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Ethics and the ruling relations of research production

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Abstract

The role of research ethics committees has expanded across the UK and North America and the process of ethical review has become re-institutionalised under proposals for research governance proposed by government. Ethics committees have gained a powerful role as gatekeepers within the research process. Underpinning the re-constitution of ethical guidelines and research governance, are a range of measures which protect institutional interests, without necessarily providing an effective means to address the moral obligations and responsibilities of researchers in relation to the production of social research. Discussion of research ethics from the standpoint of research participants who in this paper, are service users within health and social care, provides a useful dimension to current debate. In this paper I draw upon experiences of gaining ethical approval for a research study which focused on user participation within a community mental health service. I discuss the strategies used to gain ethical approval and the 'formal concerns' raised by the ethics committee. I then describe and discuss ethical issues which emerged from a participants' perspective during the actual research as it was carried out. These experiences are analysed using aspects of institutional ethnography which provides a framework to explore how the experiences of research participants are mediated by texts which govern the processes of research production. The paper highlights incongruities between the formal ethical regulation of research, and the experiences of research participants in relation to ethical concerns within a research process.

Keywords:
Institutional Ethnography; Mental Health; Participatory Research; Research Ethics; Research Governance
Introduction

1.1 Debates relating to ethics and research governance have gathered new momentum in recent years with social research coming under increased scrutiny and social researchers being held more accountable for what research they undertake and how they undertake it. Within the UK, professional associations across different branches of social research have begun to re-formulate guidelines on ethical practice. The process of ethical review has become re-institutionalised as role of research ethics committees (RECs) has expanded across the UK and North America. RECs have gained a powerful role as gatekeepers within the research process. Approaches to ethics within traditional (scientific / positivist) approaches to research frequently assume a role to 'protect' dependent and 'vulnerable' research subjects within the research process. The usefulness and appropriateness of such an approach is questionable in relation to qualitative and / or participatory approaches to research design. Researchers working within qualitative and / or participatory research paradigms are often acutely aware of ethical dilemmas contained within the process of conducting research with vulnerable groups, but try to address such dilemmas within an emergent process consistent with conducting democratic research. Too often, such research proposals are treated in a hostile way when scrutinised under traditional regimes of ethical scrutiny. There is little debate relating to the types of ethical dilemmas faced by researchers working within a participatory research paradigm and yet a consequence of re-institutionalising ethical review may be detrimental to some of the most user-friendly approaches to social research. At the same time, underpinning the re-constitution of ethical guidelines and research governance are a range of measures which clearly protect institutional interests. Such measures operate within a legal framework of liability and as a consequence deflect attention away from open debate about the moral obligations and responsibilities of researchers in relation to the production of social research (Homan 1991, 1992).

1.2 In this paper I draw upon experiences of gaining ethical approval for a research study about user participation within a community mental health service[^1]. I discuss the strategies used to gain ethical approval and the 'formal concerns' raised by the ethics committee. I then describe and discuss ethical issues which emerged from a participants' perspective during the actual research as it was carried out. I analyse these experiences using aspects of a research strategy based upon institutional ethnography (Smith 1987, 1990a). As a research approach, institutional ethnography provides a framework within which to identify how the experience of individuals and groups is 'inextricably bound to regimes of ruling' (Campbell and Manicomb 1995:9). According to Smith, these regimes of ruling are 'textually mediated'. That is to say that texts are actively used within ruling relations to organise social relations (Smith 1990a, 1990b). For the purpose of this paper, it is the research process which is under scrutiny and in order to explore the extralocal organisation of everyday experience (DeVault 1999, Smith 1990b), institutional ethnography offers a useful framework to explore relations of ruling within the research process. The texts used within this paper are the guidelines for ethical practice which have been drawn up by my local research ethics committee (LREC) as well the Department of Health's Research Governance Framework for Health and Social Care (Department of Health 2001). These documents are used as texts which mobilise or constrain experiences of research. By situating the experiences of research participants within the research process, it is possible to raise questions about 'what is going on' within participatory research. Institutional ethnography, by relating research participants' experiences to issues which are mediated by these texts, provides a means to explore how
particular interests get constructed and governed in relation to ethical concerns within the production of research. For the purpose of this paper, the approach is used as a retrospective examination of the research process. Data relating to the research process comprise the application form for ethical approval, fieldnotes, records of interviews and meetings with research participants, and feedback from research participants, all of which were gathered during the research process. Within these data, ethical concerns are raised (albeit in sharply contrasting ways) by the LREC and by research participants within the research process. The research process in question was carried out using a participatory research approach and the findings of the research project have been reported in various publications and other outputs (Truman and Raine 2000, 2001a, 2001b, 2002; Raine et al 2002).

**Ethics and Research Governance**

2.1 A review of researcher accountability in UK health research has provided the main impetus for the Department of Health (DoH) to draft new guidelines on ethics and research governance (DoH 2001). The review has been undertaken to re-build public confidence in medical research, notably following two public inquiries into the 'baby organ scandal' at Alder Hey Hospital (see Browne 1999, Guardian 2001). As a consequence, all research, both social and medical, which relates to users of the National Health Service (NHS), has to come under the scrutiny of a local research ethics committee. Established to regulate medical research within the UK (see Smith 1999), the role of LRECs has been to ‘... maintain ethical standards of practice in research, to protect subjects from harm, to preserve subjects' rights and to provide reasonable reassurance to the public that this is being done’ (Royal College of Physicians 1990:3). Traditionally, LRECs' responsibilities embraced 'experiments for research'. This has meant that research carried out within the social sciences has occupied an ambivalent relationship to LRECs as it would not fall into the category of 'experiment'. LREC approval is now required by many funding bodies for funding to be released. There are examples where qualitative researchers have complained that LRECs are not well placed to assess ethical dimensions of their work (Hunt 1992, Kent 1997, Gelling 1999). Indeed, 'when ethical review is based on the principles and epistemology of deductive research, it tends to erode or hamper the thrust and purpose of qualitative research [and] ... The social processes underpinning research-ethics review ... are similar to those associated with a moral panic' (van den Hoonoord 2001:19-20).

2.2 Traditionally, most social research has remained outside the formal regulation of ethics committees (Bulmer 1982). Where social science has addressed questions of ethics, it has done so in a voluntary way under the auspices of professional associations (e.g. British Sociological Association 2002, or RECs. Such measures have been widely criticised on grounds that they are voluntary, and that there are no penalties for breach (Humphries 2000). In practice, informal codes of ethics often contain such ambiguities and contradictions that mean most social scientists could justify any course of research as 'ethical' (Truman and Humphries 1994), without necessarily providing effective protection for vulnerable groups in society (Gallagher et al 1995). There remain fundamental questions about how, by whom, and in what context, ethical concerns within research might be addressed. In the remainder of this paper, I draw upon the incongruities between the formal ethical regulation of research, and the emergence of actual ethical concerns within a research process.
Ethical Concerns from the Standpoint of Research Participants

3.1
The research study which I draw upon is an evaluation of community mental health project. The project was an exercise facility in the form of a community gym for people with, or at risk of developing mental health problems. The gym was funded by the health authority, but operated within a framework of strong inter-sectoral collaborations between health and social care. Users of the Gym came from a wide range of medical and non-medical referral routes. By using exercise as a basis for promoting health and well-being, the gym drew upon a social model of mental health and well-being, more than the medical model of treatment for mental health problems. The Gym placed considerable emphasis on user involvement in the management, development and running of the service. Users were represented on the management committee; they produce their own newsletter; and a formal volunteer scheme exists which has enabled some users to become trained as fitness instructors (Truman and Raine 2002).

3.2
As an innovatory project, and in climate of evidence-based health and social welfare, senior management in the Region wanted to attach a research study to the project. The gym was located in a geographically isolated part of the region with an array of economic problems, and the Region was keen to develop a research culture in that area, on the grounds that if a service could be successful in that location, it could succeed anywhere. I was commissioned to write a research proposal to evaluate the gym. This proposal outlined a qualitative study to explore users' experiences of the gym. It was refereed by peers within health research and subsequently approved. I was notified that funding for the research would be released once LREC approval had been secured. The research protocol followed a funding trajectory that is familiar to most researchers in health and social care: although the methodology and context for the research, were approved as suitable for funding through a process of peer-review, the funders themselves insisted that the research protocol receive 'independent' ethical review. Issues raised by this process will be used throughout the paper to explore ethical scrutiny in terms of 'how it works' within the context of an institutional ethnography of the process.

Control over the Material Production of Research

3.3
The funding process I have briefly described is one which will be familiar to those who have applied for research funding. It is a process which is subject to rigorous scrutiny and control. The process requires lengthy applications, peer review, and budgets subject to justification to the minutest detail. This extensive review process determines what are worthy research topics, and who the worthy researchers are. Whilst the processes of securing research grants is a familiar part of life for almost all researchers, there is surprisingly little literature relating to the material production of research, despite a widespread acknowledgement of ways that funding for research is tied up within systems of power and control.

3.4
The LREC system, which is integral to research funding within health, operates in ways which exacerbate the distance between 'professionals' who scrutinise research, and 'non-professionals' who may be research participants or 'targets' of the research process. Members of LRECs 'protect' users from the worst excesses that researchers may inflict on them, but a consequence of the process is that research participants have limited ways of entry into that
process of deciding what is ethical and what is not. The LREC model is one which removes or at best distances research participants from processes of research, and hence knowledge production. An effect of such distancing within this research study meant that no user consultation occurred in the commissioning and design process of our research at the community gym. Thus from the outset, the relationship of users to the research process was constructed as passive, rather than active and their involvement characteristic of research participation through coercion (see Truman and Raine 2001a). However, despite these processes, it was apparent from the outset of the research that service users have strong views about the material production of research as illustrated in the following example:

My first meeting with the management committee of the gym brought the funding process into sharp relief, when I explained about the research that was going to take place. After my introduction about what the research would involve, how the gym might benefit from the research, and how users could contribute to the research process, the first question the users on the management committee asked was ‘How much is the research costing?’ I knew that the research budget was almost as much as the running costs for the gym over several months, and it was with a degree of embarrassment that I explained to them that research is very expensive. Large research grants may carry prestige within universities, but I did not dare to reveal how much the research cost as I sat in a management meeting in an upstairs room of the Salvation Army premises in one of the most economically deprived towns in Britain. At this point, one user said that he felt that the gym didn’t need a research project as much as it needed a stair lift to provide disabled access, so couldn’t the money be better spent there? Fortunately, the manager of the gym, who was aware of the politics of why the research needed to take place, came to my rescue and smoothed over the cracks before they became a chasm. The management committee duly gave approval for the research to go ahead.

3.5
The experience I describe relates to issues of financial and more general accountability in research. Such concerns are echoed in the DoH Framework for Research Governance which contains a strong rhetoric on the public accountability of research:

‘Proper governance of research is ... essential to ensure that the public can have confidence in, and benefit from, quality research in health and social care. The public has a right to expect high scientific, ethical and financial standards, transparent decision making processes, clear allocation of responsibilities and robust monitoring arrangements’ (DoH 2001).

3.6
Part of this accountability relates to financial aspects of research studies on the basis that since research is funded from ‘public’ finances, it should be both worthwhile and represent good value for money. But in light of my experience of talking to users about the research, questions might be raised about who are the public, and on what basis do the public connect with research processes? If the users within my research study could be designated as ‘the public’, it is clear that they would have used the money for a stairlift, not for research. One might argue that service users are not a legitimate body to decide how public money should be spent. However, who is to say that the gym needed a research study more than it needed a stairlift? The decision to proceed with the research study became a legitimate choice on the
basis that it was taken by professionals, rather than by users. Professionals who approved the research decide what constitutes 'public accountability', on behalf of 'the public', which may not be along the same criteria that users as 'the public' might use.

Ethics as aligned with methodology

3.7
It is often the methodology of a research study which provides the focus for ethical committees (Ramcharan and Cutliffe 2001). LRECs thus use judgements about whether or not a study is well-designed as the basis for granting or refusing ethical approval. Current debate around research governance has pressed questions about whether or not it is within the competence of ethical committees to judge the methodological merits of the full spectrum of research methods (Gauld and MacMillan 1999, Gelling 1999). Guidelines issued by my LREC states that it

'receives many applications and has developed a form of application which enables it to deal expeditiously with new applications. It is not, therefore, prepared to receive applications on any other form than that which is made available to potential applicants' (South Cumbria Research Ethics Committee 1997:1).

3.8
The application form I was required to use to describe my research had clearly been designed around assumptions which favour deductive research using quantitative methodologies (van den Hoonaard 2001). Ethical issues in qualitative methodologies often emerge as research studies unfold, but current systems of ethical review are unable to address the nature of this process (Ramcharan and Cutliffe 2001). In practice, many qualitative researchers struggle to describe their research within the required format. This means that research proposals may go backwards and forwards whilst questions are asked and responded to whilst underlying ethical issues within the research remain unaddressed (Popay et al 1998). Consequently, researchers often view the process of ethical approval more as a bureaucratic hurdle to be negotiated, rather than as a constructive part of the research process.

3.9
The DoH guidelines (DoH 2001:12) reiterate the view of Lynoe et al. (1999:52) that ‘a poorly designed study is by definition unethical’. Underpinning this perspective is a question about who is best placed to judge the value of whether or not a study is well-designed. However, research design, on paper at least, is one area of research that can be left in the capable hands of trained, professional researchers - especially if, as in the case of this research, the proposal has had to undergo extensive peer review in order to get funding. But even the most robust research design requires the co-operation of research participants, as the following example illustrates:

In our research study, an array of outside experts had approved a research protocol which outlined that eight focus groups would take place over a twelve-month period; each group would involve between eight and ten users. The project's full-time research assistant spent considerable time at the gym, making links with service users with a view to recruiting participants to the first focus group. Although payment of expenses was offered to participants, recruitment proved difficult. Many users were unwilling to take part in a focus group, and half of those who agreed to take part failed to attend on the day. The research assistant for the project felt that she had
developed a good relationship with users, so in the end, we began to ask direct questions about what prevented them from joining focus groups. Various factors emerged, including: variation in mental health symptoms which could preclude attendance; users felt they had little to contribute; and anxiety concerning group situations. In some cases, no specific reasons were given by individuals who simply did not want to join a focus group. For example, a number of users, whilst happy to talk to the research assistant, clearly had no interest in the research study and simply 'drifted off' at the point that focus groups were mentioned.

3.10
This example illustrates that what appeared to be a sound research design on paper failed to stand up to the test of what service users might consider to be an appropriate design to ensure their participation. However, the concerns, or barriers identified by users were not the ones raised in processes of ethical approval or peer review.

3.11
In line with guidance given by the LREC, our research proposal stated that users would be paid appropriate expenses for their involvement. 'Appropriate' expenses are deemed as sufficient recompense for taking part in the study, but not so much that they could 'be seen as an undue inducement' (SCREC 1997:1). Six users who did participate in Focus Group One took part in ice-breaking exercises and contributed to discussions. Feedback at the end of the session suggested that those who took part were reasonably comfortable with the process. Recruitment improved for Focus Group Two. Although the drop-out rate (50%) was consistent with that of Focus Group One, two users who were present in the facility at the time of the group agreed to take part, thus boosting the numbers participating. This may have been because for the second focus group, we provided participants with lunch as well as travelling expenses. As researchers, we believe that provision of lunch provided an inducement for users of the gym to take part in the research. Provision of lunch made the experience of a focus group more of a social event, and less the experience of groupwork within a clinical setting. Most members of the focus groups participated in discussions and exercises, and thus contributed to the research. But what of those whose main motivation for attending the focus group was to receive a free lunch? Could this be considered undue inducement? My own perceptions of a providing lunch which was shared by researchers and research participants, was it transformed the research process from being a scientific event into more of a social event. By doing this, the ambience of the research process became more closely aligned with the ambience of the gym which draws upon a social model of mental health.

Inside 'Informed' Consent

3.12
The principle of informed consent is also something that appears within almost all statements of ethical guidelines that professional bodies have developed (Bulmer 1982). Superficially at least, the principle of informed consent, is designed to ensure that research participants are made fully aware of the nature of the research in which they are taking part, and the consequences of their participation. The issue of 'informed consent' came under scrutiny by the Alder Hey Inquiry, where it was revealed that the public are often quite ignorant of what they are consenting to in the context of medical research. Informed consent also raises questions about the competency of some groups and individuals to agree on their own behalf to take part in research. Consequently, the topic of whom, and under what circumstances,
consent may be given has received extensive discussion, particularly in research with vulnerable groups such as in the field of learning disability (Brown and Thompson 1997, Stalker 1998), mental health (Usher and Arthur 1998) and in research relating to women and children (Ribbens and Edwards 1998).

3.13
In the case of our research, the LREC required that research participants are given an information sheet about the research. Guidance also suggested that consent forms should be used, and these should provide reference to a written information sheet and space for signatures of the participant and witness. Informed consent has taken on greater importance within UK research following the Alder Hey inquiry where it was revealed that the safeguards which are supposed to follow informed consent may be ambiguous. Informed consent is often seen as a means to 'protect research participants' and to ensure that they are informed about research processes. However, it is clear that the principle of informed consent also operates within a legal framework which safeguards research organisations if adverse events occur within research. In this respect, informed consent becomes aligned with processes of indemnity and thus operationalised within a legal framework. In practice, this means that from a participant's perspective, signing forms to agree to take part in research may appear to take on similar legal significance to writing a Will or getting married. Whilst this process may satisfy the legal obligations of research organisations, it does not address some core issues about consent to take part in research.

3.14
Within social research, informed consent goes beyond an understanding of the nature of the research in question and extends into the terrain of the social consequences or repercussions of taking part in research. For example Coomber (2002) describes how the process of obtaining informed consent from participants to take part in a research study of criminal populations may contravene anonymity and thus expose research participants to risk. Alderson (1999:60) notes how, in the case of children, formal ethics requirements, which have the intention of protecting vulnerable people, can lead to them being excluded from research studies. She argues that the requirement to opt into a study will silence those who would participate more easily in research based upon informal personal contact, rather than those which deploy consent forms and formal protocols. Alderson also identified issues relating to confidentiality and risk, where parents are required to give parental consent on behalf of children as this may be seen as a threat to confidentiality between the child and the researcher.

Consent as Contingent

3.15
As an alternative to insisting that formal consent is obtained, Alderson (1999) suggests that ethics committees could have a more productive role by ensuring that research studies are respectful to their participants, and not against their interests. For this to happen, ethical research would be highly contingent upon the relationship of research participants to the research process in terms of its approach and the methods used.

3.16
Within our research study, we drew up an information sheet and pre-designed a form that followed a standardised format since we felt that this approach was most likely to get the approval of the LREC. All research participants who took part in the first two focus groups
had a copy of the information sheet and signed our consent form. Under ethical guidelines, informed consent is often constructed as a binary division between research participants and non-participants; between those who provide consent against those who do not. Many ethical guidelines stress that the granting of consent is something that has to be reviewed throughout the research process and as such protect participants' right to withdraw from research. In practice, we found that consent from the perspective of research participants was far more contingent than is allowed for within the narrow definition used in most ethical guidelines. Some service users said they would like to take part in the research, but only if they could be interviewed on their own, rather than within a focus group. Within the gym, there is a high level of user involvement and positive environment for service users (Raine et al 2002). Many of the users viewed being involved in the research as a way of giving something back to the service. Consent was thus contingent upon the methods we used to enable users to take part in the research along the lines in which they participated within the gym. In order to meet the aims and objectives for the research, we made on-going changes and constant adjustments to the study. Eventually, we fully embraced a participatory research approach developed which centralised experience of users within the research process. Our exit strategy for the research, was to leave the gym with a fully operational user-led evaluation process (see Truman and Raine 2001a). By this point, some users had become researchers, and were undertaking research with others. The boundaries of who was party to informed consent had thus become quite blurred.

Replacing 'risk' with 'well-being' in research

3.17
A shift in the social relations towards a more participatory research process provided some interesting insights into how being involved in research can be a positive experience for research participants. The new guidelines on research governance identify that 'research can involve an element of risk, both in terms of return on investment and sometimes for the safety and well-being of research participants' (Department of Health 2001:1). Within our research, notions of risk and well-being varied with the construction of social relations within the research process. As our research became more participatory in nature, users identified a range of positive reasons for being involved in the research. For example, a member of the evaluation group wrote about her experiences of being involved in the research:

My name is Rebecca and I have been nominated by the evaluation group to tell you what we are about. The evaluation group consists of a staff member, two researchers and four gym users. As part of Lancaster University's research, the evaluation group was set up to compile information on the gym by way of a questionnaire. For the evaluation group this posed quite a challenge. We had to organise a set of questions that would:

- Give answers that could be put in a database.
- Ask questions that would highlight both positive and negative aspects of the Gym.
- Show areas in which the gym could make improvements.
- Give gym users a voice.
- But most importantly, be COMPLETELY ANONYMOUS.

Personally, I found the process of setting up the questionnaire a challenge with many rewards. What originally seemed a very daunting
task soon became interesting, fun and it gave me the chance of doing something worthwhile. Another reward was the chance to work with a fantastic group of people! Cheers Everyone!

We have now finished the questionnaire and are hoping to send it out to users. We would appreciate your help and co-operation in completing these questionnaires. Don't worry these are not going to be personal questionnaires and they are anonymous. But, when the answers are compiled on database, it should highlight areas in which the gym is working, areas that need improvements, and also find out what YOU the users want from YOUR gym. Please don't think, oh no, not another form, as it is the results from these questionnaires that will give you the user what you want. So be warned a questionnaire will be circulating in your area soon. I wish to thank you all in advance for filling out the questionnaires and also everyone that helped make this happen.
Thanks, Rebecca.

(Extract reproduced from a booklet which provides a short summary of the research)

3.18
In the above extract I have highlighted Rebecca's description of the benefits she describes of being involved in the research. The extract as a whole also raises issues relating to anonymity and confidentiality which are almost always a feature within ethical guidelines. However, anonymity and confidentiality are contingent, rather than absolute (Robinson 1991). In describing the research to other users, Rebecca addresses their concerns about anonymity which were present throughout the research process. Anonymity was an area where users expressed most concern and suspicion since they needed to know how the data were to be treated. They were conscious that protocols of anonymity would not prevent them from being identified on the basis of what they said. Similarly, users also talked about the importance of being able to trust researchers, and this trust developed over time. Trust enabled users to feel confident about telling researchers about their experiences in ways that was different from what they would have said to professionals who might exercise control over their lives. Rebecca's reference to the questionnaire as a form provides an illustration of this point.
Service users in the NHS are familiar with having information about them recorded on forms. Participants in our research talked about how they often had a general mistrust of forms because the information gets used by professionals who make judgements about their mental health status and thus use the information to control their lives. For users involved in the process of developing a questionnaire, it was important to build trust in the questionnaire as being different from the forms which are routinely used in systems of mental health care.

3.19
Feminists have highlighted ways that trust is an integral but complex part of the research process (Stacey 1988, Finch 1984, Oakley 1981, Song and Parker 1995). It is often articulated as something which occurs between researchers and research participants on a personal basis, as individuals. However, within our research, trust was an on-going process which was transferred between service users, as one user identified:

'well I didn't want to do it [interview] at first, and then I saw [another service user] giving you information, and I thought "oh well, go on, do it yourself."'
3.20
In this example, trust was fundamental to being able to carry out the research. The nature of trust is such that it is given a social meaning within the research process, in terms of how it is experienced by users, rather than as something which can be conferred either by researchers or through processes of ethical review.

'Adverse' Incidents in Research

3.21
The new DoH guidelines for research governance reflect concerns about the occurrence of 'adverse events' within research. The LREC which gave ethical approval to our research asked to be informed of such events. When such events occur, there are questions about who defines them as being adverse. For example, it is clear from the findings of the Alder Hey Inquiry that established medical practice was not considered 'adverse' until it came to the attention of the public. How such events are dealt with, depends upon what is at stake for the parties involved with the event. Having research users directly involved in producing the research presented different types of ethical dilemma, as illustrated by the following example:

The user evaluation group (referred to in the extract from Rebecca) undertook to do an on-going user-led evaluation of the gym. This involved users designing, administering and analysing an evaluation tool which took the form of a short questionnaire. The evaluation group usually worked in pairs to administer the questionnaire. On one occasion, they approached another user of the gym and asked him if he would be willing to complete a questionnaire. The user said that he was experiencing a psychotic episode at that moment (he said he was hearing voices). The researchers said they could easily ask the questions at some other time and thought it best to leave him alone. However, the user said that he was trying to manage this psychotic episode by being active and that he would like them to help him complete the questionnaire. The researchers sat with him and helped him to do this.

3.22
When the researchers reported this incident to me, my first reaction was one of anxiety about the intrusion and possible harm that may have occurred to the user as a consequence of taking part in the research whilst experiencing a psychotic episode. This incident represents a real ethical dilemma in research, and was identified as such by the user-researchers. It is likely that the LREC would have viewed the incident differently to me, and that had I administered the questionnaire, my response would have been different to that of the users. I believe that had the LREC known about this event, it might have been labelled as an 'adverse incident' and outlawed as legitimate research practice. As a researcher, I would have been reluctant to continue the research process with someone experiencing psychological distress. However, in this case, the user wanted to manage his distress by being engaged with other users. Upon reflection, I believe that it would have been harmful to ignore the user's wishes that he wanted to take part in the research at that time, within the context through which the research was taking place.

3.23
Hidden within this scenario are various investments and risks in pursuing different courses of action. Such courses of action are underpinned by the social relations of research production...
and the power relations that underpin those actions. Within this scenario, the judgement of the LREC would always carry more weight and authority than the judgements of the user-researchers. Yet, from the perspective of the research participant, the decision to proceed with the research, seems to be less harmful than the alternative which was to exclude him from the process. LRECs make their judgements based upon the norms of the medical profession, which is translated into written guidance for those who apply for research funding. In contrast, the user-researchers decided upon their course of action as a result of engaging in dialogue within the context of the situation itself. This is an approach advocated by Rossiter et al who state that:

'Professional codes of ethics are the justified norms of the profession. However, the application of those norms is interpretive, and depends on the local and particular features of each situation. ... the interpretive aspect of application is best carried out in a dialogical process ... a partner in dialogue helps us to recognise our unconscious investments, our blind spots, unrecognised feelings, or unchallenged attitudes ... the centrality of ethics ... depends upon the possibility of unconstrained dialogue’ (Rossiter et al 2000:95).

The Ethics of 'Ethics Avoidance'?

3.24
My discussion of ethics within research has a range of implications for the conduct of researchers and the way that we articulate and address the ethical dimensions of research. Furthermore, my analysis also provides insights into how professional researchers relate to those who seek to govern ethical conduct in research.

3.25
A condition of ethical approval being granted, is that LRECs ask to be informed of any changes to the research protocol. Many professional researchers share anecdotes of research designs on paper which do not translate into practice when fieldwork actually begins. As I have already illustrated, ethical issues are intricately woven into the social relations of research processes. Research methodology is often required to change once research participants become part of the research process, yet the relationship of LRECs to research processes means that some researchers may be reluctant to re-enter the ethical approval process once initial approval has been given. There are two reasons for this - first, re-submission could risk ethical approval being withdrawn; secondly, the bureaucratic nature of LRECs means that they are not able to respond in a timely or constructive way to genuine ethical concerns which unfold during the course of a study. For this to happen, there needs to be ‘a shift in our common-sense understanding of ethics as a property of individuals who monadically reflect on dilemmas, to a notion of ethics as social relations that produce individuals and organisations in ways that limit or potentiate ethical decision making. ... it requires attention to issues of communicative process, and ... it requires a much broader set of activities than is associated with conventional professional ethics.’ (Rossiter et al 2000: 97).

3.26
In the research that I have described, a communicative process, albeit limited, was established by the LREC which prescribed the format in which they were prepared to review ethical issues within research. The research study in question has subsequently been highly regarded at a Regional and national level. For example, it has been used as a case-study in a national review of participatory research (Baxter et al 2001). Even so, we felt reluctant to take our
design modifications back to the LREC as the research evolved. Firstly, the research process became one which went through a series of changes, so at what point should we report those changes to the LREC? Secondly, we were not convinced that the views of the LREC could add anything constructive to the ethical aspects of the research process. In contrast, the views of research participants added considerably to the efficacy of the research and also provided a means for addressing ethical issues from the perspective of those who are participants within the research process.

3.27
My experiences are not dissimilar from those of others who operate under professional codes of ethics. Research undertaken with professionals in human services settings found that most participants treated ethics codes as irrelevant and they tended not to employ internal cognitive schemes to resolve ethical dilemmas. Within each setting, there were multiple interacting forces which create participants' ethical subjectivities. 'These subjectivities, forged as they are within power relations, condition what is perceived as ethics, and how ethical dilemmas can be resolved.' (Rossiter et al 2000:95).

Conclusions - some policy implications

4.1
Existing models of ethical practice are based upon a principle of 'harm reduction' which is consistent with a bio-medical model of research. Processes of ethical review, whilst ostensibly about taking a distanced, independent perspective on the production of knowledge are entirely bound up with power relationships and the ruling relations of knowledge. The balance of power in the research process is in favour of experts, rather than research participants. LRECs reinforce this power imbalance in ways that preserve and promote the interests of the powerful, and in ways which distance, alienate and pacify research participants. If the experience of users and research participants who are allowed to actively engage in the research process is used, we might move towards an 'ethics as promoting well-being' model for research. Such a model is equally complex, and problematic, as suggested by accounts of feminist research, but it provides a different orientation on the dilemmas of producing research knowledge, which can be based on constructive dialogue, rather than one of regulation and fear. As Rossiter et al (2000) identify, this dialogue might involve confrontation, problem solving, political engagement.

4.2
In this paper I have drawn upon institutional ethnography as an approach to explore how processes of ethical review are implicated within the ruling relations of research production. Processes of ethical review and new guidelines on research governance act in ways which reinforce experts' control of knowledge. Concerns addressed within existing processes of ethical review are part of wider social relations which distance research participants from processes of research production, and renders them as passive within knowledge that is produced about them. RECs too often concern themselves with procedural aspects of research within a bureaucratic framework. This has the effect of creating two worlds of ethics within the research process. The first world is the world of ethics created by ethical committees contained within a rarefied space and unaffected by practice. The second world of ethics exists in practice of research where the ethical subjectivities of participants in the research process are implicated with relationships of power. By exploring ethical concerns from the
standpoint of research participants, I have highlighted issues around ways in which ethics might more usefully inform moral choices within research processes in ways that are respectful to groups and individuals who experience social exclusion.

4.3
The new DoH framework for research governance replicates and expands on guidelines and principles that were drawn up in response to the misuse of scientific research under a fascist regime. The guidelines do not provide any means for helping researchers to explore or address those ethical dilemmas which are inherent to the messy world contained in the social relations of research production. The way that processes of ethical review have been formulated is particularly problematic for researchers working within a participatory paradigm since they add a further set of barriers to the creation of democratic knowledge whereby people who are the subject of research production can influence how knowledge about them is conceived, produced and disseminated.

Notes

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