10 Ethical Research

Chapter Objectives

By the end of this chapter you will be able to:

- Recognize the up-to-date standards required for ethical research.
- Understand why ethics matters.
- Interpret ethical guidelines in the context of actual qualitative research practice.
- Understand how research governance works.

10.1 Introduction

Given the many demands faced by the apprentice researcher, obtaining ethical approval for your project may seem like a further unnecessary chore. However, because qualitative research inevitably involves contact with human subjects in the 'field', ethical problems are not usually far away. Consider the following examples of ethical dilemmas in qualitative research:

- In the course of gathering data for a study of male sexuality, a doctoral student guarantees confidentiality to the men he interviews. Taking him at his word, a number of them confide that they have been involved in the sexual abuse of children. To tell or not to tell? (adapted from *Education Guardian*, 22 August 2006).
- In a study of complementary and alternative medicine (CAM), 'no matter what we said or how we disseminated our information, the practitioners remained focused on the idea that our study would provide scientific legitimation of CAM's positive effects. Morally, we were placed in a position where we were obliged constantly to remind practitioners that the knowledge produced would not provide them with strong evidence, or even a vague hint as to whether their particular treatment actually "worked". As researchers, moreover, we found ourselves in the position of bartering, where the only thing that we could exchange for the hope and goodwill of the practitioners was our professional interest' (Baarts, 2009: 429).
- Giampietro Gobo studied 'juvenile delinquents' using lists of youths with criminal records as possible informants. 'However, the lists were furnished in exchange for my promise that I would

not tell the future interviewees how I had obtained their names. The reason for this secrecy was that the youths had "paid their debt to society" and were therefore of no further concern to the social services. If they had found out that their names were still on the social workers' lists they would consider themselves branded for life. Consequently, when I contacted the youths and they asked me how I had got hold of their names, I was faced with a dilemma: tell them a lie or break my promise to the social workers? In either case, I would have breached a norm of my professional code of ethics' (Gobo, 2008: 135).

- A sociology student gains access to an inner-city gang. The gang leader asks him to decide if and how two subordinates should be punished for a minor misappropriation of drug funds. What should he do (Venkatesh, 2008)?

Although these may be extreme examples, you will be lucky if you do not come across some ethical dilemmas in the course of your research. That is why modern universities make so much fuss about protecting the dignity and safety of the research participants and the general public.

Link

You can read reviews of Venkatesh's (2008) book on a Chicago gang at: www.amazon.co.uk/review/product/1594201501?sortBy=bySubmissionDateDescending

While such concerns are widely shared among social scientists today, we should remember that this has not always been the case. Most of us are aware that the Nazis used concentration camp victims as guinea pigs in their diabolical medical experiments, but relatively few are familiar with equally egregious but lesser publicized violations of human rights under the auspices of research in democratic societies. In one of the most troubling examples of unscrupulous research, a group of 399 African-American men afflicted with syphilis unknowingly became participants in a medical experiment that lasted nearly 40 years until it was finally exposed in the early 1970s (Jones, 1981: 1–23). From the 1930s to the 1970s, the physicians assigned to these men deliberately did not treat them for their ailment, even after penicillin was developed and could have been used as a cure. Instead, the patients were secretly experimented on to examine the effects of untreated syphilis. By the time this US Public Health Service study was exposed and subsequently terminated, many of the patients whose condition had gone untreated for years had either died horribly or become severely ill.

Instances of unethical research are not limited to medical experiments. Among social scientists in the United States, a well-known example of unethical research is Laud Humphreys's *Tearoom Trade* (1970). Humphreys studied anonymous homosexual encounters in semi-public places. Specifically, he was interested in the background of men who had sex with other men in public restrooms. After positioning himself in a restroom in a city park, he gained the trust of the men who frequented it by acting as a lookout for them while they engaged in sexual activities. Humphreys secretly recorded their licence plate numbers, and with the help of the police discovered who they were and where they lived. Months later, he visited the

men in their homes disguised as a survey researcher. He gathered additional information about these men and their families and subsequently published his research in a book that was widely praised before questions were raised about its ethics. One of the main findings of his work was that many of the men in his study were married and of middle class background – a discovery that was made possible through the covert invasion of the subjects' privacy.

Such flagrant abuses of research subjects in the name of science have led to the establishment of codes of research ethics. While these may vary across disciplines and national boundaries, there are a number of general principles that most researchers would agree with. Most prominent among these are:

- voluntary participation and the right to withdraw
- protection of research participants
- assessment of potential benefits and risks to participants
- obtaining informed consent
- not doing harm.

In many countries, including the UK, your supervisor is the person who decides whether your planned research meets appropriate ethical guidelines. Many if not most universities now have research ethics committees by which all research involving human subjects must be approved. Particularly when you are seeking to obtain access to an outside organization, you will often need to comply with the demands of such an ethics committee. This tends to be mandatory when you are studying healthcare organizations.

Ideally, when you successfully obtain ethical approval for your research, you accomplish two things. First, you have benefited from the advice of at least one academic trained to detect any potential flaws in your research design that could pose a threat to the participants. The advantage of this guidance cannot be overstated. A qualitative researcher's enthusiasm and desire to become intimately familiar with a topic could blind her to the adverse consequences of her research. Your supervisor or organization's research ethics committee could alert you to problems before any inadvertent harm is done.

Second, when you assure your research participants that your study has been approved by a university and/or medical research ethics committee, you earn their confidence that you are a trained researcher with the backing of a legitimate academic institution. This could help you establish rapport and address any reservations people might have about answering your questions or sharing their private lives with you.

10.2 The Standards of Ethical Research

Throughout this chapter, I will offer further advice about ethical issues illustrated by many student examples. However, now is a good time to confront the 'official line'. Table 10.1 sets out the instructions regarding ethical research provided by the British Economic and Social Research Council (ESRC). Do not despair if you find this too dense or demanding. Shortly, we will see how other graduate students have handled such matters.

TABLE 10.1 What is ethical research?

1 *Research staff and subjects must be informed fully about the purpose, methods and intended possible uses of the research, what their participation in the research entails and what risks, if any, are involved*

(a) This principle underpins the meaning of informed consent. Informed consent entails giving as much information as possible about the research so that prospective participants can make an informed decision on their possible involvement. Typically, this information should be provided in written form and signed off by the research subjects. The primary objective is to conduct research openly and without deception. Deception (i.e. research without consent) should only be used as a last resort when no other approach is possible. Consent here is not simply resolved through the formal signing of a consent document at the start of research. Instead it is continually open to revision and questioning. Highly formalised or bureaucratic ways of securing consent should be avoided in favour of fostering relationships in which ongoing ethical regard for participants is to be sustained, even after the study itself has been completed.

(b) This emphasis on the individual can seem inappropriate or meaningless in some cultural contexts, where the individual may take less precedence than broader notions of kin or community. This may be especially so when social scientists work in developing countries.

(c) In cases where research involves vulnerable groups such as children, older persons or adults with learning difficulties, every effort should be made to secure their informed consent. However, in cases where this is seen as impossible or where the research subjects are considered not competent to give their assent to the research, the issue of honesty and consent may need to be managed via proxies, who should be either those with a duty of care or who can provide disinterested independent approval (depending on the individual circumstances). In the case of research on children, one cannot expect parents alone to provide disinterested approval on their children's behalf. In such cases, every effort should be made to deal with consent through dialogue with both children and their parents (or legal equivalent). Again, there may be circumstances where this could jeopardise the research (again in some areas of deviance, such as research into teenage sexuality or teenage pregnancy). In such circumstances, researchers will need to regard the potential risk to the principal subjects of the research as a priority.

2 *The confidentiality of information supplied by research subjects and the anonymity of respondents must be respected*

This requires that researchers take steps to ensure that research data and its sources remain confidential unless participants have consented to their disclosure, and in this latter case ensure that plans have been made for their storage and access to them.

3 *Research participants must participate in a voluntary way, free from any coercion*

In all cases of research, researchers should inform subjects of their right to refuse to participate or withdraw from the investigation whenever and for whatever reason they wish. There should be no coercion of research subjects to participate in the research. Consent has to be freely given in order to be valid.

This is linked to the issue of covert research and deliberate deception. Deception by definition precludes consent and should only be used in a research setting where open and transparent research is impossible, whether because of the risks it might create for the researcher or participant, or in work where consent can be secured without providing the participant with full information about the project to avoid jeopardising its performance.

4 *Harm to research participants must be avoided*

This principle requires that social science research should be conducted in such a way that it minimises harm or risk to social groups or individuals. Participants' interests or well-being should not be damaged as

a result of their participation in the research. [It is important to take account of] the way in which research is communicated, especially where material is sensitive or results could be misconstrued and subsequently used by third parties against the interests of the research participants or researchers themselves.

5 *The independence and impartiality of researchers must be clear, and any conflicts of interest or partiality must be explicit*

The research should be conducted so as to ensure the professional integrity of its design, the generation and analysis of data, and the publication of results, while the direct and indirect contributions of colleagues, collaborators and others should also be acknowledged. In addition, this principle requires that investigators ensure that there is no undeclared conflict of interest (which may be personal, academic or commercial) in their proposed work and that the relation between the sources of funding and researchers' control over results is made clear, specifically in relation to the ownership, publication and subsequent use of research data.

Source: Research Ethics Framework, ESRC, July 2005, pp. 23–5

Links

For a useful discussion of ethical issues which includes tips from experienced researchers, go to: www.the-sra.org.uk/documents/pdfs/ethics03.pdf

For a US view of research ethics go to: www.youtube.com/watch?v=YFyzxQoaUhQ

10.3 Why Ethics Matter for Your Research

I would not be surprised if many readers are overawed by Table 10.1. Indeed, it is very tempting to think that, simply by paying lip-service to these principles, one may save a lot of time for the 'real' topics of your research.

In this section, I am not going to preach you a sermon about ethical practice. Instead, I want to use a student example to show you why thinking through ethical issues properly can help you do better research.

John Moore's study of families' reactions to suicide shows that if you don't think through the issue of informed consent, your research access may sometimes disappear.

STUDENT EXAMPLES

Reactions to Suicide

I had been contacting various helplines and discussing the issue of data collection. I wanted somewhere where mental health topics and suicide were being discussed ... I contacted a number of self-help groups in the search for data. I received a great response from one in Norfolk, which was for relatives of people who had committed suicide. I had many conversations on the phone with the group's founder. [He told me] that they had agreed to me coming down and video-recording one of their sessions, and they were all keen to be part of the research. I discussed discursive psychological research in great detail with him, and he liked what I was proposing.

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When I got there and had set up the camera, people started to arrive. It soon became clear that they were not expecting me, had given no consent to being recorded, and did not know each other or meet regularly (one person said she had attended one session four years ago and had been phoned out of the blue and asked to attend that night). It also became clear very quickly that they were all still very much in a great deal of emotional distress and pain. I turned the camera off and decided to just sit the meeting out. The group leader then announced to the group that he had no idea what I wanted or what my research was about. It then turned very unpleasant, with one member telling me that I was making her pain worse by being there, and I felt physically threatened by another member who appeared quite angry. I cannot express how terrible I felt.

Lessons learned: I should have spoken to participants and not just the group leader before showing up with a camera to the meeting, and if I ever approach a similar group again, I would get consent forms signed before attempting any data collection. I think attending some meetings to get a feel for them before collection starts would also be the way to go. [John Moore, Social Sciences, Loughborough]

John Moore also studied helplines available to people contemplating suicide and their families. His experience shows that one aspect of ethical practice is thinking through what your research can offer participants. By doing this, as he shows, you are more likely to obtain research access. So good ethical practice can produce better research.

STUDENT EXAMPLES

What's in It for Us?

When I started discussing data collection with MindinfoLine, it was very useful to bring along some sound-files of the ethics exchanges from another helpline where calls had been recorded for research. This helped them to decide to use a recorded message as opposed to asking each caller for individual permission, as they felt that the ethics exchanges sounded too disrupting to the calls. Most importantly, it helped to bring along examples of how similar research had been used in feedback to helplines in the past, to clearly demonstrate that the research could be beneficial to them. I also made a point of encouraging them (if they were to decide to go ahead with call recording) to give me some questions to answer for them, which they did. This feedback has been a great way to continue my relationship with the helpline staff, and I have been back once to discuss the way callers who cry during calls are supported, and will be back again to discuss callers who are unclear as to what they want from the line. [John Moore]

10.4 Ethical Guidelines in Practice

One could spend hours trying to decode the ESRC's list of principles set out in Table 10.1. A better learning strategy might be to consider how other graduate students have addressed ethical issues in their research. In this section, I consider what their experience can tell us about:

- obtaining consent
- research in different cultures
- research with vulnerable groups
- confidentiality.

Obtaining consent

10.4.1 My PhD student, Sally Hunt, sought to obtain audio-recordings of a mental health team's weekly case conference. As well as completing the paperwork for an ethics committee, Sally Hunt also discussed her proposal with the chairman of the trust's mental health board, a practising consultant psychiatrist. He voiced no objection in principle and recommended that she contact the team's consultant and team leader to seek their individual permission, which she did. As she remarks:

> Being a participant-observer raises a number of ethical issues which extend beyond formal consent to the research. Before the research began, I decided that the best way to carry out participant observation, both morally and practically, was to be as open as possible with the team. My rationale for making this decision was that this would permit me to be free to ask questions as the fieldwork progressed without creating too much suspicion. [Sally Hunt]

Rachael Dunn's PhD at Murdoch University, Western Australia, focused on a clinic treating young people with eating disorders. Like Sally, she needed approval from a participating organization and needed to adjust her proposal accordingly.

STUDENT EXAMPLES

Working with Ethics Committees

In the course of the ethics approval process, a number of stipulations were made by the committee concerning data collection protocols. To minimize any effect the taping of the therapy sessions might have on patients, or the therapeutic process, the participating clinicians made an informed clinical decision as to which patients to approach for consent. This potentially produced bias in which sessions were ultimately recorded, as clinicians could exclude certain patients. To minimize this, the clinicians were instructed to record a representative sample of therapeutic interactions. Patients were advised on the patient information sheet and verbally before recording commenced that they were able to withdraw their consent before, during or after the therapy sessions. Patients were also informed that withdrawal or non-participation in the study would not affect the care they received. Patients were further advised that no identifying details would be made public in the study and that the audio-tapings of therapy sessions would not be played publicly. In addition, the hospital ethics committee required a final amendment to the application, which stipulated that all original recordings and sound file copies be destroyed subsequent to the analysis phase of the study. [Rachael Dunn, Psychology, Murdoch University]

TIP

Note that Rachael allowed participants to withdraw their consent at any time. This is known as 'process consent' and is a better way of safeguarding participants than a once-and-for-all 'informed consent'. Process consent may also imply your commitment to debrief participants afterwards. This is a common feature in focus group research where people may be allowed to talk about their contributions immediately after the event and given a contact number should they wish to talk to a researcher at a later date (see Barbour, 2007b: 82).

The information sheets you give to potential participants should be carefully constructed. Your research needs to be fully described in a way that the people concerned can understand. As noted above, it is also sensible to stress that, if consent is given, it can be withdrawn at any time. As an example of good practice, you will find below the information sheet used by Rachael Dunn.

STUDENT EXAMPLES

Patient Information Sheet

Project Title: Therapeutic Interaction in Anorexia Nervosa Treatment

Thank you for taking the time to read this information.

My name is Rachael Dunn and I am a PhD student at Murdoch University. The purpose of my study is to look at how language is used in therapy sessions between clinicians and adolescents diagnosed with an eating disorder. Results from this study will have the opportunity to provide new information on the role of language in the therapeutic process with patients in the area of eating disorders. It is hoped that this will enhance our understanding of what is helpful for the adolescent with anorexia nervosa.

You can help in this study by consenting to have your therapy session recorded using a digital MP3 recording device. Participation in this study is voluntary. You may withdraw your consent at any time during or after the therapy session, at which time the recording will be destroyed. No names or other information that might identify you will be used in any publication or documentation arising from the research. If you decide to withdraw from the study or do not take part, this will not in any way affect the care you receive at [named] hospital.

Being in this study will not involve any extra time for you. It will only mean that the therapy session you are already having will be recorded. After transcription, the original recordings will be stored at the hospital in a locked filing cabinet on an MP3 recording device. The tapes will be kept through the data collection and transcription parts of the study (maximum 10 months) and then they will be destroyed. Written transcripts will be made from the recording and will contain no names or details that might identify you.

A report on this study will be given to the Eating Disorders Team at the hospital and will be available for you to read. If you are willing to participate in this study, could you please complete the attached consent form. If you have any questions about this study please feel free to contact me, Rachael Dunn, on [phone number] or my supervisor [name] from the Eating Disorders Team [phone number].

Kind regards

Rachael Dunn

BA (Hons) (Psychology)

Rachael used a similar information sheet with the parents of the adolescent patients in her study. This is an excellent example of such information, which incorporates full description of the purposes of her research, details of what will actually happen if you participate, and provision for 'process consent' as well for extra information from respected others. My only minor reservation is that the description of her research in terms of 'the role of language in the therapeutic process' may be a little bit heavy on academic jargon. Can you think of a more down-to-earth way of phrasing Rachael's topic?

Go to Exercise 10.1

TIP

When preparing information sheets it is sensible to avoid terms that are potentially sensitive. For instance, in a study of obesity management in general practice medicine, the term 'weight management' was used with potential participants. In subsequent interviews it was discovered that most respondents found the terms 'obese' and 'obesity' hurtful (Barbour, 2007b: 75).

10.4.2 Research in different cultures

What is a 'different' culture? Does this mean a different society, or can 'different' cultures be much closer to home? For instance, in the examples given at the beginning of this chapter, were the gang members and complementary medicine practitioners not members of cultures quite different from those of the researchers?

Of course, it is always wise for researchers to consider the way in which their assumptions and practices may be different from those they study. Even in the familiar medical settings studied by Sally and Rachael, they did not take for granted the way participants would understand what they were doing. In this section, however, I focus on the specific issues in studying people from another society.

Sometimes this can be a quite straightforward matter. Maddie Sandall studied the experience of international students. During her research, she interviewed 'partnership programme' students who have transferred to the UK for the final year of their degree.

STUDENT EXAMPLES

Studying International Students

I didn't require ethics committee approval, but did create an ethics statement which I sent to each interviewee which covered issues of anonymity and confidentiality. This was particularly important as I had been seen as a member of staff in one light and then a 'fellow student' in another. I wanted them to be clear that I was in my student role for the interviews.

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Other ethical considerations included ensuring I had knowledge of their cultural differences and also being clear on the questions which could have different meanings in different cultures. I also reassured the students that the research will only be read by the markers and will not in any way be fed back to their partner college or to the university.

One particularly tricky issue was when one of the students turned the interview around and started to interview me – asking me what the Western view of Asians was – I felt like I was really put on the spot and asked to generalize on behalf of all Westerners! Although I do of course have an opinion, it's quite difficult to know the 'right thing to say'. An issue I am sure the interviewees had themselves. [Maddie Sandall, Management, University of the West of England]

It is often difficult to import ethical principles from one culture and apply them without modifications to another. The experienced sociologist, Catherine Riessman, conducted research in villages in Kerala, South India, between 1993 and 1994. Her interest was in the meaning and management of infertility which, she remarks, was 'an invisible problem in the Indian context'. Here is a shortened account of how she describes her ethical dilemmas.

Researching Indian Villagers

My research proposal ... included procedures for obtaining informed consent from childless women. But ... the very language of Western research practice – 'obtaining' informed consent – indicates who will be in control.

The first hint of trouble happened shortly after I joined my host institution, the research unit of a small college in Kerala. [My] research assistant, Liza – a 26 year old Malayali graduate level social worker, educated in Kerala ... was surprised ... by my consent form: 'we don't do that here,' she told me gently ... I persisted, and asked her to translate into Malayalam the form I had prepared according to my University's guidelines ...

Because women in Kerala are educated and literate, many informants read along as we communicated the contents of the consent form. Most women signed it. A significant number, however, were reluctant to affix their names. They were suspicious, not about interviewing or taping, but about the form. Perhaps they thought it a government document.

Reflecting now on the refusal of some women, I hear their worry. The consent form *was* a government document – an import from the West, designed to meet my University's Institutional Review Board requirement ... Signing documents in the Indian context carries a history of well-deserved suspicion: government intrusion into property rights, inheritance, marriage customs, and reproductive health. Strangers seeking information and bearing forms are not easily trusted, especially in rural villages. (Riessman, 2005: ms 8–9)

It is not always just a case of suspicion. People in non-Western cultures may regard their consent to research as a purely instrumental matter. As Anne Ryen observes:

I have frequently met expectations that I will reciprocate in one way or another in African settings ... These have been of different kinds, from expecting me to cope with local poverty and offering grants, to gift exchanges and sexual offers. (2004: 238)

In some cultures, however, it may be difficult to say 'no' to a researcher's request for access. As Anne Ryen notes, on the basis of her research in East Africa:

> For many poor Third World interviewees, local norms make it difficult to turn down a request from a visitor to be interviewed or they do not know the potential implications of participating in research. [This means that] the general ethical correctness of informed consent irrespective of the location of the field may be questionable with reference to the North–South dimension in Third World projects. (2004: 232)

Queenie Eng did her PhD research on Chinese people with diabetes living in the UK. Like Anne Ryen, she found that 'informed consent' was quite different to that imagined in Western-based research protocols.

STUDENT EXAMPLES

Why Do Non-Western People Give Consent?

In the UK, the rules of engagement in research are modelled along the Western ethical framework. On the other hand, the research participants are Chinese migrants whose rules of engagement are moulded by the Eastern customs and traditions.

Within the group setting, the social role of the researcher is problematic because of her position as an academic amongst participants who were largely illiterate. The reverence for and importance of education in Chinese culture is documented in literary and historical texts. In accordance with the Western framework of conducting research, participants are asked for their consent, and this is indicated by their signature on a consent form. However, the signing of a form between individuals who have verbally consented to carrying out a promise is a foreign import. Within the Chinese tradition, agreements are sealed by the 'gentleman's honour', not a signature on a piece of paper.

So, what does one do in this case? Should the researcher get the participants to sign before or after the interview? The point is, when dealing with people who come from a non-Western culture, a seemingly simple act of the signing of a consent form has cultural repercussions. Researchers need to be aware of this and know what it means for the participants as it can impact on how much information they are willing to divulge.

The participants also misunderstood the benefits they were to get out of the research. One of the reasons for participation was because some of the participants thought that they would learn something about their illness from the researcher. Despite thorough explanation at the outset of the discussion from the researcher and her assistant about the nature of the focus group discussions, misunderstanding persisted. They were angry when SE [Queenie Eng] did not accede to their demands for information on diabetes in exchange for participation in the focus groups. Arguably, the 'mutiny' was justified.

In the process of sharing their experience, both participant and researcher had to find a middle ground to satisfy the needs of both parties. [In this setting] deviation from the Western norm of conducting research is inevitable. These deviations include recruitment, obtaining consent, upholding confidentiality and anonymity, handling reciprocity and managing conflicts. [Queenie Eng (S. Eng), Medicine, Leeds]

Eng's, Ryen's and Riessman's research with non-Western people shows that obtaining consent can be far more complicated than Western ethical guidelines would suggest.

Go to Exercise 10.2

TIP

As with every aspect of your research, success is not measured by passive rule following. Understand the rules but then ensure that you think through their relevance for the people and situations you wish to study. Success depends upon thoughtful, well-informed ethical practice. Sometimes this can mean deviating from rules.

10.4.3 Research with vulnerable groups

10.4.3 Issues of consent become even more complicated when you want to study vulnerable people such as children or adults with disabilities. For instance, I welcomed the idea of colleagues researching the old people's home where I do voluntary work. However, the ethical issues involved in studying people with dementia are vast and apparently intractable, particularly if you want to use video data. Families, carers and care managers will all have to be consulted. But what happens when the camera accidentally includes a resident or carer for whom you have no permission to record? Moreover, how satisfactory is it to use family permission to record intimate details of somebody's daily life?

Anne Patterson carefully attended to these issues in her PhD research on young people with learning disabilities. Her account is as follows.

STUDENT EXAMPLES

Studying People with Disabilities

In my PhD research, which studies telephone calls between family members, one of whom has a learning disability, the 'dilemma' is associated with ethics in what I think is a fairly unique way. I obtained appropriate ethics committee approval (at university level) since some of the participants were in a recognized 'vulnerable' group, and I approached three families direct, asking them to record their telephone calls with the young adults in their families who were at residential school or college and were making calls home. I gained informed consent as far as possible from all individuals involved, but it is still a concern whether it is possible to obtain 'true' informed consent or whether the motives of the research are truly understood and the individual's rights to refuse to take part are fully appreciated. Some researchers question whether individuals truly understand the research and their position within it. With this in mind, an information sheet was designed which could be read by or read to all participants. In the case of the young adults with learning disabilities the form was supplemented with extra explanation of the contents therein. It was possible then to be satisfied that the interests of these participants had been fairly served and that informed consent had been given as far as was practically possible. In order to build an even

greater awareness of the purpose of the research it has been possible to show one of the young people some transcripts and allow them to listen to the recordings (much to everyone's amusement). This certainly provided a further, very practical opportunity to try to ensure that one of the young adults was aware of what was being done in the study and to understand their part in it. [Anne Patterson, Social Sciences, Loughborough]

Sometimes the complex ethical issues involved in studying potentially vulnerable groups may be redefined in terms of the research design itself. Pia Kontos applied to the research ethics board (REB) of a long-term care facility where she proposed to conduct ethnographic research on their Alzheimer's support unit. While the proposal was approved by the REB, in their letter of approval there were concerns expressed about her methodology. It was indicated that while they appreciated that there are significant differences between quantitative science and qualitative studies, they had an ethical responsibility to ensure that the residents of their facility were only subjected to research which was based on sound design. Of particular concern to the REB was that she intended to be the sole observer, which in their view carries an inherent potential for bias. In the interests of increasing her ability to obtain meaningful data, it was thus strongly recommended that she strengthen the validity of her study design by including triangulation of observations through the involvement of secondary observers. It was suggested that family members might be particularly appropriate in this role. Pia's response is shown below.

STUDENT EXAMPLES

Using Your Supervisor to Support You

In response to the REB's recommendation, my thesis supervisor wrote a letter indicating that their recommendation to involve 'secondary observers' was not methodologically appropriate. She explained that verification or trustworthiness is a central topic in the qualitative research literature and that verification in the case of my thesis research would be ensured by following standard qualitative methodology criteria including: (1) the articulation of an explicit theoretical framework which informs data collection and analysis; (2) prolonged engagement in the field; (3) the production of detailed fieldnotes (**thick description**) after each engagement in the field; (4) iterative data collection and data analysis ('constant comparison method'); (5) attending to negative or disconfirming evidence; and (6) frequent debriefing with thesis committee members about the research process and development of preliminary coding categories.

This experience highlighted the importance of having qualitative researchers on REBs to ensure that qualitative studies are properly and fairly reviewed. [Pia Kontos, Department of Public Health Sciences, Toronto]

10.4.4 Confidentiality

Issues relating to confidentiality can usually be met straightforwardly, as the following student example shows.

STUDENT EXAMPLES

Keeping Sensitive Information under Wraps

In a study of leadership, Alastair Rylatt used number-coded transcripts and all references to names of people and organizations were deleted. The names of the individuals and interested parties were changed without destroying the integrity and usefulness of the research. All written transcripts, recordings of interviews and content analysis were kept in a fireproof and secure location for long-term security. [Alastair Rylatt, Management, University of Technology, Sydney]

This is Sally Hunt's account of how she approached this topic when making audio-recordings of a mental health team's weekly case conference.

STUDENT EXAMPLES

Preserving Anonymity

I undertook to use pseudonyms for the names of staff, clients and care areas throughout the research to preserve anonymity and to safeguard confidentiality. In the event, even references to months or seasons of the year in the transcripts were changed as the work got under way. Dates of legislation were retained as were dates of fieldwork and any reference to clients' ages, as such data were necessary to the analysis. As it is not usual for a PhD thesis to be published, this further helped to maintain anonymity. In addition, I undertook to write a report on the progress of the study for the ethical committee, should this be required at any stage of the work. [I did not seek] to interview clients or to access their case records. I guaranteed to keep all audiotapes at home under lock and key and to do all my own transcribing rather than eliciting secretarial assistance. I also promised to destroy the tapes at the end of the study. [Sally Hunt, Sociology, Goldsmiths]

However, as we saw at the beginning of this chapter, confidentiality issues can be more complex. When I showed this chapter to my then Sage editor, Patrick Brindle, he remarked that, in his own PhD research, anonymity was not the choice of most of the people he interviewed.

STUDENT EXAMPLES

Do People Want To Be Anonymous?

One thing that I encountered doing oral history interviewing for my PhD was that many of my interviewees did not want to be anonymized. They regarded their interview as public testimony and stated that they were looking forward to seeing their names in print in my book. When I put it to the interviewees that I would have to change their names and hide their identity they became quite upset, and one of them said that she would not have let me interview her if her identity was to be concealed.

Which made me think: who are we trying to protect? Once it was anonymized, there was nothing to stop me from tampering with the testimony knowing that there could be no comeback from the respondent. I did not, of course, but anonymization would have made it easy to do so. So a critical question for me is always: who benefits? [Patrick Brindle]

What respondents want is not the only issue regarding anonymity. Should you keep quiet when people reveal criminal offences in the course of a 'confidential' research interview? And, if you are using video data, what can you properly reveal in seminar presentations and publications? Once again, there are no easy answers.

Link

For a useful discussion of how participants view social research go to: www.civilservice.gov.uk/wp-content/uploads/2011/09/ethics_participants_tcm6-5783.pdf

TIP

If you are faced with an apparently intractable ethical problem, consult your supervisor and read about how more experienced researchers handled such a problem. Here, as elsewhere, don't try to reinvent the wheel!

10.5 Complex Ethical Issues

Here the waters muddy still further. In this section I deal with a number of issues which are barely mentioned in ethical guidelines such as those provided by the ESRC, namely:

- consent to observational research
- consent to internet research
- whether there can be 'appropriate' deception
- paying participants
- the unintended consequences of good ethical practice.

10.5.1 Consent to observational research

Qualitative researchers sometimes encounter unique problems in obtaining ethical approval, particularly when their data depend upon observation. Indeed, a guidebook published by the US Department of Health and Human Services explicitly notes the difficulties confronting qualitative researchers where informed consent is concerned. Specifically, in a section titled 'Fieldwork' the guidebook states:

> Fieldwork, or ethnographic research, involves observation of and interaction with the persons or group being studied in the group's own environment, often for long periods of time. Since fieldwork is a research process that gains shape and substance as the study progresses, it is difficult, if not impossible, to specify detailed contents and objectives in a protocol.
>
> After gaining access to the fieldwork setting, the ongoing demands of scientifically and morally sound research involve gaining the approval and trust of the persons being studied. These processes, as well as the research itself, involve complex, continuing interactions between researcher and hosts that cannot be reduced to an informed consent form. Thus, while the idea of consent is not inapplicable in fieldwork, Institutional Review Boards [US ethical committees, referred to henceforth as IRBs] and researchers need to adapt prevailing notions of acceptable protocols and consent procedures to the realities of fieldwork. IRBs should keep in mind the possibility of granting a waiver of informed consent. (Penslar, 2007)

Evidently, even the US government agency in charge of defining and enforcing guidelines for dealing with human subjects is aware that qualitative researchers face unique challenges in gaining IRB approvals (it is worth noting that this guidebook was prepared by a lawyer, Robin Levin Penslar JD, the 'ORRR Program Officer', and a physician, Joan P. Porter DPA).

A case study illustrates how the student ethnographer may need to work out different forms of consent for different groups. Keith Abbott carried out doctoral (sociological) research into spiritual enlightenment at Loughborough University, and his subjects included internationally famous spiritual gurus as well as some lesser known individuals who teach about enlightenment.

STUDENT EXAMPLES

Fieldwork on Spiritual Enlightenment

I have been using audio- and video-recordings, and photos I have taken. I have recorded people to whom the gurus speak during short courses or fairly public events. I've taken the view that different 'subjects' require different levels of consent (so gurus have massive consent forms; people in the audience at public events being recorded anyway may not get a form at all).

When recording live events where there is an audience, I generally did not seek prior consent from all present, only the main speaker. I tried several times to catch up with people who had contributed to the event from the audience afterwards, to ask retrospective consent, but was never quick enough to intercept them and soon gave up on this as a strategy. However, such events were generally rather ostensibly recorded by the organizers anyway, sometimes unannounced and sometimes with something like the mention of a possible podcast or CD/DVD becoming available. I took it that on such occasions all those who spoke or remained had already implicitly consented to becoming part of a worldwide spectacle and so were ethically available to my own recordings. In such cases I tried to anonymize all but the main speaker or anyone who had explicitly consented.

For small events running over several days or encounters, particularly where I was using video- as well as audio-recordings, I had a very short single-page consent form, different from my more elaborate 'guru form', which simply allowed course delegates the possibilities of altogether opting

out of being recorded, being recorded anonymously (such as by their images being edited), or being recorded without anonymizing. There were occasions however where producing even the short form would have been hugely disruptive and instead I relied upon being open about my research intentions and simply asked people if they minded being audio-recorded, refraining if there seemed to be any hint of concern. [Keith Abbott, Social Sciences, Loughborough]

Although Queenie Eng's study of Chinese people living in the UK used focus groups rather than fieldwork data, she faced similar issues to Keith in deciding what counted as 'appropriate' consent.

STUDENT EXAMPLES

Delayed Consent with Non-Western Respondents

For people who come from a non-Western culture, a seemingly simple act of signing a consent form has cultural repercussions. Researchers need to be aware of this and know what it means for the participants as it can impact on how much information they are willing to divulge. The participants' attendance of the focus group meeting was construed by the researcher as a sign of consent and hence agreement to take part in the study. Therefore, it can be argued that signing the consent form would only formalize the whole interaction and put the participant into another mindset. For this reason, I delayed the signing of the consent form till towards the end of the session and did this in conjunction with the distribution of gift vouchers.

Thus, apparently simple protocols were difficult to adhere to. For example, the signing of consent forms which was supposed to be done before the beginning of each session was sometimes left to the last part of the interview, as the act of signing could affect the terms of engagement. Ironically, it was my moderator who reminded me that I should do what the Western protocol expects, i.e. obtain written consent before conducting the interview. As it turned out, the signature *per se* was not to be an issue but the verbal explanation of the consent form was. This was due to the low levels of literacy among these groups of Chinese participants. [Queenie Eng (S. Eng), Medicine, Leeds]

What Queenie calls 'the Western protocol' may be inappropriate to many fieldwork settings even when the participants are Western Europeans. Sally Hunt's account reveals that, faced with an ethical form based on medical research, the fieldworker needs to show considerable mental agility.

STUDENT EXAMPLES

Redefining 'Hazard'

I put forward my proposal to the ethical committee of the trust hospital to which the team was attached. I found the form I was required to complete somewhat problematic. It conformed to the standard type for purely *clinical* research involving human subjects rather than to any proposed sociological research. Predictably, it was very 'physically' oriented. One question asked for 'potential hazards' and the precautions I might take to meet them. The possible contravening of confidentiality was my written response to this enquiry. [Sally Hunt, Sociology, Goldsmiths]

Sally's experience concerning inappropriate ethical issues is very common in research involving fieldwork. If you are studying a public setting like a shopping mall, football stadium or concert, it may be impossible to obtain consent from the people you are observing. Moreover, as Giampietro Gobo (2008: 108) argues, such consent may not even be necessary because you do not interact with anyone and people know that their behaviour is open to public inspection.

10.5.2 Consent to internet research

It is sometimes assumed that the internet is a public space where people assume that what they say can be seen by others. However, in a study of internet sex sites, Gabriella Scaramuzzino saw that complex ethical issues arose.

STUDENT EXAMPLES

Internet Sex Sites

I stayed on the internet and I stayed there a lot, much longer than researchers had done in previous studies. I started to notice that if you observe contributors that closely you tend to get quite a lot of information about them. They do not only interact around issues that relate to prostitution, they hang out and write about many things, often personal and private stuff. How anonymous are they then? In Sweden it is also illegal to purchase sexual services but not to sell, which makes it even more [problematic]. Maybe their anonymity could be presumed in a sense. Maybe sometimes they also forget that they are interacting in a public place. People on the internet in general tend to write private matters publicly.

To cope with these ethical dilemmas I erased all personal and sensitive information and edited pictures before they were downloaded and stored. I also noticed that some of the contributors were 'famous' in the virtual red-light district and had made themselves a name. Some of the users are not even anonymous to each other as some of them have met offline not only for sexual encounters but also socially. Therefore, I decided not to use their usernames and not to write the names of the websites included in the study. So looking at my text you cannot trace quotes made by the same user to the same person. However, the data are still there on the internet. All posts and threads are saved in archives, like the virtual red-light district's own collective memory. Anyone can take part in the exact situations that I have done. I think that instead of dismissing unseen observation as a technique the potential harm should be weighed against the relevance of the knowledge gained. [Gabriella Scaramuzzino, Sociology, Malmö University, Sweden]

Gabriella graphically demonstrates the ethical traps when you work with internet data. The following list covers these and other dilemmas in this area:

- Many users perceive publicly accessible discourse sites as private. For example, although many online discussion groups appear to be public, members may perceive their interaction

to be private and can be surprised or angered by intruding researchers. Other groups know their communication is public but nonetheless do not want to be studied.

- Anonymity is difficult to guarantee. For example, some users have a writing style that is readily identifiable in their online community, so that the researcher's use of a pseudonym does not guarantee anonymity. Also, search engines are often capable of finding statements used in published qualitative research reports. The potential harm to individuals, relationships, families and careers is not to be dismissed lightly.
- Online discussion sites can be highly transient. For example, researchers gaining access permission in June may not be studying the same population in July. Therefore, while a researcher may have gained consent from a group at one moment, this consent may not apply at later points in time.
- Vulnerable persons are difficult to identify in certain online environments. For example, age is difficult if not impossible to verify online (Markham, 2011: 122–3).

Although there are no easy answers to these issues, Robert Kozinets (2010: 136–56) has provided a helpful discussion of problems and solutions when attempting what he calls 'ethical netnography'.

Link

For an interview with Kozinets, go to: www.youtube.com/watch?v=21etoaddZLs

10.5.3 Appropriate deception?

Informed consent suggests that you should be entirely open with participants about the purposes of your research and that any other course involves an unacceptable degree of deception. However, such openness gives rise to two problems:

1. Revealing your true interests may influence what people say or do.
2. People may not be able to make sense of the scientific terms you use to define your research problem.

This problem arose in Charlotte Baarts's (2009) study of complementary medicine. Knowing that practitioners hoped her research would show that such medicine worked, she concealed her scepticism. She comments:

> With hindsight I see that I should have acknowledged and articulated my scepticism more thoroughly during my collaboration with the practitioners. I should have recognized that ethical research does not imply a comfortable sort of neutrality, and that taking a standpoint as a researcher means adopting a third position distinct from both the dominant and the marginal positions within the controversy. Had I expressed my scepticism, the practitioners might still have seen me as a potential 'convert to their cause'. Taking a stand within the framework of highly politicized and commercialized subject

> matter, and making that position public, is part of conscious ethical practice, and at the same time reflects the recognition that science is both partial and political.
>
> Taking a stand does not necessarily imply communicating everything to collaborators or participants. But it does mean that one must reflect on the part played by one's personal values and beliefs. (2009: 432)

These issues have been directly confronted in psychological experiments where a fully open statement of the research problem is thought to 'contaminate' the results. In these cases, a degree of deception is thought to be appropriate providing the well-being of participants and their privacy is respected. Indeed, one should never deceive people about what procedures they will undergo during your research, and always undertake to answer any questions they have both before and after the research has taken place (for further discussion of these issues, see Christians, 2005: 144–5).

Paying participants?

10.5.4 Sometimes it may be tempting to offer some reward to respondents who agree to be interviewed or to participate in a focus group (notice Queenie Eng's use of gift vouchers in the example in Section 10.5.1). This follows the practice of many psychological studies involving students and of drug companies in certain kinds of drug trials. However, both can raise ethical issues if the reward offered tempts people to participate against their initial judgement. One way of handling this problem is to avoid advertising the payment or to omit to provide details of the payment involved (Barbour, 2007b: 80).

Unintended consequences of good ethical practice

10.5.5 Just as there can be no rules that cover every instance, following ethical rules can sometimes have quite unintended consequences. In Keith Abbott's research, a well-meant gesture (sharing data with participants) led to potential copyright problems.

STUDENT EXAMPLES

Consequences of Sharing Data

Legal and ethical rights and obligations relevant to researchers' own materials can also cause problems. I left some research subjects with some JPEG digital images I had taken from a personal development course I had researched as a memento and 'thank you'. All people in the data were happy for others to share their images in this way. However, some of those photographs were used in a training manual prepared by the course organizers without asking for any further permission, thus becoming part of a text intended to elaborate and teach the practices being researched. I did not anticipate such usage, and the publication in what was in effect a commercial manual

prompted me to check the university's position on what was potentially an infringement of its (and possibly my) copyright in the images and a usage which demanded some consideration to its ethicality. Since in any case, ethically and under the Data Protection Act, subjects may expect to be given copies of recordings of themselves (or their works), it can be wise for researchers to give some early thought, before any such request is made and certainly before passing on research recordings, to limiting further reproduction of released materials (by for instance annotating prints or images, or only releasing low-quality or watermarked materials). If subjects are only happy if researchers share recordings fully with them, researchers may need to question whether or not such research is acceptable to them. [Keith Abbott, Social Sciences, Loughborough]

Fortunately, following ethical guidelines can unintentionally sometimes enrich the analytic breadth of a research study. Sally Hunt's efforts to achieve informed consent with her homelessness workers meant that they were prepared to allow her to audio-record as well as observe their meetings.

Keith Abbott's pursuit of materials went in the opposite direction, moving him away from recording equipment towards observation. As he puts it:

> I've had some particular 'troubles' to do with getting permission for visual recordings, and objections leading me unintentionally into ethnographic research on one particular occasion, though this made future recordings easier as I thus became something of an insider. [Keith Abbott]

A further unintended consequence for the research process arises from the fact that 'ethical practice' as a matter of concern is now widespread among many occupational groups. On some occasions, this offers a fascinating topic for the fieldworker, as Sally Hunt recognized.

STUDENT EXAMPLES

Participants Doing Ethics

There were almost certainly times in this study when members responded to my presence in terms of what might be called 'ethical correctness'. I sensed that there were some occasions when members overtly displayed their moral adequacy as a consequence of being observed. My general *impression* was that members responded to me as a more senior member of staff, i.e. as an older, experienced professional now working in higher education. I felt that the team's display of moral adequacy in my presence was particularly marked especially where ethical dilemmas were prominent. [Sally Hunt, Sociology, Goldsmiths]

10.6 Research Governance

Sally's observations of nursing staff doing 'ethical correctness' reveal that 'ethics' has become much more than a matter of individual researchers seeking to employ good practice. Instead, a vast system of interlocking organizations (governmental, semi-governmental, medical

and legal) now confronts the contemporary Western researcher. The way in which these organizations survey and discipline researchers is described as 'research governance'. Linnie Price gives an example of what this can mean to an experienced qualitative researcher.

STUDENT EXAMPLES

Surveying the Researcher

As well as ethics, research governance is now a huge hassle. For our project, for which ethics approval was in place when I came in post, research governance delayed the start by four months, and we had to go cap in hand for more funding. For any contact with 'vulnerable' service users (some of ours had long-term mental illness), *every* person having contact needed an honorary contract with the local health authority *and* a Criminal Records Bureau check. In one of our sites, everyone had to have an occupational health medical with HIV test, including the principal researcher who is dean of a medical school.

The other pitfall is service user (SU) involvement. Few funding bodies will now support a project without SU involvement, which raises all sorts of other issues. Similarly, kapo-like data protection officers in health trusts can completely sabotage your ethics approved recruitment procedures. [Linnie Price, Plymouth University]

While ethical and governance requirements can play a significant role in ensuring the safety of research participants, their survey-friendly protocol may in the long run discourage more innovative research projects, especially those aimed at investing social inequality (e.g. poverty, racism, sexism). Such studies may invariably involve some degree of risk, both for the subjects and for the organization where inequality is practised. As Nelson states:

> Of course, 'respect for persons' can hardly entail respect for every human action, but IRBs are ill equipped to negotiate the difference. Instead, they often give unquestioned allegiance to a concept that might be given more nuanced application to, say, Ku Klux Klan or Nazi Party members, who might merit humanity qualified with disapproval and who might on occasion appropriately be challenged aggressively in an interview. A historian might well wish to investigate the self-understanding of a Ku Klux Klan member and might choose to present a neutral account of the organization, but academic freedom means that the decision to do so needs to be the historian's, not that of an IRB. One consequence of an unreflective commitment to 'respect for persons' is that IRBs have great difficulty accepting research destined to be critical of its 'human subjects'. (2003: 32)

As seen in the passage above, an increasing number of US social scientists, and academics in general, are concerned about IRBs' growing 'ethics creep' (Haggerty, 2004) into their research. Initially, the social scientists responded to IRB demands with incredulity and amusement. For example, in a magazine interview, Howard Becker joked that if he was required to undergo rigorous IRB reviews, he would circumvent the bureaucracy by redefining his research as 'conceptual art' (Shea, 2000). Four

years later, in response to Haggerty's 'Ethics creep: governing social science research in the name of ethics' (2004), Howard Becker wrote:

> What began years ago as a sort of safeguard against doctors injecting cancer cells into research patients without first asking them if that was OK has turned into a serious, ambitious bureaucracy with interests to protect, a mission to promote, and a self-righteous and self-protective ideology to explain why it is all necessary ... I never had occasion to try out the idea I suggested to the reporter from *Lingua Franca*, of describing my work as conceptual art or performance art ... But if I did I suspect the response would be to change the rules to include art projects. (2004: 415–16)

Becker goes on to point out that some of his research on medical students, for example, could not have been conducted with the same academic rigour under the new IRB rules. His final recommendation to social scientists is: 'Start fighting this thing full time and don't give up an inch we don't have to' (2004: 416). Increasingly, UK research ethics committees are taking on the function of IRBs (see Richardson, 2007; and see Flynn, 2000, on the cost of REC review).

Research ethics committees and North American IRBs may inadvertently block the aspirations of researchers who want to dig deeper, as it were. Moreover, in their capacity to monitor and approve research, IRBs can become a sort of 'university research police' that controls the production of knowledge. Given that IRBs are a relatively new institutional invention, it remains to be seen how they will evolve to fulfil their mission.

TIP

One way of cutting through the jargon used in research governance is simply to ask yourself: what might my research question mean to possible participants? What will they be confronted with if they agree to participate? As an exercise, think about the experience of being interviewed about your future if you have early-stage dementia, or what it may be like for a homeless person to be asked about their earlier family life (Flick, 2007: 71). Although Flick's idea will help your application, you do need to be aware of the time it can take to get ethical approval, and so you need to start seeking approvals in good time.

10.7 Conclusion: Managing Unfolding Ethical Demands

The challenge for student researchers is to package the open-ended contingencies of qualitative research in a way that convinces your supervisor and any organization that you are studying that no risk is involved. Survey researchers have an easier job with this because the survey questions are designed in advance and clearly demarcate the boundaries of the project. In contrast, qualitative research moves in unpredicted directions; an informant's answers to a question may result in a line of inquiry that was not planned from

the start. In the example below, Michelle Miller-Day offers advice for overcoming this sort of challenge.

STUDENT EXAMPLES

Planned Flexibility

The biggest problem for qualitative researchers, as I see it, is that in our data collection we have to be flexible and attuned to 'emergent data'. While qualitative researchers can dance to our particular rendition of flexible and emergent, lawyers and some quantitative researchers find this rendition lacking in rhythm (structure) and believe it is chaotic (not systematic). We need to provide structure and a systematic *outline* of what is planned and give possible outcomes of 'planned flexibility'. The phrase 'planned flexibility' is one way of handling ethical issues in qualitative research proposals. It may not be enough to inform your supervisor that you are doing qualitative research and therefore are not sure about the type of questions asked, where, and how. This applies even more to the organization you want to study. They just won't understand and agree with that line of reasoning. Instead to the best of your ability, give an outline of what shape or direction your research might take. In other words, give them something they can work with within the parameters of their institutional roles. [Michelle Miller-Day, USA]

Some research projects have to be considerably modified due to ethical constraints. For example, Michael Arter states about his PhD on a US police force:

> In the earliest planning for my research I had considered interviewing the spouses of the officers for the familial aspect of police stress. Based upon past decisions of the IRB at my institution, the plan to attempt to interview anyone other than police officers was abandoned. [Michael Arter]

Other researchers go through such a complicated ethical approval process that the experience itself becomes part of the dissertation. This was certainly the case with Sylvia Ansay, who encountered particularly stringent demands in her research on US citizens under house arrest.

STUDENT EXAMPLES

Which Organization is Doing the 'Governance'?

I experienced a major hurdle that seemed to come out of nowhere. I had worked closely with the IRB administrator in writing my proposal. She assured me that we had covered all our bases and there appeared to be no problems. Approval should be automatic, she said, just a matter of waiting a couple of weeks until the board met. The process became complicated when the IRB decided that, although I was not receiving funding from the National Institute of Health (NIH), I should have NIH approval for the project. The board didn't give me any reasons for the decision; however, I filed the proposal with NIH as they required. An administrator at NIH telephoned me, surprised at the request because I was not seeking funding from them. I had no answers for her.

She ended the conversation by saying the requirement raised 'red flags' which they'd have to check out. That was the first of three or four phone calls between us. (I instigated two of these in response to letters from the administrator.) The first criticized the methodology, saying they had never heard of using life stories or narrative analysis as research. It wasn't 'good science', she said. Later, I had to explain and defend every aspect of the research point by point. In the end, their argument against approval shifted to a concern with my personal safety. They requested a conference call with my professor, during which an NIH attorney urged him not to support the in-home interviews, to consider the liability. When he could not be persuaded, they approved the project with a disclaimer that approval would not have been given if I had been applying for NIH funding. My experience with NIH became a chapter of my dissertation and has been published in *Studies in Symbolic Interaction* (Vol. 25). [Sylvia Ansay, USA]

The IRB committee in this case seems to have been overly protective of Sylvia and her research participants. Though she eventually secured approval for her project, it is evident that her research would have been completely stymied without the support of her dissertation chair. This sort of overprotection is especially noticeable where 'sensitive topics' or 'deviant populations' are concerned. Consider, for example, Sara Crawley's description of the IRB mandates for her research with lesbians.

STUDENT EXAMPLES

Governance Bodies Unhappy with Research on Minorities

I did have to take some pains to make the IRB comfortable with the group I was interviewing. Given that I wanted to interview 'lesbians!', the IRB was more worried about protecting confidentiality than most of my narrators. Although I was careful to respect narrators, I found most participants were very willing and expected that they might talk about lesbian experience in the lesbian groups they normally attended to talk about lesbian experience. Ironically, for me, getting IRB approval was more about making the IRB comfortable about issues that the naturally occurring community was already comfortable discussing. [Sara Crawley, USA]

In Sara's case the IRB approval seemed to hinge around the board's comfort level with lesbians and talk of lesbianism rather than the community members' ease about discussing their lifestyles. In a related case, Eileen O'Brien, in her study of anti-racists, found that the research participants wanted to be identified by name in the research despite the IRB requirements for anonymity.

STUDENT EXAMPLES

Breaking Confidentiality?

I was dealing with an area of activists who are pretty silenced/ignored in history – white anti-racists – and some people felt that this neglect was very calculated because it prevents whites

(Continued)

(Continued)

from having visible alternative models of whiteness to follow, thereby subverting any major transformations of the dominant group in society. So I asked my advisor about it, and he said as long as I had it documented that they gave me permission to use their real names, he didn't think it would be a problem. But this issue never actually went back to IRB. I think this illustrates how qualitative research needs to be adaptable, and that following 'standard protocol' will not always work best depending on the topic and context of the data you need to obtain. [Eileen O'Brien, USA]

I conclude with Eileen O'Brien's experience because it demonstrates once again that what she calls the 'standard protocol' may not always be entirely appropriate to a qualitative research study. Indeed, thoughtless rule following may blind you to unexpected ethical dilemmas. In this context, Table 10.2 gives a jargon-free list of questions to ask yourself when you pursue informed consent.

TABLE 10.2 Ethical questions for researchers

- What am I expecting participants to do?
- How will I explain my research questions to participants?
- What will happen to my data (e.g. who will see any transcripts or recordings?)
- Where will I store my data?
- How can I ensure confidentiality and anonymity?
- How can I try to make my study harm-free?
- What are the communication barriers between me and my participants (e.g. culture, age, gender, impairments?)
- Have I satisfied my accountability to my university, my supervisor, my participants, any gatekeepers and the wider research community?

Source: adapted from Churchill and Sanders, 2007: 48–52

KEY POINTS

While these may vary across disciplines and national boundaries, there are a number of general principles that most researchers would agree with. Most prominent among these are:

- **voluntary participation**
- **protection of research participants**
- **assessment of potential benefits and risks to participants**
- **obtaining informed consent.**

However, good ethical practice means that one should think through the appropriateness of each ethical principle to the precise context of one's research.

Further Reading

Israel and Hay's *Research Ethics for Social Scientists* (Sage, 2006) is a valuable textbook on research ethics. Judith Green and Nicki Thorogood's *Qualitative Methods for Health Research* (Sage, 2004) provides an excellent chapter-length account of ethical issues in health research. Anne Ryen's chapter 'Ethical issues' (in Seale et al. (eds), *Qualitative Research Practice*, Sage, 2004) is a key source which includes fascinating material on her ethnographic research in East Africa. For more details of some fascinating case studies, see Les Back's chapter 'Politics, research and understanding' (in Seale et al. (eds), *Qualitative Research Practice*, Sage, 2004, 261–75) and Catherine Riessman's chapter 'What's different about narrative inquiry? Cases, categories and contexts' (in Silverman (ed.), *Qualitative Research: Theory, Method and Practice*, third edition, Sage, 2011, 310–30). For a discussion of the ethics of interviews, consult Caroline Gatrell's 'Safeguarding subjects? A reflexive reappraisal of researcher accountability in qualitative interviews' (*Qualitative Research in Organizations and Management*, 2009, 4 (2), 110–22).

Exercise 10.1

Draw up an information sheet for participants in your research. Now consider whether you have succeeded in the following:

- providing a clear and truthful account of your research
- avoiding jargon
- avoiding potentially sensitive terms.

Refer to:

Feminism & Psychology, Vol. 17, No. 2, 149–61 (2007). DOI 10.1177/0959353507076547. 'Feminist research practice: using conversation analysis to explore the researcher's interaction with participants'. Estefania Guimaraes. fap.sagepub.com/cgi/content/abstract/17/2/149.abstract

Based on her own PhD research on sexual abuse in Brazil, Estefania Guimaraes shows how ethical issues enter into the nitty-gritty activity of collecting data.

Exercise 10.2

Earlier in this chapter, I listed some features of good ethical practice:

- voluntary participation and the right to withdraw
- protection of research participants

(Continued)

(Continued)

- assessment of potential benefits and risks to participants
- obtaining informed consent
- not doing harm.

Assess your research proposal in terms of each of these rules. Now consider if there are any circumstances in which you might need to bend any of these rules. Refer to:

Qualitative Inquiry, Vol. 12, No. 3, 541–61 (2006). DOI 10.1177/1077800405282801. abstract. 'Between overt and covert research: concealment and disclosure in an ethnographic study of commercial hospitality'. Peter Lugosi, Bournemouth University, Dorset, UK. qix.sagepub.com/cgi/reprint/12/3/541.

Peter Lugosi's paper addresses the issues of concealment and context in a different research setting.