

# FOUR

## Ethics and Research Governance

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

- know what research ethics and research governance ethical guidelines are;
- see how ethical issues affect the design and execution of research projects;
- understand the principles of informed consent and anonymity;
- recognise professional standards and what research misconduct is;
- know how to apply for formal ethical approval.

### Introduction

This chapter will begin by describing what ethics and research governance are. The chapter will then discuss ethical considerations arising from the relationship between the researcher and the research participants. In particular it will focus upon the two main cornerstones of modern research ethics: informed consent and anonymity, including a discussion of when and if, research can be conducted without either of these and yet still remain ethical.

The chapter will then cover professional integrity including research misconduct. It will discuss the importance of researcher independence and potential conflicts of interest between researchers and project funders and also includes a section on intellectual property. Finally this chapter will present a discussion on formal procedures such as ethics committee approval, and there will be directions on how to find more specific guidelines for different types of research.

### Ethics and Research Governance

Ethics in practitioner research are the moral principles that guide activity from inception to completion (including the publication of results). Research governance,

conversely, is a code of practice that is applicable if you are conducting research in the field of health and social care. The regulations concern ethics, science, information, health and safety, finance and quality. This chapter is primarily concerned with the framework's position on ethics. The framework's section on ethics covers a lot of the same ground as ethics generally and therefore this chapter discusses the two areas largely as one subject. It is worth remembering that, although all research must adhere to general ethical guidelines, not all research must adhere to the ethical standards of research governance. In spite of this, research governance ethical guidelines will be useful to practitioner-researchers in any field.

It is worthwhile, at this early stage in the chapter, to make it clear which types of research are covered by research governance. Fortunately, it is a relatively simple distinction, although if you are uncertain, there is lots of information available, for example on the Department of Health's website (<http://www.dh.gov.uk>), that will clarify whether or not your proposed research falls under its remit and if so whether you need to apply for NHS ethical approval.

In summary, if you are conducting research that includes any of the following then you must adhere to the principles of research governance:

- patients or users of the NHS and anyone who is recruited to the research by virtue of their current or past treatment by or use of the NHS;
- anyone who is a carer or relative of those defined as a patient or user;
- NHS staff participating in the research by virtue of their professional role;
- any research on NHS property.

Ethics originate from a branch of philosophy that was developed by the Ancient Greek philosophers, Socrates and Aristotle. The Greeks saw connections between conducting oneself in the correct manner or 'doing the right thing' and achieving what they considered to be the most desirable outcome of all, human happiness. As such, it follows that the principle concern of modern research ethics is human happiness and well-being. Thus, it is important that all researchers take steps to ensure that their research does not cause unhappiness to any of its participants. Furthermore, the researcher must use a broad definition of what happiness is and consider not only how a project affects participants in terms of physical harm but also in terms of social and psychological well-being.

This is, of course, no simple task and there is no easy set of rules to follow. The new researcher soon finds that, in order to conduct research ethically, they must learn to think and reflect upon their project holistically and to see ethics as an integral part of the research, rather than as something that is tacked on at the end (Soobrayan, 2003). Indeed, researchers must weave ethics into the very design, fieldwork, analysis and dissemination of their work.

## **Informed Consent**

Informed consent is, essentially, a term made up of two parts. For the first part, research should always be conducted openly, honestly and participants should be aware of what taking part in the research entails. For the second, participation has to be voluntary and participants must give their consent to being involved in your project. These two parts, when combined, are, essentially, what is meant by the term 'informed consent'.

Before you begin any fieldwork, it is important that you obtain the informed consent of your research participants. In particular, there are six areas that you must consider and make arrangements for.

### **1. Participant Understanding of the Elements of the Research**

You must make it clear to research participants, at the outset of fieldwork, what their involvement entails. For example, if you are planning to conduct a focus group followed by one-to-one interviews with the same participants, you must inform them of this at the outset. It would be poor ethical practice to surprise them with news of the second part of the research half way through the focus group (although of course, there are times when the research design has to be adapted to changing circumstances). In addition and if possible, you should write down what is expected and give it to participants in the form of a 'participant consent' document to read and sign. Of course, some methods of research, such as online or postal questionnaires, make this type of informed consent impossible as there is no face-to-face interaction. In these circumstances, you should make it explicit what they are participating in with accompanying information in a clear and accessible language.

### **2. Participation Is Voluntary**

Research participants should be made aware of the fact that they can refuse or withdraw consent at any point and furthermore, that they do not have to give an explanation for their withdrawal. If a participant withdraws from the research, then you must ask if you can keep and use the data that you have already gathered or if their withdrawal signifies that you no longer have their consent for any part of the research. If the latter is the case, then you must respect the wishes of your research participant and destroy the data that you have collected. Although, of course, it is unfortunately possible that you will already have used the data and made the findings available. If this is the case, then the ethical thing to do is to inform your research participant of this situation. On other occasions, you may come across examples of partial consent, for example, if you are conducting research with carers of very ill spouses or partners, research participants may feel

that subject areas such as personal care or sexual relations are too personal to share with a researcher, but are happy to talk about issues such as transport or home adaptations. Some might agree to be interviewed but do not wish the interview to be recorded. Experienced researchers have all switched off the recorder at the end of an interview, only for the participant to reveal interesting information, or else snippets are disclosed during the interview but as an aside 'off the record' or 'just between you and me'. In situations like these, you must always ask if that particular piece of information can be included in the research.

### **3. How Long the Research Will Take**

You must also ensure that you inform participants of the likely timescale of their participation. This maybe as simple as telling participants a date for their interview or how long a questionnaire will take to complete, noting that certain research participants, for example, some older people, may take longer to complete a questionnaire. Conversely, some projects require a more substantial commitment from participants, such as longitudinal studies or projects that need participants to complete diaries. In cases such as these, you must inform participants of the time period that this will entail. For a longitudinal study, there might be an expected date that you will return to conduct another interview or, for the completion of diaries, it might include how many days, weeks or months that they are expected to fill in the diary.

### **4. Participant Risks**

The potential risks to participants can be wide ranging and can include physical harm/discomfort as well as emotional distress or embarrassment caused by questioning on sensitive issues. Research that is conducted thoughtlessly can also damage a person's social standing, their privacy, their values and beliefs as well as their relationships with their family, community or employer, for example, if you are conducting research about the career aspirations of young British Pakistani women, it would be unethical to do this in front of family members who might hold traditional views and thus disapprove of their responses. Research governance ethical guidelines state that risks in research must always be proportional to the potential benefit of the research (Department of Health, 2005). Of course, when we consider non-clinical research of the type covered by this book, potential risks and benefits can be difficult to quantify. However, the researcher still needs to ensure that participants are subjected to minimum risk and one way of achieving this is to gain informed consent at the outset of the research.

### **5. How the Results Will Be Used**

It is important that participants are aware of how the findings will be used. For example, if you are planning to disseminate the results in a report that will be

published on the Internet, writing a summary document that is distributed to the local community or presenting the findings at a practitioner conference then you must ensure that each research participant is aware of this and gives full and informed consent. In addition, if you are planning on combining the results of this research with data from another project and using that information to form the basis of a third project, this is also something that you must gain informed consent for. Furthermore, you must disclose if you are going to discuss the individual's research responses with colleagues or if there are any other team members who will see non-anonymised data from the project.

## **6. Nature of Any Compensation or Incentive**

Some forms of research commonly use an incentive to encourage people to take part in the research. This is something that must be considered in relation to informed consent and participants must be told what they will receive and when they will receive it, before any fieldwork takes place.

### **Additional Considerations**

Informed consent is harder to achieve with some groups of people than others. For example, certain vulnerable groups, such as frail older people or people with learning difficulties, may lack the capacity to consent to research on their own. If this is the case, then consent must be sought from someone close to that person, a gatekeeper, who can make an independent assessment of the participant's interests. Research with children is a particularly sensitive area and you will need both the consent of the child and a parent or carer. Furthermore, when you are conducting interviews with groups such as these you must provide relevant material in an appropriate written or pictorial form so that they can understand what you are asking of them. Additionally, if you are planning to interview vulnerable adults or children, it is likely that you will need to have a Criminal Records Bureau (CRB) check to demonstrate that you do not have a history that would make you unsuitable for work involving these groups (see Box 4.1).

### **Box 4.1 Criminal Records Bureau checks**

The Criminal Records Bureau (CRB) is part of the UK Government's Home Office and provides information about criminal records for employers as well as some professional, licensing and regulatory bodies. It aims to ensure that anyone working with children or other vulnerable groups is suitable to do so. Therefore, for example, anyone planning to undertake face-to-face interviews with children must undergo a CRB

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check. The self-employed or individual researchers cannot apply to have a check conducted on themselves so you must arrange for either your employer or funder to apply for you.

There are two types of checks available, standard and enhanced. The former looks at criminal records and, if relevant, at information on the Protection of Children Act List, the Protection of Vulnerable Adults List and information held under the Education Act 2002. Enhanced checks are generally conducted on people who are in charge of children or vulnerable groups, such as teachers or scout leaders, and look at the same information as standard checks but also at relevant information held by the local police.

There is a fee for CRB checks and the process does need to be built into your research timetable. Fortunately though, it does not take an unreasonable period of time and the CRB aims to process 90% of standard checks within two weeks and 90% of enhanced checks within four weeks.

Further information and guidance on the application process is available on the CRB's website at <http://www.crb.gov.uk>.

Some forms of research extend over a period of time and, as such, consent becomes something that is ongoing. You may wish to develop a system of review, so that as the project progresses, you will still have the full and informed consent of your research participants. This might be achieved, for example, by asking participants to read and sign a shortened or adapted version of the participant consent form each time you ask them to take part in a new stage of the research.

Research in some communities may also require that any information regarding consent is translated into languages that can be understood by your research participants. If a participant is not able to read or understand the information, this information should still be provided in a written format as they may wish to consult with others before giving their consent. When conducting research, it is also important that you are fully prepared and aware of any cultural, ethnic or religious issues that you will need to consider when conducting fieldwork to ensure that you do not threaten or offend participants through ignorance or insensitivity.

Finally, you should take special care when conducting research over the Internet (for example when using comments gathered in chatrooms, weblogs or discussion boards, information submitted via email) as obtaining informed consent, security of data, negotiating a participant consent document and the boundary between the private and the public can all become problematic. Therefore, researchers who adopt this medium should spend some time familiarising themselves with the current ethical debates on Internet research before beginning any fieldwork (British Sociological Association, 2002).

An area that is related to informed consent is user involvement, which is the participation of representatives from your target research group in aspects of your work. Examples include conducting discussion groups to help formulate questionnaires or setting up a steering group with representatives whose skills and experience will help direct your research. This type of involvement is stipulated by research governance ethical guidelines and must be demonstrated to some funding bodies. For example, the Big Lottery research programme particularly looks for innovative ways of involving and empowering research participants.

This collaborative approach is also important in action research and there should be a transparent sharing of information between the participants and the researcher-practitioner. Of course, action research, although different from other methodologies, also requires the informed consent of all participants (Mockler, 2007: 95; see also Chapter 7 of this volume).

## **Covert Research**

The emphasis on informed consent in ethics is, of course, a reflection of current mores in our society and therefore research that is conducted without this type of consent is generally held in low esteem. However, covert research used to be a much more popular method than it is today and produced some of Social Science's most respected and famous research. For example, Erving Goffmans (1991) 'Asylums' (a study of life for people with mental health problems incarcerated in hospitals) and William Foote Whyte's (1993) 'Street Corner Society' (a study of an Italian slum in Boston) were both the result of covert research involving a considerable period of participant observation.

If you are thinking of adopting a covert approach, it would be wise to consider whether or not the information you wish to gather could be obtained by other means. The Economic and Social Research Council (ESRC) states:

Covert research may be undertaken when it may provide unique forms of evidence or where overt observation might alter the phenomenon being studied. The broad principle should be that covert research should not be undertaken lightly or routinely. It is only justified if important issues are being addressed and if matters of social significance which cannot be uncovered in other ways are likely to be discovered. (ESRC, 2005)

Therefore, covert research should only be undertaken after all other methodologies have been explored and found to be inadequate.

## **Anonymity**

It is usually a requirement of research ethics that the identity of individuals (and sometimes groups or organisations) who have participated in research is not revealed.

As such, no research material, in any shape or form, should be published or disseminated that makes participants, actually or potentially, identifiable without their consent, nor should research data be shared with colleagues unless it is anonymised. It is helpful to distinguish between anonymity and confidentiality, as the two terms are often used interchangeably although they do have separate and discrete meanings. Anonymity refers to hiding the identity of the person who provides information, although the information itself can be disclosed. Confidentiality, in contrast, means that the information itself cannot be revealed. Therefore, anonymity is more likely to come up as an issue when conducting research. The principles of anonymity apply across all media, whether you are writing a report, giving an oral presentation or placing a summary on a web page. You should remember that ensuring anonymity quite often depends upon context and what is already known by the audience. For example, if you are conducting research with excluded pupils in schools, you should not disseminate the findings back to teachers (in a way that reveals the school involved) as they are likely to be able to identify the pupils who took part in the research.

Another potential threat to anonymity occurs when reporting on small groups within your sample as this can easily lead to identification of participants. For example, if you are conducting research in a workplace that largely employs men and only a handful of women, reporting on findings from the women and men separately would make it relatively easy to trace particular responses back to the women who had made them.

Ensuring the anonymity of research participants is a legal requirement stipulated in the Data Protection Act 1998 (DPA), which protects the rights of individuals in respect of data held about them. The DPA came about as a result of growing concerns about how new technologies could store information on individuals and how this could be used (although the range of the DPA is not limited to electronic methods). The DPA has a major influence on the conduct of ethical research as it is now a legal requirement to either comply with the DPA or else anonymise data to the degree that it is impossible to reconstruct an individual's identity from the information held.

Complying with the DPA is not as daunting as it may sound and its main principles are largely covered by the ethics of informed consent. However, it is worth specifically mentioning the seventh principle of the DPA that states that you must ensure that any non-anonymised data that you store is completely secure and not accessible by others. For example, paper copies of documents or audio recordings should be kept in locked cabinets and electronic data should be stored on password protected files. If you transfer data from one place to another, for example from your computer at work to a computer at home on a mobile device (such as a USB memory stick) you should make sure that the data is encrypted so that no-one else will be able to read your files. Box 4.2 gives a brief summary of the Act, although you may wish to investigate further. Specifically, many universities have useful web pages devoted to how the DPA affects research, which

you can easily find through an Internet search engine by, for example, searching 'DPA anonymity'.

## Box 4.2 Data Protection Act 1998

All organisations that hold personal data about people must comply with the Data Protection Act (DPA). The DPA covers how information about living and identifiable people is used and is intended to protect the rights and privacy of people and to ensure that any data held about them is only processed with their knowledge and consent. The DPA places obligations on those who process personal information in the form of eight principles.

The data must be:

- (1) fairly and lawfully processed (the participant knows how and by whom their data will be used);
- (2) processed for one specified purpose (for example, research);
- (3) adequate, relevant and not excessive for the specified purpose;
- (4) accurate and up to date;
- (5) not kept longer than necessary;
- (6) processed in accordance with the individual's rights;
- (7) secure, that is, manual data should be kept in a locked facility and computer files should be password protected;
- (8) not transferred to countries outside of the European Economic area unless that country has adequate protection for the individual.

In addition, Section 7 of the DPA gives an individual the right to be informed by someone using personal data about him or her including what data is held, the purposes for which it is held and the people to whom it may be disclosed.

There are a number of exemptions to the DPA when data is collected for research purposes, although the exemptions are a complex legal area. Generally speaking, data that is gathered for research is exempt from the second and fifth data protection principles. Therefore, your data can be processed for purposes other than those for which it was originally obtained and can be kept indefinitely. However, this is only the case if the data is not processed and used to support measures or decisions that affect individuals or cause damage or distress to an individual. Therefore, it is possible for researchers to keep data, questionnaires and interviews transcripts and revisit this information when working on similar research in the future. It is important to remember, however, that this is not a blanket exemption from the DPA and most of the data protection principles still apply. It is also good ethical practice to consider the legal issues every time research data is collected and processed.

If you do not comply with the DPA, for example by passing on your data to third parties without the consent of your research participants or by storing data in a non-password protected computer file or network, you are legally obliged to anonymise your data, preferably as soon as possible after collection and before any analysis is undertaken. In addition to removing all direct identifiers such as names, addresses or similar personal information, you may wish to go further and remove indirect identifiers, such as places of work and geographical location.

Anonymising qualitative data is more complex than anonymising quantitative data. If you remove identifiers, it may result in a distortion of the data and so you may want to consider the replacement of identifiers with pseudonyms. If you do use pseudonyms, though, do take care to choose ones that are not culturally or ethnically sensitive and as such minimise the possibility of causing distress to your research participants. Another option would be to replace names with letters or numbers. How you choose to anonymise your data should be discussed with your participants and they should be informed that the process of anonymisation could result in a measure of distortion being introduced. Unfortunately, it is possible that a researcher may come across information that means that you must override the pledge of anonymity given to participants. This might include uncovering abuse of vulnerable people such as children or discovering other criminal or immoral activity.

Also, some types of research lend themselves well to a non-anonymised approach. In particular, oral historians and especially those studying groups that have been historically marginalised, argue that anonymising the identity of participants may actually go against the wishes of the participants themselves. When oral history became popular in the 1970s many historians argued that giving a voice to certain groups, such as racial minorities, women or people in poverty, gave them a place in history that they had previously been denied. Furthermore, their involvement in the research process restored dignity and self-confidence. As such, oral historians generally give participants the opportunity to state whether or not they are willing to have their identities revealed. This approach was adopted by Anne Grinyer, who conducted research with the families of young adults diagnosed with cancer. She felt that the use of pseudonyms might not be appropriate when the young adult had died, as they might now be doubly 'lost' as a result of the research not referring to them by their real name. Grinyer asked her participant families if they wanted anonymity but only a quarter responded that they did (Grinyer, 2002).

However, given that anonymity is now seen as an integral part of ethical research and is the usual and expected way of conducting research, if you are thinking of adopting a different approach it would be sensible to consider carefully whether the research and/or the participants will actually benefit if anonymity is waived. Additionally, permission to reveal identity must always be sought from the research participants and preferably, at the beginning of the project, so that participants are aware that all they are saying can be traced back to

them as individuals. Of course, if participants decide to ‘opt in’ to revealing their identity half way through the project, this too is acceptable. However, the researcher has certain responsibilities and it has also been suggested that people who give their consent to having their identities revealed do not necessarily fully understand the impact that this will have on their lives once their words and ideas are placed into the public arena (Janovicek, 2006). Therefore, it is very important that you gain informed consent from participants and discuss the likely effects that the waiving of anonymity could have on participants before the research begins. However, it is worth emphasising once more that the identification of participants is unusual in modern research.

### **Professional Integrity and Quality**

It is important, that as well as conducting yourself ethically throughout your research project you also adhere to certain professional standards. Of course, mistakes and errors are, to some degree, inevitable. However, it is important to minimise the risk of error in your research and conduct yourself honestly and professionally. Examples of unprofessional research activity, or research misconduct, are:

- The fabrication or the invention of data, such as filling in additional questionnaires to ‘make up the numbers’ or inventing data with particular ‘desirable’ responses.
- The falsification of data through distortion or misrepresentation such as rejecting ‘undesirable’ results or misrepresenting the findings of other researchers to ‘fit in’ with your own findings.
- Plagiarism, the unattributed copying of other people’s work (see Box 4.3 on intellectual property).
- Deception, which is the failure to declare a conflict of personal interest or giving misleading statements when applying for research funding.
- Non-compliance, which is the wilful failure to comply with statutory obligations concerning the use of human subjects.
- Facilitating misconduct by collusion or concealment which is failing to challenge or deliberately ignoring unethical research practices among colleagues or students. (Sheffield Hallam University, 2004).

#### **Box 4.3 Intellectual property**

Intellectual property (IP) is the name given to different types of knowledge including ideas, tunes, blueprints or databases. It is both similar and dissimilar to property. It is similar in that it can be valuable, although it may be that you have to invest money and time into its development in order to realise that value. It is dissimilar in that, when a person trespasses in a house and steals items, if they are

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caught and made to return the items, that is the end of the matter. However, if someone hears a tune, then they will always know that tune and no matter how many sanctions are applied, that tune can never be reclaimed in the way that stolen property can (Doctorow, 2008).

IP can apply to research in a number of ways. For example, if you develop a research proposal and submit it to an authority such as a council or charity and they do not fund your research but take your ideas and carry out the research themselves, then they are using your IP. However, if, conversely, you have a funder for your research that helped to develop the research questions, then the issues involved may be different. Indeed, that funder may have some claim to the IP rights of the research. In order to clarify such issues, it is worthwhile establishing who owns which ideas or outputs before the research begins.

It is also worthwhile mentioning two other aspects of IP: plagiarism and copyright. Plagiarism comes from the Latin word for 'kidnapper' and means using the ideas or words of others without acknowledging the source and/or passing them off as your own. Copyright is less concerned with the referencing of work and more to do with its actual use. If you use too much of another's original work, or distribute it too widely, even if the source is properly acknowledged, this may be a copyright infringement. Copyright law is complicated but generally, whoever writes an article or book owns the copyright to it (journal articles are an exception although practice is changing and some publications now only require a licence to reproduce). Copyright also extends to photographs, diagrams and pictures so you must always get permission from the author before you reproduce.

To conduct research professionally it is necessary to begin with an open mind, to not bring your own personal or political agenda to work and to be impartial. If you are undertaking the research with the aim of finding particular 'results', not only do you run the risk of being disappointed, you are also in danger of biasing your research by trying to make your research 'fit' in with what you already hold to be true. Of course, you cannot 'switch off' your personality when conducting fieldwork or analysing results but by recognising your own beliefs and experiences and how they could impact upon your research, you are going a long way towards conducting yourself both ethically and professionally.

Research misconduct can also creep into a project due to pressure from others who have a vested interest in promoting particular outcomes and downplaying others. Political interference can be very difficult to deal with, especially if it comes from an individual or body who has some form of power over you, such as your employer or the funder of the research. The researcher is left in the

quandary of trying to please the other party and yet struggling to fulfil the ethical requirements of the research. This type of pressure can take a number of shapes and forms and might include being asked to interpret results in a particular way that distorts the data or being asked to use other (more politically acceptable) research findings and calling them your own. Action researchers are particularly vulnerable to this sort of difficulty as the boundaries between researcher, participant and funder are often blurred (see Chapter 7 of this book). To minimise the possibility of this sort of interference, you should at the outset of all research projects have open and honest discussions with interested parties about what they wish to achieve from the research. This will enable you to marry the sometime conflicting needs and expectations of third parties with your ethical and professional considerations.

Researchers may also find themselves under pressure to relax the ethics around informed consent and anonymity and once again, interference of this sort should be resisted. It is not unknown, for example, to be put under pressure to reveal the identity of particular participants, so that a third party can 'intervene' and improve things for the research participant concerned. For example, if you are conducting research about employees and discover instances of bullying in the workplace, a manager may wish to know who has reported this, so they can 'solve' the situation for the participant. However, in such a situation, this would not be ethical and the researcher should relay the request to the participant, explaining the consequences of waiving their anonymity. Under no circumstances should identities be revealed without the express permission of the research participant.

Researchers also have responsibilities towards those that are funding their research. Not only must they not accept conditions that may run contrary to professional integrity, they also have a responsibility to deal honestly with funders of research or other interested third parties. This might include being truthful about the advantages or disadvantages of different methodologies and approaches to the research and also being honest about the progress and development of the project.

## **Formal Procedures: Applying for Ethical Approval**

Before you begin your research, you must consider whether you need to obtain approval from an ethics committee to conduct your research. You will not need to apply for approval on all projects, however, you should always check with the relevant authorities that this is the case as rules and procedures will vary from organisation to organisation.

Which particular ethical committee(s) you apply to is dependent both upon what type of project you are doing and your place of employment. All ethical approval submissions require that you complete a form and provide enough information to demonstrate that you have thought about and then made appropriate

arrangements to ensure that your project is conducted ethically. Obtaining ethical approval can be a lengthy process and depending on which body you apply to, and whether or not you are granted immediate approval, it can take a substantial period of time from weeks to months. This time frame is something that you need to build into the design of your project and you need to be prepared to wait for approval before you begin any fieldwork.

As discussed earlier, certain categories of research are covered by the research governance code of practice and as such you must apply for ethical approval through the National Research Ethics Service (NRES). The exact nature and form of this application depends on a number of contextual variables and furthermore, the process is also subject to regular change. It is a complicated process and there are a number of interested parties that you must obtain permission from before you can proceed with your research. The interested parties might include the site where the research is taking place (for example, a hospital), the sponsor (possibly the funder of the research or your employer) as well as the regional NHS ethics committee.

However, a new single streamlined online system was introduced in January 2008. This system enables you to enter the information at the Integrated Research Application System (IRAS), and collates the information submitted by researchers and sends the appropriate forms to the appropriate regulatory bodies. The website is open to anyone seeking ethical approval for a research project, and has extensive advice and guidance to help you through the process. The IRAS form can be found on the NRES website (<http://www.nresform.org.uk>).

Practitioner-researchers should always personally approach the site's research and development's office or representative before undertaking the application process. Otherwise you risk going through the process of application, which generally takes from three to six months, only to be turned down by the site at the last hurdle. While NHS ethical committees are legally bound to process applications within a certain timeframe, site research and development offices are not bound by the same rules, and some are slower than others. Therefore, it might be wise to ask colleagues about their experiences and build this into your timetable.

If your research does not need NHS ethical approval, the process of seeking ethical approval is generally a lot easier. If you work in a large organisation, such as a town or city council department for housing, education, social services or similar, there will almost certainly be established procedures for ethical scrutiny and a few simple enquiries should guide you to the appropriate authority. Similarly, most universities have established ethics committees of their own to which employees can submit their research proposals for ethical scrutiny. Within each university there are usually a number of research ethics committees that cover different subject areas. If you work in a smaller organisation that does not have established procedures for ethical scrutiny, you may wish to consider whether there is a similar procedure that you will have to go through.

If there is no particular procedure that you must go through to ensure that your project is conducted in an ethical manner, then you may consider contacting a local university to see if their relevant ethical committee would look at your research with an ‘ethical eye’.

The ESRC’s ‘Research Ethics Framework’ states that:

although it is expected that a research organisation will establish its own REC (Research Ethics Committee) or RECs to review research, smaller institutions or those that do not conduct a substantial number of studies involving human participants may make arrangements to secure ethical review in another institution. (ESRC, 2005)

Less formally, you could make contact with individual researchers in your field, either from universities or other organisations, to see if they would run their eye over your project. Of course, if you do not seek official ethical approval, it is still good practice to conduct your project in an ethical and professional manner.

Box 4.4 presents a list of questions that should give you a flavour of the sorts of issues you need to consider when completing your ethical approval form. These questions are a useful starting point for ensuring that ethics are woven into the design of your research project and will be helpful even if you do not need to officially apply for ethical approval.

### **Box 4.4 Questions to consider for ethical approval**

#### **General issues**

- What is the main research question?
- What methods are you adopting?
- How will you report and disseminate the findings?
- Who will benefit from the research? In what ways?
- Are there likely to be any conflicts of interest as a result of you conducting this research?
- Are there any risks to the researchers themselves? (You may be required to carry out a risk assessment.)

#### **Research participants**

- How will you sample or recruit your participants?
- How will you brief them and gain their informed consent both at the outset of the project and as the research progresses or develops? This should include copies of any documents that they will receive and written consent forms.
- Are there any possible negative consequences of participation in the research? What are these possible negative consequences and how will you limit this?

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- For how long will each participant be asked to take part in the research?
- Will the participants benefit from taking part in the research? If yes, in what ways?
- How will the participants be made aware that their participation is voluntary?
- How will the participants be made aware that they can withdraw from the research at any time?
- Does your research involve sensitive issues? If so, how will you ensure that participants are not harmed by the research?
- Does your research involve participants who are prisoners or young offenders?
- Does your research involve work with children or other vulnerable members of society, who are unable to give informed consent?
- If yes, have you undergone Criminal Records Bureau screening?
- What are the arrangements for debriefing the participants? Will you inform participants of the findings?

### **Anonymity**

- How will you ensure participant anonymity?
- Does the research involve the cooperation of a gatekeeper for initial access to research participants? How will you ensure that participant anonymity is respected with regard to the involvement of this gatekeeper?
- Will the research data be available outside of the research team?
- How will you store the research data? What procedures will you use to ensure security?
- Will the data be anonymised?
- For how long will you store the data?

Obtaining ethical approval is not always straightforward and you may be turned down when your first apply. Although this might seem like a frustrating delay, it is something that you will need to accommodate if you wish to proceed with your research. Often the board will suggest changes for you to make that can be quite easily worked into the project. If this is the case, you can quickly make the changes to your research design and resubmit your ethics approval form. On other occasions, the board will require that you make more substantial changes in order to meet the standards required. Then it is possible that you will need to rethink your whole approach to the research.

Of course, ethics committees are not infallible or necessarily always right. If you believe that the committee has made a mistake then you may wish to appeal and persevere with your original approach. Other researchers before you have successfully disputed the rulings of ethics committees and been able to conduct their research in the way that they had originally proposed. For example, Cummins' (2006) proposed research revolved around one-to-one interviews with children

and the ethics board, in its concern to protect the children involved, requested that she had a neutral third party present during her interviews. This was problematic for Cummins as she did not know who this third person could be and whether they would respect the anonymity of the research participants. Cummins appealed and argued that the original make-up of the ethics board had been inappropriate as it did not include a sociologist, and therefore, she argued, no one on the committee fully understood what she was proposing. Her appeal was successful and she was given permission to conduct the research as she had originally intended, although the whole process had taken a year from start to finish.

## Conclusion

This chapter has introduced research ethics and research governance to the reader and should have equipped you with the knowledge to place ethics at the centre of your practitioner-research project. Specifically, you should now have a detailed understanding of how informed consent and anonymity need to be built into your project at the design and proposal stage. You should also appreciate how ethics are integral to the professional standards that are expected of the practitioner-researcher and how to avoid some of the ethical problems that can arise as you try to maintain professional integrity. This chapter has also supplied guidance on obtaining ethical permission for your project and given details about which authorities you will need to approach for different types of project, including advice on how to apply, the sorts of questions you will be asked and where to find further information.

## Acknowledgement

The author would like to thank Dr Peter Allmark for his advice on research governance.

### Further Reading

British Sociological Association (2002) *Statement of Ethical Practice for the British Sociological Association*. Available at: <http://www.britisoc.co.uk/equality/Statement+Ethical+Practice.htm> (accessed 2 December 2009)

Although an old publication, it still contains very useful information, but does have a particular slant towards the Sociological Association.

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Campbell, A. and Groundwater-Smith, S. (2007) *An Ethical Approach to Practitioner Research*. London: Routledge.

This is an international collection of essays on the ethics of practitioner-researcher. It is not a 'how to' guide, but interesting and thought-provoking nonetheless.

The Data Protection Act 1998

This document contains everything you need to know about the Act, but is not easy going. More accessible information can be found by searching the Internet for university websites that have information pages about the Act that are very specific to research.

Department of Health (2005) *Research Governance Framework for Health and Social Care*, 2nd edn. London: Department of Health.

The research framework document has a very helpful section on ethics as well as the other areas covered by research governance guidelines. It is also useful in terms of deciphering the layers of responsibility involved in a health and social care research project. Again, you may find it helpful to look at university websites, many of which have very clear information about research governance. In particular, those universities with a strong tradition of medical research are particularly good at providing information.

Economic and Social Research Council (2005) *Research Ethics Framework*. Available at: [http://www.esrc.ac.uk/ESRCInfoCentre/Images/ESRC\\_Re\\_Ethics\\_Frame\\_tcm6-11291.pdf](http://www.esrc.ac.uk/ESRCInfoCentre/Images/ESRC_Re_Ethics_Frame_tcm6-11291.pdf) (accessed 2 December 2009).

This is an accessible and all round guide to research ethics that is useful to the practitioner-researcher. The document is periodically reviewed after consultation with stakeholders; for the latest Framework readers are recommended to check the ESRC website (<http://www.esrc.ac.uk>).