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4 Anonymity and confidentiality

Introduction

Issues of anonymity and confidentiality are key considerations in ethical research practice and, in common with informed consent, are concepts that underpin professional research guidelines for social scientists. The management of confidentiality and anonymity is closely linked with the management of consent in that participants need to be informed about how confidentiality and anonymity will be managed and what the implications of taking part will be in relation to these issues before consenting to participate. In other words, they need to be made aware what will happen to the data, how they will be reported, whether it will be possible for them to be identified from these data and what the implications of that might be for them. Consideration of the implications of participating in relation to confidentiality and anonymity is something that the individual participant needs to assess in the light of their views about what is public and what is private and the risks involved. However, they need to be guided in this by the researcher who will know how the research will be disseminated and who the likely audiences will be.

The terms confidentiality and anonymity tend to be conflated in research but are in fact distinct but related concepts. Iphofen (2009: 91) usefully notes that confidentiality is a continuous variable in that some information is 'mundane' and does not need to be kept private while other information may be viewed as highly confidential by research participants and not for sharing with others. Anonymity, on the other hand, is a dichotomous variable – a person's identity is either anonymised or kept secret. Nevertheless, in most qualitative research, confidentiality (through the process of anonymity) cannot be assured; researchers can tell participants that they will endeavour to ensure that they are not able to be identified but they cannot guarantee this will be the case. While anonymisation of research participants has traditionally been the norm in

social research, there is an increasing awareness that research participants may want to be identified in research outputs. Indeed, in some types of research identification of research participants is accepted practice.

This chapter will discuss the concept of confidentiality in relation to social research and the situations in which deliberate and accidental breaches of confidentiality can occur. It will also explore processes of anonymisation and debates around the identification of research participants.

Confidentiality

Confidentiality is commonly understood as akin to the principles of privacy and respect for autonomy (Oliver, 2003; Gregory, 2003) and is taken to mean that information given to another person will not be repeated without their permission. In the research context, confidentiality is taken to mean that identifiable information about individuals collected during the process of research will not be disclosed and that the identity of research participants will be protected through various processes designed to anonymise them, unless they specifically choose to be identified. Additionally, confidentiality may mean that specific information provided in the process of research will not be used at all if the participant requests this (sometimes referred to as 'off the record' comments). The concept of confidentiality is closely connected with anonymity; in social research anonymity is the vehicle by which confidentiality is operationalised. However, anonymisation of data does not cover all the issues raised by concerns about confidentiality. Confidentiality of data also includes not deliberately or accidentally disclosing what has been said in the process of data collection with others in ways that might identify an individual. A deliberate breach of confidentiality would involve, for example, telling a parent what a child had said in an interview or telling a health professional what a patient participant had said without the study participant's consent. An accidental breach of confidentiality would involve, for example, someone being identified through information that a researcher provided about an individual even though they had not named them.

Breaking confidentiality

The intentional breaking of confidentiality by researchers is an action which is frowned on by the research community. However, it is recognised that there may be occasions when researchers might be obliged, or feel they need, to break confidentiality (see American Sociological Association, 1999; British Sociological Association, 2002; British Educational Research Association, 2004; British Psychological Society, 2009). Legal and regulatory frameworks influence how these issues are dealt with (Masson, 2004; Montgomery, 2002). This is particularly the case in some areas of research, such as in research with children and in health contexts. Regulatory frameworks, such as research governance procedures or ethical guidelines, may also influence the freedom researchers have to make decisions on these issues. Legal frameworks include Article 8 of the Human Rights Act 1998, the Children's Act 1989, 2004 and the Data Protection Act 1998 which have relevance to confidentiality in relation to research (Montgomery, 2002).

In general, researchers have a common law duty of confidentiality to research participants but there are certain circumstances which may override this duty, for example if there is an overriding duty to the public such as might occur in relation to a serious criminal offence or in life-threatening circumstances. 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); where researchers view a child or young person at risk of physical or psychological harm it would be expected that they would take some action to report it. Practitioner researchers, such as social workers and teachers, have a professional responsibility (a 'duty of care') to report situations or individuals they have concerns about to their managers or other professionals. They are at risk of 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 (for example specific local authority child protection procedures in the UK as set out in the Children's Act 1989, 2004). Health professionals may also feel a 'duty of care' as part of their professional registration to inform others if they have concerns about individuals that are uncovered during research, for example those perceived to be at risk of serious ill health by not complying

with a medical regimen. There are additionally some diseases that must, by law, be notified to public health authorities.

Situations in which promises of confidentiality might need to be breached should be minimised by researchers thinking through the circumstances in which they might feel they need to break confidentiality prior to approaching research participants. Study participants should be alerted to these as part of the consent process (Ritchie and Lewis 2003; Wright *et al.*, 2004; the DVRG, 2004). This means that participants are made aware of the circumstances in which confidentiality cannot be maintained and leaves the decision with the participant whether or not they identify them. In identifying the issues that warrant breaking confidentiality, researchers need to consider participants' safety and well-being and also various legal, regulatory and professional frameworks to which they are subject. This involves giving careful consideration to the types of issues that might emerge in the context of a specific research project that a researcher might feel it is in the best interests of research participants to report to others and setting these out when they consent people to a study. This might involve, for example, saying to research participants 'everything you tell me will be kept confidential unless you tell me something about you or someone else being harmed or being at risk of harm. If this happens I will need to talk to you about what we should do about it'. Research ethics committees are likely to expect to see evidence that researchers have given careful consideration to these issues. 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 unanticipated issues emerge during a study, the researcher should always discuss the need to disclose this and get participants' permission before doing so (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. Most researchers appear to feel that unless a research participant gives permission for information about them to be disclosed then researchers should not do so (Wiles, Crow *et al.*, 2008). The exception to this would be cases of people (especially minors) at risk of serious harm, although of course what constitutes 'serious harm' in different research contexts will be subject to varying interpretations. In such cases discussion of the issue with supervisors, peers or a research ethics committee prior to taking action is appropriate. If the decision to disclose

information without the permission of the participant is made, it would be expected that participants are informed of this decision. It is clearly important that researchers are aware of what their legal responsibilities are and that they think through, and can justify, their moral duty to participants in such cases. One researcher participant taking part in our research study on informed consent noted:

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 we have to report. 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. (Wiles, Crow *et al*, 2008: 420)

Criminological research raises some specific issues in relation to confidentiality in that information about illegal or criminal activity might be identified in the process of the research. The identification of illegal activity, or activities on the boundaries of legality, such as drug taking, falsely claiming benefits, underage drinking or sexual activity might of course arise in any research project. The decision about whether or not illegal or immoral activity should be kept confidential may be a difficult one. Reporting of criminal activity identified through a research project inevitably risks alienating research participants and perhaps preventing subsequent research being conducted. In our research project on informed consent, we found that researchers do not feel obliged to report criminal or immoral activity, providing no one is at risk of physical harm (Wiles, Crow *et al*, 2008). Indeed in some research contexts concerning illegal activity, the fieldwork is conducted on the understanding that the information provided will be kept confidential. However, researchers need to be aware that they may be forced to breach confidentiality and provide information should the authorities become aware that they have it. 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 North America (Lee, 1993: 164; van den Hoonaard, 2002: 8). This appears to be an area of great uncertainty for researchers which involves them having to balance issues of legality and morality in how they manage their research. Iphofen (2009: 101) sums this up in this way:

The prime dilemma is to balance the moral stance of confidentiality, with the legal position, while also judging the 'seriousness' of any reported offence and balancing that against the potential danger to 'as yet unknown' others who could be harmed by non-reporting.

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, increasing levels of ethical regulation and concerns with risks to institutional reputation may present a challenge to these ways of working (see Adler and Adler, 2002). Researchers working in such areas should seek advice from their organisation's legal representative or research support office prior to conducting research.

Accidental disclosures

Accidental breaches of confidentiality can occur in a range of ways. Accidental disclosures can occur when researchers discuss their research with peers (or others), in the process of presenting research at conferences or other forums and in publications. It needs to be remembered that the anonymisation of individuals does not mean that they cannot be identified by others. Clark (see Wiles, Prosser *et al*, 2008: 30), for example, found that despite his best efforts at anonymisation, someone attending a presentation he gave was able to accurately identify the specific individual presented in a quote. In this specific case, the presence of visual clues about an anonymised place provided enough information to enable the participant to be identified:

Despite our best efforts, we did not entirely resolve the challenges of anonymising place. In some instances a failure to anonymise place can also unwittingly reveal the identities of individual participants as well. For example, the use of a quotation positioned alongside a particular photograph (in this case, of a patch of waste-ground in my research site) during a seminar paper I gave was sufficient to enable one member of the audience who was familiar with the research site to identify the participant who gave the quotation, even though I believed I had anonymised both participant and name of the fieldsite and ensured there was, seemingly, no identifying feature in the photograph.

Particular difficulties with disclosure of confidentiality occur in research projects involving high profile and distinctive individuals, such as Government ministers or a CEO of a company. It may be impossible to anonymise such individuals, and not necessarily desirable to do so. Indeed it may be that individuals such as these choose to be identified and to speak 'on the record'. These individuals are likely to be clear about what they are willing and not willing to discuss in a research interview and the implications of doing so. For these individuals, concerns about confidentiality may be minimal.

Research involving individuals who have distinct roles and who choose to be anonymous, such as a head teacher of a school or hospital manager, may pose greater difficulties in relation to confidentiality, particularly when a study involves one or a small number of organisations or groups. In part the risks to confidentiality arise because, even though a research site and an individual may be anonymised, views expressed often need to be identified by a particular position (for example, head teacher) in various dissemination fora for the research to make sense. Confidentiality of individuals can often be easily breached by the inclusion of contextual information, such as a general location (for example 'a city on the South Coast of England' can be only a few places), a description of an organisation or some factual information about it. It is often easy to take an educated guess on the basis of descriptive information or to conduct a Google search that will identify, for example, the identity of a school on the basis of its Ofsted Report or the identity of a hospital on the basis of waiting times for specific surgical procedures. Once an organisation is identified, readers may feel they are able to guess at the identity of an individual's views set out in a report of the research. Although of course this may be only a guess on their part this will not necessarily prevent consequences flowing from it. Research with people who have distinct experiences which might enable them to be easily identified are another group for whom confidentiality issues are raised.

As well as considerations of confidentiality to the external world there are considerations of internal confidentiality to consider; that is, confidentiality of participants to other participants in the same organisation or group. Study participants within an organisation taking part in research are likely to know who else is taking part and may ask a researcher what their colleagues have said or indeed a manager may ask what their employees have said about particular issues. While it may be clear that such requests

for information should not be met, a researcher may nevertheless inadvertently recount a seemingly innocuous event or comment to a participant that has arisen through the research that has unanticipated consequences for another participant. Additionally, participants within a specific organisation or group that are the subject of research are likely to be able to take an educated guess at people's identities within a research report and this can have unintended consequences. These issues of internal confidentiality are not necessarily confined to research taking place in organisations and may equally apply to research focusing on families or friendship networks. In research taking place in organisations or with networks of individuals, great care needs to be taken to ensure that confidentiality is maintained and that sensitive material is managed in ways that do not jeopardise individuals' well-being and their relationships with others. It has been noted that a number of harms might arise from confidentiality breaches which, depending on the context, may range from embarrassment to violence (Lee, 1993: 191). A researcher interviewed in our study on informed consent (Wiles, Crow *et al*, 2008: 424) noted in the context of research within families that a number of difficult issues arise in relation to this:

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 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. 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.

In situations where accidental disclosures of confidentiality might occur, various steps can be taken to limit disclosure (see Lee, 1993). In some cases it may be possible to write about particular findings in general ways, and to avoid the use of direct quotations, to limit the risk of identification. However, in other cases it may be necessary to omit some data, especially when data are particularly sensitive or when its inclusion could have negative consequences if the individual were identified. Sometimes it may be necessary to exclude individual cases altogether in order to protect people's identities, especially in cases where dramatic or extreme

situations are described which are likely to make individuals identifiable. Another strategy is to change some aspect of the identity of an organisation or an individual in the description of a case or in the attribution given to various individuals when quotes are used. So, for example, an individual might be ascribed a different gender, job or medical condition in order to reduce the likelihood of their being identified. However, if such an approach is used, great care needs to be taken to ensure this doesn't affect the integrity of the data. Some researchers are very much against the idea of 'tampering' with data in this way and methods textbooks and research guidelines note the difficulties in balancing 'disguise and distortion' (Lee, 1993: 187; Becker and Bryman, 2004: 345; British Sociological Association, 2002: 4; Social Research Association, 2003: 39). Certainly such an approach needs careful consideration and justification. One researcher from our study on informed consent (Wiles, Crow *et al*, 2008: 423) noted:

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.

In situations where there are specific concerns about confidentiality, it is advisable to liaise closely with study participants about the ways in which data will be reported. This may involve sharing transcripts or other data (such as observational notes or photographs) with participants and getting consent for their use. In the case of transcripts this may involve inviting study participants to amend the transcript and agree to its use. It may also involve showing, and getting agreement for, the use of specific pieces of data (such as photographs or interview extracts) in outputs. Arguably, this is an approach that should always be adopted regardless of specific concerns about confidentiality. Certainly people's concerns about confidentiality and the limits of confidentiality that can be provided are influenced by the form of dissemination. A public viewing, community presentation or an article in a local paper or organisational newsletter are likely to raise more concerns for individuals about confidentiality than a presentation at an academic conference or a paper in an academic journal. Researchers are best placed to explain to study participants the risks

involved in particular forms of dissemination to enable participants to make informed decisions about how their data are used.

'Off the record' comments

Another form of confidential data that researchers sometimes have to deal with is comments which study participants make during the course of research which they don't want included in the research. Such comments are often prefaced with 'I wouldn't want this included', 'I wouldn't want anyone to know about this' or 'this is off the record'. Sometimes a participant may ask for a recording device to be turned off while they make the comment but in other situations the comments may be recorded. Managing these sorts of comments can be difficult. Clearly once a researcher has been told something, albeit confidentially, they cannot be unaware of it. Indeed, study participants may want the researcher to know certain things so that the research is informed by these issues even though they do not want the comment to be ascribed to them personally. In general, comments made by individuals that they ask to be kept confidential cannot be used; it would be a breach of confidentiality to do so. However, it may be possible to negotiate with study participants the ways in which they would be willing for (and perhaps even want) the information they have provided to be used. Where a full transcript including the 'confidential' comments has been made, participants can be sent the transcript and asked if they would still like it excluded or whether they might be willing to reformulate the points in a way that would enable the information to form part of the research, if appropriate. Research exploring people's experiences of particular services, such as experiences of health care provision, can result in people complaining about poor levels of care. While they may not want to have their specific case identified, they may still want the research to reflect the concerns they have.

Anonymisation

The primary way that researchers seek to protect research participants from the accidental breaking of confidentiality is through the process of anonymisation, which occurs through the use of pseudonyms applied to research participants, organisations and locations. Anonymity of

research participants is a central feature of ethical research practice which is written into the various guidelines to which social researchers work. Additionally, the Data Protection Act (1998) provides the legal framework for anonymisation of data. While complete anonymity may be difficult to achieve, it is recommended that all identifying data are removed prior to publication and, where an individual may be identifiable, explicit consent must be obtained before publication can proceed.

Pseudonyms are generally chosen by the researcher, but are sometimes given by a transcriber or suggested by participants. The use of pseudonyms is not without its problems in relation to successful anonymisation. Iphofen (2009: 94) notes that selecting pseudonyms that appear well-suited to the characteristics of a participant can pose confidentiality risks in that they may 'offer subtle or latent clues' to an individual's identity. Grinyer (2002), however, notes that using pseudonyms that are not 'equivalent' in some way to a participant's real name can seem inappropriate. Names can have specific social class, age and ethnic connotations and, arguably, their use can distort the meaning attributed to quotations. Providing people with the opportunity to choose their own pseudonym can also pose problems; Corden and Sainsbury (2006) note that researchers have found that participants sometimes choose the names of real people, such as their friends and Grinyer (2002) notes the difficulty of managing the situation if more than one participant wishes to choose the same pseudonym.

Pseudonyms are often given to locations; however, the descriptions and/or images provided, as noted above, make it relatively easy to identify, or at least make an educated guess, where a study is located (Clark, 2006). There are considerable examples of community research where people have been unhappy about the way they or their community has been characterised and of the ramifications this has had (see Crow and Wiles, 2008). This indicates a need to consider issues of anonymity and consent in relation to place as carefully as to people.

Identification

Some researchers have questioned the assumption that participants always want to be anonymised. There has been a growing trend to recognising that research participants often want to be identified in research outputs and that, in much social research, there is no good reason not to allow that to happen (Tilley and Woodthorpe, 2011). Anne

Grinyer's (2002) important paper on this topic describes her experience conducting research with parents of young adults with cancer in which she sought her research participants' views about the anonymisation of their accounts and the use of pseudonyms. Grinyer found that three quarters of her respondents wanted to have their own names used in the research rather than a pseudonym and, as a result, a mix of real names and pseudonyms were used in publications, reflecting participants' wishes. Researchers conducting research with children and young people as well as the bereaved have found that research participants often want their own names and/or the names of their deceased relatives to be used (see Wiles *et al*, 2011). In a study of research participants' views of the use of verbatim quotations in qualitative research, Corden and Sainsbury (2006) also found that research participants did not like the use of pseudonyms. Grinyer (2002: 4) notes the importance of providing research participants the opportunity to use their own names but notes that this must be balanced with protecting them from harm:

The balance of protecting respondents from harm by hiding their identity while at the same time preventing 'loss of ownership' is an issue that needs to be addressed by each researcher on an individual basis with each respondent.

A further difficulty arises in research being conducted within a specific group, network or organisation in which some people opt for identification but others do not. The identification of some individuals can lead to the identification of others who wish to remain anonymous. In this situation, identification cannot be offered without breaching confidentiality for others. A similar situation occurs in relation to an organisation; in cases where an institution wants to remain anonymous it may not be possible to enable participants to opt for identification, at least not without the consent of the institution. One of our participants in our study on informed consent noted (Wiles, Crow *et al*, 2008: 425):

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.

Visual data and anonymisation

Visual research, particularly where photographs and film are used as data, presents particular challenges for anonymity. Much of this type of visual material makes the anonymisation of individuals or locations problematic if not impossible (Clark, 2006; Wiles, Prosser *et al*, 2008; Wiles, Clark and Prosser, 2011). Challenges to anonymity may also arise with other forms of visual data, such as drawings and collage (see Prosser and Loxley 2008; Wiles *et al*, 2011). The situation is complicated by the fact that individuals appear commonly to want to be identified in their visual images, a similar situation to that which emerges in some text-based research as discussed above.

Still and moving visual images that portray clearly identifiable individuals can be anonymised only by altering the image in some way so as to obscure an individual's identity. More commonly, visual researchers present these types of visual material in their entirety, thereby enabling individuals to be identified, with their consent (see Pink, 2007). Methods of obscuring people's identity include increasing the pixilation of facial features in order to blur them, the use of specific anonymisation software that converts visual images into drawn images and blocking out eyes, faces or other distinguishing features (see Wiles, Prosser *et al*, 2008). Obscuring facial features alone may not be adequate to ensure anonymity in that there may be a range of other visual clues in the image that enable an individual to be identified. Obscuring facial features has been subject to criticism by some social researchers (Williams *et al* (undated): 7; Sweetman, 2008). Nevertheless, it is recognised that there are some individuals, groups or types of images that necessitate the identities of individuals being obscured. It is common practice, for example, for researchers working with children to use specialist software to anonymise children's images (Flewitt, 2005; Wiles, Prosser *et al*, 2008).

The more common approach favoured by many social researchers is to present visual data in their entirety, with consent, and not to attempt to anonymise individuals (see for example, Back, 2004; Holliday, 2004). In this mode of working, pseudonyms are not generally used. Many researchers who work with visual material have identified the importance of developing relationships of mutual trust with study participants so that the images that are taken emerge from collaborations between researcher and study participant and are jointly owned (Banks, 2001; Gold, 1989;

Harper, 1998; Pink, 2007). This involves showing images to participants, and allowing them to comment on them, prior to publication or presentation, as well as consideration by researchers of the political, social and cultural contexts in which images will be viewed and interpreted. There may however be a tension between study participants' wishes about how images of them are used and researchers' responsibility to protect them from harm. Collaboration with research participants on issues around anonymity and dissemination involve more than simply meeting participants' wishes; researchers need to consider carefully and explain the various implications to individuals and in some cases it may be necessary to override their wishes if this is viewed as being in study participants' best interests.

The longevity of visual and other data which can remain in the public domain through publication in books and articles for many years, if not indefinitely, also raises some issues that warrant consideration with research participants. While an individual may be happy for a specific image or expressed view to be made public at one point in their lives they may be less so in the future as their circumstances change, yet once something enters the public domain it may be difficult or impossible to remove it. The internet offers considerable opportunities for global dissemination but, without restricted access to sites, raises the possibilities that data can be copied and reproduced in contexts other than those for which they were obtained. This also raises specific issues in relation to the storage and archiving of research data. There is a need to ensure that all data are stored in ways that ensure confidentiality and that express consent is provided for their continued and subsequent use.

Summary

Confidentiality and anonymity are distinct but related concepts; confidentiality refers to the need to keep identifiable information about individuals private and anonymity is one of the ways in which data are kept confidential. Intentional disclosure of information may be necessary in certain circumstances if research participants are viewed as being at risk. Accidental disclosures of information also occur but care should be taken to avoid these where possible. There is an increasing trend in research towards research participants being identified rather than anonymised.