



Anonymity and Confidentiality

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Confidentiality and anonymity

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

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 expect

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

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

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

censorship 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

‘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 what

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

(FG1)

Attention to issues of confidentiality are importa

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



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