and/or carers – and how can this be demonstrated in terms of feedback or other evidence from service users and/or carers?*

Similar issues arise in terms of the notion of **propriety.** While it is appropriate that research is judged in relation of ethical standards, there may need to be more clarification as to who defines what is 'proper'. Within the overall context in which research has taken place it has conventionally been those in positions of power and authority who have promulgated their own particular versions of what is and is not 'proper' – and this is still reflected in the current composition of many ethics committees. It may therefore be suggested that research must not just demonstrate the exercise of 'due care' towards all stakeholders; it must also be evaluated on the basis of questions such as:

* *How were service users and/or carers involved in discussing ethical issues? Were there any differences of opinion between stakeholders and how were these resolved?*

It is hard to see how the definition of **accessibility** could be improved on – apart from emphasising the possibility of presenting results in more than one format.

In conclusion, we may suggest that the quality assessment criteria proposed by SCIE provide a helpful framework for the assessment of social research in mental health, irrespective of the chosen methodology. They may be seen to provide a broader focus than the more conventional concern just with methodological rigour. However, they would benefit from further clarification and development if research is to be assessed in terms of its potential contribution towards the social inclusion and emancipation of service users, and the development of mental health services that help to deliver such goals.

The approach rightly acknowledges the variety of stakeholders involved in social research and is designed to appeal to "knowledge producers as well as users, practitioners as well as policy makers, service users as well as providers and regulators" (Pawson et al, 2003, p 37). However, there may need to be a more explicit emphasis on the primacy of service users and carers: unless research findings have the potential to make a positive difference, in terms of enabling them to live their lives as they would wish to, then it is of little value.

6 Conclusion

This paper has presented important developments in social approaches to mental health research, while recognising that there is much still to be done in terms of developing research capacity among the service user, carer and academic communities. The paper seeks to speak to various audiences, including commissioners and users of research, to promote an awareness of the important relationships that exist between the social objectives of research and the methods employed by researchers. Throughout there has been an acknowledgement that these debates take place in arenas where there are still contested views on some of these relationships but, nevertheless, there are some fundamental propositions that can be asserted:

- that users of services and their carers are experts in their own situation, and that research should recognise and build on their expertise
- that users of services are active participants in their own recovery, and research should respect that potentiality, and
- that research should be directed towards changing the social environments and constraints that impact on mental distress, as much as individual change.

The paper has then elaborated how those principles can be developed and promoted through various strategies including: the development of equal partnerships between the various stakeholders in research, the recognition of the validity of knowledge that derives from the direct experience of mental distress, the use of frameworks that address the wholeness of people's lives rather than reducing them to clusters of symptoms, the recognition of diversity of standpoints and heritages, and the need for research to reflect emancipatory purposes.

The choice of research strategies and methods that embrace these principles, we have argued, transcend the sterile oppositions between quantitative and qualitative research. In judging the quality and appropriateness of research, there is a need to acknowledge methodological pluralism and the necessity of relating methods flexibly to research questions and purpose rather than being derived from a fixed positivist hierarchy. The complexity of the causes of mental distress and needs of service users and their carers calls for research strategies that can capture the interactions between social structures and individual agency; often this suggests multi-method studies.

Not least, the paper has underlined the need to build research capacity in mental health and to develop a critical mass of social researchers signed up to the approaches we have espoused. Already there is a body of researchers who identify themselves as past or current users or survivors of mental health services, producing emancipatory research. There are also academic and professional researchers aligned to this project. The priority remains to influence funding bodies, commissioners and users of research that the way forward is to enhance progressive social research in mental health through the funding streams, research programmes and training opportunities that they support. This paper provides some important directions for the promotion of that research agenda.

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