

## Anonymity and Confidentiality

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ESRC National Centre for Research Methods

NCRM Working Paper Series

2/06

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Paper presented at the ESRC Research Methods Festival, University of  
Oxford, July 2006

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Project website:

[http://www.sociology.soton.ac.uk/proj/informed\\_consent/index.htm](http://www.sociology.soton.ac.uk/proj/informed_consent/index.htm)

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## **Confidentiality and anonymity**

This paper focuses on confidentiality and anonymity and explores the ways in which these issues are managed by researchers. It draws primarily on data collected from a study funded as part of the ESRC Research Methods Programme focusing on researchers' views and experiences relating to the issue of informed consent in research. The focus is on these issues in relation to qualitative research.

Confidentiality and anonymity are related but distinct concepts. The Concise Oxford Dictionary defines confidentiality as: 'spoken or written in confidence; charged with secrets' while anonymity is defined as: 'of unknown name, of unknown authorship'. In the ethics literature, confidentiality is commonly viewed as akin to the principle of privacy (Oliver, 2003; Gregory, 2003). This principle is integral to our societal beliefs that individuals matter and that individuals have the right for their affairs to be private, although as Bulmer (2001) notes, in our information-led society upholding this right is far from straightforward. To assure someone of confidentiality means that what has been discussed will not be repeated, or at least, not without permission. The notion of confidentiality (and anonymity) is invariably raised and discussed with research participants prior to their participation in research. However, in the research context, confidentiality (as it is commonly understood) makes little sense.

Confidential research cannot be conducted; researchers have a duty to report on the findings of their research and they cannot do so if the data they collect is confidential (i.e. cannot be revealed). What researchers can do is to ensure they do not disclose identifiable information about participants and to try to protect the identity of research participants through various processes designed to anonymise them. The extent to which anonymisation is successful varies according to the research context. In this respect confidentiality cannot be assured; researchers can claim that they will endeavour to ensure to the best of their ability that participants are not able to be identified but they cannot promise that this will be the case. As, van den Hoonaard notes (2002: 8), 'promises of confidentiality are easier to make than to keep'.

We do not know as much as we might about what sense research participants make of the notions of confidentiality and anonymity in relation to research. Promises of confidentiality are made in relation to other areas of life, such as in interaction with financial institutions and health organisations, but in these contexts meanings differ. We cannot assume that research participants understand the ways in which researchers intend these notions to be understood. Corden and Sainsbury's (2005) work on this topic certainly indicate that researchers' and study participants' understandings and expectations may vary. Ritchie et al are currently conducting some work exploring this issue further (see [http://www.gsr.gov.uk/professional\\_guidance/ethical\\_relation.asp](http://www.gsr.gov.uk/professional_guidance/ethical_relation.asp)). Furthermore, work by Grinyer (2002) and others (see BERA, 2004: 8-9) have indicated that the research community's commitment to confidentiality may not be shared by all research participants. The trend towards 'the interview society' and celebrity culture have been identified as factors encouraging research participants to prefer identification over confidentiality (Silverman, 1993, 1997; Wiles et al, forthcoming)

Confidentiality and anonymity tend to be conflated in much of the literature on research methods. In general, issues of confidentiality and anonymity are addressed

together in methods textbooks and research ethics guidelines (see, for example, SRA, 2003; BSA, 2004; Ritchie & Lewis, 2003: 67; Smyth & Williamson, 2004: 28). This is not to argue that these sources use the terms interchangeably but rather that the issues raised by these concepts are closely related; anonymity is a vehicle by which confidentiality is operationalised. However, anonymisation of data does not cover all the issues raised by concerns about confidentiality. Confidentiality of data can be seen to include the following:

- Maintaining confidentiality of data/records: ensuring the separation of data from identifiable individuals and storing the code linking data to individuals securely
- Ensuring those who have access to the data maintain confidentiality (e.g., the research team, the person who transcribes the data) i.e.
  - i) Not discussing the issues arising from an individual interview with others in ways that might identify an individual
  - ii) Not disclosing what an individual has said in an interview
- Anonymising individuals and/or places in the dissemination of the study to protect their identity

In this paper we explore the difficulties researchers experience in relation to issues of confidentiality and the ways in which researchers manage these issues in practice. We focus on deliberate and accidental disclosure of confidentiality and the processes researchers use to manage these issues.

## **Methods**

Before moving on to explore these issues, we will first outline the research study on which this paper is based. The project focused on how researchers manage issues of informed consent in social research. It involved collecting data primarily through telephone interviews and focus groups with academic and non-academic researchers and focused specifically, but not exclusively, on researchers who conduct qualitative research on or with children, young people, older people, people receiving palliative care, people with learning disabilities and people with mental health problems. The focus on these particular areas of research was made because of the assumed vulnerability of members of these groups within the research process which would enable the issue of informed consent to be exposed with particular clarity.

Thirty-one individual telephone interviews were conducted with experienced researchers with reputations for work in these specific areas (n=24) or in research ethics more broadly (n=7). These individual 'experts' were identified through our own knowledge of the area, recommendations from other academics approached to participate, the literature and web searches. The six focus groups were conducted in six academic institutions which had recognised expertise in each of the topic areas. These groups comprised experienced researchers, academics and PhD students working in these broad areas (n= 35). The interviews and focus groups were designed to elicit information from researchers relating to their views and practices around gaining informed consent from people involved in their research. To supplement our data, we emailed 33 researchers inviting them to respond by email to specific issues relating to informed consent. The researchers contacted comprised those that we were unable to include in interviews or focus groups but would ideally have wanted to. We had responses from ten of these individuals.

This study has gone wider than the issue of managing informed consent in researching vulnerable groups. It raises a whole set of issues about confidentiality and it is to these issues that we will now turn.

### **Breaking confidentiality: deliberate disclosure**

The intentional breaking of confidentiality is an action which is frowned on by the research community. However, it is recognised that there may be occasions when researchers feel the need to break confidentiality (see BSA, 2004; BERA, 2004). Legal and regulatory frameworks influence how these issues are dealt with (Masson, 2004). The law requires researchers (and others) to break the confidence of a participant if they disclose having committed or being about to commit a crime. In addition, researchers may feel a moral duty (although there is no legal *obligation*) to disclose information if a study participant reports being a victim of crime or if a researcher feels a study participant is at risk of harm. This issue is particularly pertinent, and has been widely debated, in relation to child abuse (Bostock, 2002). For practitioner researchers this issue is particularly difficult as they have a professional responsibility (a 'duty of care') to report situations or individuals they have concerns about to their managers or other professionals; they risk disciplinary action if they do not do so (Masson, 2004; Allmark, 2002). There is, in addition, specific regulation in relation to the work of particular professionals and some groups (e.g. specific local authority child protection procedures).

The literature notes that researchers should think through the circumstances in which they might want, or feel they need, to break confidentiality and to alert participants to these as part of the consent process (Ritchie and Lewis 2003; Wright et al, 2004; The DVRG, 2004). In thinking through these issues researchers are advised to consider participants' safety and well-being and also various legal, regulatory and professional frameworks to which they are subject. However, a difficulty arises if issues emerge that researchers had not expected and had not alerted participants to as part of the consent process. The expectation is that, should issues emerge during a study, the researcher should always discuss the need to disclose this and get participants' permission before disclosing it (Ritchie and Lewis 2003; Wright et al, 2004). A problem arises for the researcher if the participant does not agree to the issue being disclosed and there is little discussion in the literature on how this should be managed.

Our study indicated that while researchers felt duty bound to break confidentiality where participants were at risk of harm this did not extend to a perceived duty to disclose information relating to crime or other illegal activity in which their participants and/or others were not at risk of physical or psychological harm. The decision to break confidentiality was one that was taken very seriously and was only ever undertaken where this was seen to be clearly in the best interests of the person involved.

Researchers noted that there were some situations that they were compelled by law to report (although in a number of cases researchers identified issues that relate more to a moral obligation than a legal one). Most researchers working with vulnerable groups, such as children and people with learning disability were unequivocal that they had a legal duty to report abuse but that they would always gain permission from the research participant to do so. Researchers working with vulnerable groups where issues of abuse might emerge, particularly research concerning children, reported

flagging these issues up prior to data collection. Only one case was identified where a research participant did not agree to disclosure and in this case the researcher set up support for the person involved but did not report it. This case occurred in research outside of the UK. Nevertheless, even with participants' consent for disclosure, it was clear that decisions to disclose information were not made without considerable thought and concern as to the consequences:

'Well I think it's a bit of a grey area because the teachers have a duty to report [but] do researchers? I think we may not be covered by the letter of the law but I think in the spirit of the law that we have to report. And I think I would have to say to the child, the promise of confidentiality would have to be framed in terms of the fact that if I find they're in danger, then I would have to speak to somebody but I'd try and do it with them. But by disclosing that kind of stuff you can make it so much worse for the child, I think it's tremendously fraught ... because one of the issues for children who've been sexually abused is often that they have had their agency removed and so if you just barge on in and do it, you're just compounding the loss of agency in quite complicated ways'

(int 26, childhood researcher)

For researchers conducting research in the area of illegal activities or where issues might be disclosed relating to criminal activity, the issues are somewhat different. While researchers (and others) are legally obliged to report a potential or actual crime, such disclosure would mean alienating research participants and furthermore, that research on illegal activities could not be undertaken. Researchers did not feel compelled to report such information. In some cases researchers reported undertaking active strategies to avoid such information being disclosed to them in fieldwork so that they would not be placed in the position of having to decide whether or not an action needed reporting:

'I would find it terribly hard to break confidentiality. I personally would find it terribly hard to go in there and say "I would respect what you say as confidential but if you tell me .." I mean what we do is, because our study is connected to euthanasia, the minute they start talking about euthanasia we say "right we don't, that's not part of our study" we stop it right there and get back onto the topic'

(FG3, palliative care researcher)

'Working in the drugs field, there's certain guidelines you need to follow and you need your participants to be aware of what's confidential and what can't be confidential and what you want to know and what you don't want to know'

(FG4, youth researcher)

In some research contexts relating specifically to illegal activity, the fieldwork was conducted on the understanding that the information provided was confidential. However, researchers were aware that they might have to provide information should the authorities become aware that they had it. No cases were reported where this had occurred. Indeed the research literature indicates there have been no cases where social researchers have been forced to reveal information collected for research purposes in the UK although such cases have been reported in the US and Canada (Lee, 1993: 164; van den Hoonaard, 2002: 8; Adler & Adler, 2002). Nevertheless researchers in our study expressed an awareness that this could happen:

‘well the criminals we’ve just interviewed were disclosing crimes that they’ve done which they hadn’t been caught for and I said to them “this will not go any further than me and the rest of the research team” but if for some reason the police found out I think we would have been on very dodgy ground in terms of perverting the course of justice if we wouldn’t give them the information or whatever’  
(FG4)

‘the information they give us does not enjoy any legal privilege and if we are subpoenaed you know we have to ... I don’t know many sociologists who would be prepared to go to prison to protect [their] participants’  
(int 15)

Our data indicate that this is an area of great uncertainty for researchers. This uncertainty is reflected in the research ethics guidelines for researchers. It is interesting to note that while the BSA guidelines (2004: 5) state that ‘research data do not enjoy legal privilege and may be liable to subpoena by a court’ the SRA guidelines (2003: 40) note that, citing Grinyer (2002), ‘it is the social researchers responsibility to ensure that the identities of subjects are protected even when (or perhaps especially when) under pressure from authoritative sources to divulge identities’. Researchers working in the area of illegal activities recognise their research involves them having to balance issues of legality and morality in how they manage their research. Most researchers in the UK working in these areas appear to work in ways that enable them to avoid any legal pressure to divulge information. However, there is an awareness that this situation might not continue indefinitely. Increasing levels of ethical regulation and governance mean that researchers working in the area of illegal activities may not be able to operate in ways that protect participants awareness, thus rendering some research undoable (Wiles et al, forthcoming; Adler & Adler, 2002)

### **Breaking confidentiality: accidental disclosure**

#### 1. ‘Letting something slip’

All ethical guidelines for social researchers are clear that confidentiality is an important element of social research and that research participants should be made aware of who will have access to their data as well as being provided with details about the processes of anonymisation (BSA, 2004: 3; Oliver, 2003). In general, researchers note that the only people viewing the data will be those who are actively involved with the research project and perhaps additionally, the person who transcribes the interview. Both guidelines and methods textbooks are unanimous that promises of confidentiality given must be kept. There is little discussion about why and how researchers might break this promise of confidentiality other than to protect the participant from harm or through poor processes of anonymisation. It appears that any other forms of breaches of confidentiality are seen as such bad practice that the possibility of them happening does not even need to be addressed.

However, researchers in our study noted that at times they found themselves ‘accidentally’ breaking confidentiality. These situations included talking to others about their research because of a need for support or as a result of inadvertently ‘letting something slip’. It has been noted in the literature that undertaking fieldwork

can often be emotionally draining, especially when the research involves participants discussing experiences that have been difficult or disturbing (Lee-Treweek & Linkogle, 2000). Many researchers conduct their research with limited support and feel the need to 'offload' with someone, indeed it has been noted that this is an important way of managing the emotional risks inherent in conducting research (Corden et al, 2005). Even when the research has not been emotionally challenging, researchers may feel the need to discuss particular interviews with colleagues or even friends or relatives simply because the issues emerging have been interesting or exciting in relation to the overall research project or because they have particular resonance for them. The research literature notes that there should be processes for supporting researchers, such as de-briefing among the research team, and that research participants should provide consent for this (Gilbert, 2001; Corden et al, 2005). Most researchers recognise the importance of this but nevertheless researchers in our study recognised how difficult it was at times to avoid 'letting something slip':

'I have to say sometimes [keeping confidentiality] was a tough one because sometimes you've got something really juicy ... and there were times when I, and we've all done it, interviewed some complex and interesting people and been dying to talk about it ... and you can be really careful at first and then two months down the road you can say something and you know that person could be identified ... it's not difficult all the time but it can be difficult, you can let something slip'  
(FG3)

'It's very hard especially with some of the stuff that we do which is on very, very sensitive issues. I mean you're talking about death and dying on a regular basis and you do need to speak to someone and have all that debriefing so you need to make sure you speak to someone but [that] it's not to someone who can use that information in a wrong way. So you discuss it with your research team or someone who has similar interests and, or within your group.  
(FG3)

There is little discussion in the literature or indeed emerging from our study of accidental or deliberate disclosures made by people who transcribe data. Nevertheless this is an issue that warrants some attention. While it may be good practice for researchers to have formal agreements with transcribers in relation to confidentiality we do not know the extent to which this occurs. Where transcribers are part of a research team such agreements or good practices are more easily established than where data is 'sent out' to professional transcribers. However, even with 'formal' agreements, transcribers may not fully understand, or abide by, such rules of confidentiality. They may feel similarly inclined to researchers to 'let something slip' because of a need to tell someone a story that they have experienced as distressing. This is likely to be especially the case for professional transcribers outwith research teams who often work at home with little support or scope for debriefing.

A second issue relating to confidentiality concerns the use of data for teaching. Anecdotal evidence suggests that it is common practice for some researchers to use anonymised data that they have collected for teaching on research methods courses. This has significant implications for confidentiality.

## 2. Anonymisation

The chief way that researchers seek to protect research participants from the accidental breaking of confidentiality is through the process of anonymisation. Ethical guidelines and methods textbooks all note the importance of anonymising research participants through the use of pseudonyms. There is increasing awareness that research participants, particularly children and young people, may want to be identified and not anonymised in research outputs (Grinyer, 2002; BERA, 2004). In these circumstances, researchers are advised to obtain written consent that an individual wishes to waive their right to confidentiality (BERA, 2004). This indicates that anonymity through the use of pseudonyms is still the norm (SRA, 2003; Corden & Sainsbury, 2006:22).

However, ethical guidelines and methods textbooks contain limited discussion or advice about the ways in which identities can be disguised beyond the use of pseudonyms and the implications anonymisation might have on the data. Methods textbooks note the difficulties in balancing 'disguise and distortion' (Lee, 1993: 187; see also Becker & Bryman, 2004: 345). The British Sociological Association (BSA) guidelines seem to point to the undesirability of changing characteristics of individuals when presenting data with the aim of protecting identities because of the impact this may have on the integrity of the data:

'Potential informants and research participants, especially those possessing a combination of attributes that make them readily identifiable, may need to be reminded that it can be difficult to disguise their identity without introducing an unacceptably large measure of distortion into the data'  
(BSA, 2004: 4).

The Social Research Association (SRA) guidelines appear to view changing identities to protect anonymity as necessary but that researchers need to carefully weigh up the potential damage to the data resulting from changing details versus the potential damage to the participant of identification:

'Social researchers need to remove the opportunities for others to infer identities from their data. They may decide to group data in such a way as to disguise identities ... or to employ a variety of available measures that seek to impede the detection of identities without inflicting very serious damage to the aggregate dataset ... Some damage to analysis is unavoidable in these circumstances, but it needs to be weighed against the potential damage to the sources of data in the absence of such action'  
(SRA, 2003: 39).

In some cases, researchers may feel it is necessary to avoid publication altogether or to omit certain aspects of their data or individual cases in order to protect people's identities. Corden and Sainsbury (2006) noted that researchers avoid using material which describes particularly dramatic or extreme situations. The literature notes a number of harms that might arise from people being identified ranging from embarrassment to violence (Lee, 1993:191). Becker notes that decisions about this should be made on the basis of balancing potential harms to participants with potential benefits of making knowledge public. However, the difficulties in making such judgements are acknowledged (Becker, 1964). Various ways to avoid self

ensorship are noted in the literature, such as working with research participants to talk through the consequences of disclosure (Lee, 1993: 190).

Most researchers in our study viewed protecting people's identity as problematic, especially in some types of research. Studies of organisations, community-based studies, applied research and evaluations were identified as particularly problematic. The issues of anonymity are less problematic in the case of research focusing on general social phenomena in which the identification of the specific context from which participants are drawn is unnecessary. Nevertheless the majority of researchers in our study still took the issue of anonymisation very seriously even though, as Corden & Sainsbury (2006:23) note this may not be adequately communicated to participants.

Researchers demonstrated different orientations to the anonymisation of participants. Some researchers viewed the responsibility for protecting the identity of participants to be theirs; they felt it was their responsibility to decide how data were used and how people were anonymised because they had the knowledge to assess the risks to participants. They viewed it as unfair to give this responsibility to research participants because they could not be expected to know what the risks might be. Other researchers held different views and viewed the responsibility to lie with participants; they felt it was for participants to decide what data that they had provided should be included and how they were anonymised (or identified) in relation to these data. These two orientations are not discrete categories; they can more usefully be seen as extremes on a continuum with researchers orientated at different points according to their research approach, the context of their research and the specific issues they faced.

Researchers whose orientation was towards them being primarily responsible for decisions about confidentiality noted that they gave careful consideration about whether to use data obtained from a particular individual if it might mean that person could be identified or if identification might have undesirable consequences for an individual or an organisation. Several researchers noted that people's stories can be very individual and that simple anonymisation, or even changing key characteristics, is not sufficient to avoid their identity being discovered. There was a sense that deciding not to use data at all because of these risks was a difficult decision to make because it meant that some of the most important data and the issues contained therein had to be omitted. Nonetheless, in these cases, researchers viewed the protection of the participants' identity to take precedence over the need to publish the data. It is important to note that our research participants were not involved with research with powerful individuals or groups. Indeed, the fact that researchers' participants occupied relatively powerless positions was viewed as a justification for why issues of confidentiality should be taken so seriously.

'I think you have to be terribly careful how you write things up to conceal people's identities and disguise them, and also quite a lot of, some of the worst things I've seen I've never written up and I feel I've betrayed the people it's being done to but I think: well, I don't think I'm going to gain anything by writing it up'  
(int 2)

‘It’s part of your responsibility as a researcher to watch out for things that might be dangerous for the person who’s talking to you so that you are able to make your own careful and ethical judgements about whether something should be used even if, because sometimes people given consent and really they shouldn’t have’  
(int 26)

‘you have to be very careful not to give sufficient information for biographies to be reconstructed ... I’ve omitted one case where there was a history of incest in the family, partly on ethical grounds and partly because it was such an unusual case’  
(int 20)

The desire to use data in cases where distinctive stories might make individuals identifiable led some researchers to change the identity of participants in various ways. Several researchers noted that they had become skilled at disguising individuals by changing the person’s age, gender, area of residence or other personal characteristic. Researchers adopting this practice noted that this could only be done if it did not affect the integrity of the data or the general argument being presented:

‘Some of the people I’ve interviewed have got very distinctive stories and you have to develop ways of ensuring their anonymity. ... Sometimes when there’s an issue that I want to get on the printed page but I need to preserve their anonymity then I might turn a him into a her or change the age or the part of the country. ... You’d only do that if it doesn’t make any difference to the message you’re giving, and sometimes it does and sometimes it doesn’t. The other thing you can do is, if you’re talking about a disabled young person, you can change their impairment. You can separate out, I had one person, a lot of whose story was very, very relevant and telling and I actually split it into two different people’  
(int 1)

‘Some of the issues with the children we interviewed, we had to go through all sorts of contortions which ultimately we weren’t always happy with, like for example, we felt we’d better change the gender of this child, we’d better change the age and you start to think: is this an ethical thing to do? But you actually felt that the imperatives of the moment were such that you would do that rather than the child be identified’  
(FG5)

Researchers who oriented themselves as having primary responsibility for protecting participants did not check back with participants to see if they were happy with how their identities had been changed. They viewed themselves as having appropriate knowledge about what would best protect participants:

‘I haven’t gone back and said ‘here it is, here’s what we’ve done, do you want to change anything?’ because I suppose I think at that stage I take responsibility for what goes in, as long as I’m protecting them. I take responsibility ... I shouldn’t put that on the people taking part in the research’  
(int 21)

Specific types of research were identified as raising additional difficulties in relation to confidentiality. Research involving data collection from couples or families in which the accounts about others, or attitudes towards them, differ present particular

problems of confidentiality and anonymisation. Researchers involved in this type of research noted the importance of careful anonymisation and decision making about how data were used so that family members would not be able to recognise the views of kin where these were not in accord with their own. As well as managing the confidentiality issues of primary participants, researchers also noted the difficulties inherent in research where other people were discussed, especially where these involved negative comments or even accusations against other people who might be able to identify themselves, be identified by others or identify the participant. Again careful consideration of anonymisation in the presentation of data were identified as important and, in the cases cited, it was researchers who made the decisions about how these should be managed:

‘There are really difficult issues when you are interviewing members of a family or couples, or people who are in a relationship and you are putting their accounts side by side. There are some very difficult issues there and we often try to side-step them by making, changing enough so that we’re hoping that the person they’re talking about won’t be able to recognise themselves if they read it’  
(int 21)

‘If someone was accusing someone of doing something illegal, if you were going to include that information, you’d have to be very careful to disguise it’  
(int 1)

‘I am very careful how I handle data when someone’s talking about someone else. It’s very common for people to tell you things that you think would be hugely problematic if their relatives knew they’d said that ... I think it’s important to exercise judgement about the impact that that could have in the network that the person comes from’  
(int 21)

There has been an increasing debate questioning the assumption that study participants want anonymity and the difficulties involved in engaging with this (Grinyer, 2002; Corden & Sainsbury, 2006: 22). This issue was raised by several study participants who noted that participants, especially children and young people, increasingly expect their own names to be used. Many of the researchers who were oriented to taking responsibility for protecting participants noted that, in such circumstances, they would not agree to the participant’s real name being used. In some cases this was because they viewed anonymisation as a core principle of ethical research practice that could not be breached. For others, it related to the difficulties inherent in breaching confidentiality for some individuals and not others:

‘I’ve been in a situation where young lesbians and gays have said to me ‘no, no I want you to use my real name’, you know, ‘I am completely out, I don’t care who knows it’s me’. And in that situation I would, I’ve always said to them ‘well that’s up to you who you choose to be out to, but I can’t do that’  
(int 26)

‘One of the intensive care units was bitterly disappointed that her unit wasn’t named, but I had to explain that if I identified the unit then there would be a cascade of identification, you know, and people would be able to potentially identify all the staff and all the patients’

(FG1)

Other researchers' orientation to confidentiality and anonymity was that research participants needed to be involved with this process. They viewed it as important to work closely with research participants in making decisions about how these issues were managed. These researchers tended to adopt participatory approaches to their research, to varying degrees. These were mostly researchers working with children and young people but also included some working in health contexts, especially palliative care. Several researchers with this orientation noted the importance of 'checking back' with research participants how the data they had provided would be used. Researchers with this orientation were happy to withdraw specific data if participants were unhappy about its inclusion:

'You can never guarantee how people will read the reports so you need to get people to clear their comments even if you do anonymise them because, you know, people will make guesses and people won't read it as fairly as you have written it'  
(int 18)

In relation to the use of pseudonyms, researchers with this orientation noted the tendency for some research participants to want their own names to be used and the importance of enabling this to happen. The assumption that anonymity is desirable was very much questioned by these researchers:

'I think increasingly there are several areas where people are beginning to say 'no, anonymisation's not the ethical thing to do'  
(int 18)

'My view is about negotiating with individuals and not blocking people into social groups or making assumptions about what they may or may not want ... there's a paper which a medical colleague and I published and it actually reports the death of one particular person, complete with photographs of him both dead and alive and he chose, he wished to have his death recorded. ... we were very concerned, as researchers, that it would be completely anonymous and actually the family were bitterly opposed to that and [the journal] agreed with the family and published his name ... I think the assumption that anonymity is always wanted by people needs to be challenged'

(FG1)

Where pseudonyms were used the importance of enabling participants to pick their own pseudonyms was also noted:

'At the very least you have to tell people that you are going to give them a pseudonym and offer to let them choose their pseudonym because sometimes the most awful coincidences can happen and you choose a pseudonym and it might be their nickname or their sister's name or something like that. So it's actually quite important that they get the opportunity to choose a pseudonym'

(Int 1)

## **Discussion**

Attention to issues of confidentiality are important in social research. In this paper we have attempted to review the range of issues that concerns about confidentiality raise and the ways in which researchers deal with them. A number of issues emerge from this.

First, our research indicates that it is common practice for researchers to change the characteristics of study participants in order to protect their identities. In the context of this study, researchers' participants were not high profile people who might risk loss of status or people whose lives might be endangered as a result of disclosure. For the most part, participants were individuals who were probably not easily identifiable to people outside of their immediate group and for whom identification might result in embarrassment or annoyance rather than harm, although of course the actual consequences of disclosure are inevitably hard to evaluate. Nevertheless, researchers viewed confidentiality as an extremely important issue and went to great pains to disguise participants to avoid them being identified. It is noted in ethical guidelines and the research methods literature that the practice of changing characteristics in order to disguise participants should not occur if this distorts the data (BSA, 2004). However evaluating the impact of such changes is difficult. Corden & Sainsbury (2006) have noted that researchers often provide limited information about how and why they choose particular cases to illustrate their points and particular attributions at the end of illustrative quotes. This suggests that one of the difficulties with the practice of changing participant's characteristics is that the readers of the research often do not know that such changes have been made at all or, if they are alerted to this, do not know precisely what these changes encompass. This means the reader cannot judge the extent to which these impact on the integrity of the data. This has significant implications for the transparency of research and for assessments of reliability and rigour. A related issue concerns the extent to which participant's views should be taken into account in making these changes. The increasing trend towards participants wanting to be identified indicates that this practice might not be viewed favourably by study participants (Grinyer, 2002).

Second, our study identified the issue of accidental disclosure by researchers resulting from a need for support or simply as a result of 'letting something slip'. This issue is one that appears to be frowned on by the research community, and largely ignored in the methods literature, yet this is the reality of research for many people. The need to support researchers, especially junior researchers and those working on sensitive issues, through de-briefing and/or the availability of counselling support is clearly an important issue (Corden et al, 2005). The ways that this is to be managed within specific research projects is something that perhaps should be written into research proposals. The issue of 'letting something slip' is more problematic. The scope for this happening is enormous. Unlike counselling, complete confidentiality in research is impossible because the purpose of gathering data is to obtain new knowledge, to synthesise this knowledge within a theoretical or policy context and to disseminate it. There are many reasons why researchers might discuss the data they have generated such as: to develop their thinking; to disseminate their findings; to assist another researcher working on a similar topic; or, for teaching purposes. Researchers cannot know the extent to which it might be possible for the people to whom they are talking to identify an individual by what they say. Perhaps it is time that we think through more clearly what confidentiality in research actually means in practice and what participants understand and expect from researchers' promises of confidentiality. The

issue of the practices and pressures experienced by those transcribing research data is a further issue that warrants investigation.

Third, our study indicated that the intentional breaking of confidentiality because of concerns about participant's safety is an issue that raises a number of concerns for researchers. These are well documented in the research methods literature. Researchers appear to feel a responsibility to report, with their participant's permission, cases where their participants are at risk of harm but not cases of illegal activity. There is a clear consensus that child abuse and abuse of vulnerable people should always be reported with participant's permission. What is not clear is what actions researchers might take in cases where participants refuse permission for disclosure. We also do not know what impact this disclosure has on the participant over the longer term and how participants feel about what has happened. There appears some confusion around legal responsibilities regarding disclosure about both risks of harm and illegal activities. In an increasingly regulated research environment there is some concern researchers may not continue to be able to make their own decisions about these matters and indeed, that some research might become undoable (Wiles et al, forthcoming). In the context of increased institutional ethical regulation and governance and increased fears about litigation, the expectations that institutions employing researchers and the gatekeepers providing access to study participants have of researchers are important issues that need exploring. As are the ways these expectations are communicated to researchers and the outcomes of researchers not abiding by these expectations.

Finally, in the context of developing technologies and innovative practices in social research and its dissemination, such as the use of visual and online methods, it may be time to re-think what confidentiality may mean for social research in the 21<sup>st</sup> century. In a culture of increasing individualisation where people want to have their story told, and have the technology to enable this to happen, might not the notion of confidentiality be one that is appropriate, or desired, only in particular types of social research?

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