

9

Ethics in Human Research

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The key to identifying ethical issues in research is to take the position of a participant. How would you feel if you were asked certain questions or observed doing certain things, or if your records and papers were examined for research purposes? How would you want researchers to handle and report on the information they have about you? The ethical issues involved in doing research on humans are very much the same for both quantitative and qualitative research.

Staff and students of Canadian universities, many research organizations, and members of professional organizations are now formally required to conduct their research according to stated ethical principles and to demonstrate this to **research ethics boards (REBs)**. Researchers must submit their research proposal or plans to advisory bodies, which evaluate it based on ethical guidelines. These ethical principles require that participants in the research must be able to give informed consent to being part of the research, the identity of informants must be protected unless they give written permission to be identified in stored data and research reports, researchers must not coerce participants into participating or divulging information, and researchers must keep data for up to seven years (depending on the province) to protect themselves against charges of forging or falsifying data.

The purpose of this chapter is to outline major ethical considerations prior to conducting the data collection. This chapter provides information to students with regard to preparing their submissions to ethics review panels. It is a good idea to contact the board directly and obtain a copy of their guidelines and rules prior to submitting your proposal. This will help you to avoid unnecessary delays in launching your data collection, protect the integrity of the scientific research process, and likely strengthen your research results.

Some of you might be asking, “If ethics is so important, why are we discussing it in Chapter 9?” This is because although **ethics** considerations influence all aspects of the research process, we cannot fully assess ethical implications of any project until the research question has been finalized, the method of data collection identified, the variables or items to be measured are considered, and the population identified. Although ethics involves each of these areas, until these elements are addressed, an application to an ethical review board and approval by a review committee cannot be attained. In short, we must think about ethics throughout the research process, but we introduce it here so that it is not lost in the discussion and learning of new concepts.

The Ethics of Research

Research in the social sciences usually involves dealing with people, organizations, and groups. Unless you are dealing only with data that have already been collected, public records (such as census data), or public documents (such as newspaper articles), you will be asking people questions, observing their behaviour, or collecting other information about them. All our dealings with other people raise ethical issues. We are familiar with the ethical issues relating to our personal lives—issues of loyalty, honesty, and integrity, to name a few. Lately, businesses and corporations are beginning to ask questions about the ethics of economic life. So, too, we need to ask if there are ethical issues in research that need to be addressed.

As with many ethical issues in other areas of life, being thoughtful and considerate of the needs and feelings of others goes a long way towards guiding the researcher. How would you react if you were a participant or member of the group you intend to study? Would you respond well to the questions you intend to ask or the procedures you intend to employ?

Be considerate. You are asking people to do you a favour. You are appealing to their generosity to help you with your work. Not everyone will share your view of the importance of your research. This is true even if you are asking friends, family, or students you know. It is even more true if you are going into the community to do your research. You have a responsibility to the participants in your research to be considerate and not to waste their time. Moreover, you have a responsibility to other researchers not to irritate and alienate the community. If you are inconsiderate or poorly prepared, you let yourself down, waste the time and effort of others, and jeopardize future research.

Part of being considerate is being prepared. Another part is to take up only as much time as is essential. Not only does an unnecessarily long questionnaire waste your time, but it also wastes the time of those to whom it is administered. Ask yourself, “Is this question necessary? Do I really need to know how many children the respondent has?” If the study is about sharing tasks between husband and wife, then yes, you probably do want to ask that question. But if you are inquiring about past achievement in math, you may decide to eliminate the question. Does each question really relate to the

hypothesis? Or does it really reflect personal curiosity? Interviews and questionnaires with a clear focus not only produce better data but are also less disruptive and wasteful.

You should also be considerate of participants because you are, to some extent, invading their **privacy**. If respondents sense that you are being intrusive or asking inappropriate questions, they may refuse to cooperate or may sabotage the research by giving misleading information. Your manner and the nature of your research should be carefully designed so as not to offend, embarrass, or annoy those you are studying. They are doing you a favour.

Part of being a considerate researcher is being careful about the way you seek permission from those you wish to study. While it is appropriate to tell people why you are doing the research, it is usually not wise to tell them what you hope to find, since this may bias the information they provide. At the completion of their projects, many researchers offer to tell participants what they found and their conclusions. This often provides interesting feedback for the researcher and those studied.

A consent form signed by you and/or your professor or head of department and the participant is a requirement for conducting most research with human participants. It will help to identify you, provide respondents with a contact if they have questions after the study, and is part of the process required to secure the cooperation of those you wish to be part of your study. The form should describe who you are (e.g., a student at a specified university), how you accessed the person's name, why you are doing your research (e.g., for a degree, a thesis, or a class project), and what the research will require from the person whose permission you are seeking (e.g., completing a questionnaire that will take 10 minutes, an interview lasting an hour, a group interview lasting 15 minutes, participating in an experiment that will involve watching and assessing some videos for half an hour). Providing this information makes it possible for the potential participant to make an informed decision about whether to participate. The consent form, or **plain language statement**, about the research is essential to ensuring that **informed consent** has been given.

A consent form usually concludes with information about what the participant should do if they have any questions or concerns about the research. This clause usually directs the participant to the research ethics board (REB) of the university or another organization responsible for the research, which is useful in situations where the participant does not feel comfortable discussing issues directly with the researcher. Figure 9.1 gives an example of a consent form. Preparing the form is also a good exercise to test whether you have thoroughly thought through your research plan. It will give your professor an opportunity to advise you about aspects of the research that remain unclear or confusing. When students do research as part of their course, their professor is responsible for them and for the conduct of the research. Therefore, it is in the interest of all for students and professors to confer carefully about each research project.

Printed on university letterhead

Consent Form: Title of Project

Principal Investigator: Professor's name

Student Investigator: Student's name

Tel: XXX-XXX-XXXX

Email: researcher@umanitoba.ca

Date

Funding organization or sponsor: Name of group providing financial support for this research (if any)

A. PURPOSE AND BACKGROUND

This project has been funded by *[indicate funding organization if the research is sponsored]*. The research is being conducted by *[indicate professor's and student's names]* at the Department of *[indicate name of department and faculty]*, *[indicate university]*.

In this research, we want to learn how people find work and whether they use their families and friends to find work. We are particularly interested in studying the work histories of youth without post-secondary education. We want to talk to you about your job experiences to better understand your feelings about Canadian society. A study of youth employment will help us to understand how it may affect you and your well-being, along with its effect on the Canadian economy.

You are invited to participate in this focus group meeting. However, the participation is strictly voluntary. Only if you agree to be part of this study will you be invited to participate in the meeting and answer the questions presented to you.

B. PROCEDURES

You have been selected to participate in this research because you have been identified as a youth without post-secondary school experience. There are two ways that we obtain names for our research. First, we may have obtained your name from a list provided by *[name of organization]*. Second, someone affiliated with *[name of organization]* may have suggested your name.

If you agree to participate in this research study, you will attend a group interview, which will last no longer than two hours, to discuss your experiences looking for work. The group interview will take place at *[indicate location of focus group, date, and time]*. The group meeting will be audio-taped if you permit us.

Continued

Figure 9.1 • Sample consent form

C. RISKS

There is no anticipated physical or psychological risk related to participating in this study. Should you decline to participate, your access to employment, settlement, and/or counselling services will not be affected in any way now or in the future. You may choose not to answer any questions and may leave the focus group at any time. Please indicate to the researcher any sensitive question related to your personal information that you do not want to be disclosed.

D. PROTECTION OF IDENTITY AND PRIVACY

Confidentiality will be secured in a variety of ways. Your name and contact information will not be recorded in the interview or used in the publication of any results. This form and any other documents bearing your name will be stored separately from your survey responses, which will be coded with an arbitrary number. When data collection is complete (not later than MM/YY), the list that links participants' numbers with their names will be destroyed, at which point it will be impossible for anyone, including the researcher, to identify data with specific participants. This anonymous data will be stored in paper form for up to 5 years post-publication of the results and for an indefinite period in electronic form. Results from this study will be disseminated through presentations at scholarly conferences and through publication in academic journals. At no time will individual responses be reported.

E. COMPENSATION

You will receive \$50 at the end of the group interview as compensation for participating in this research. We will also provide some light refreshments during the group meeting.

F. QUESTIONS

Please contact [*the professor, student*] (please refer to contact information at the top of this letter) if you have any questions about the project.

G. CONSENT¹

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights or release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The [name of REB] and a representative(s) of the University of [university name here] Research Quality Management / Assurance office may also require access to your research records for safety and quality assurance purposes.

If you have any questions about this research, feel free to phone or email me (see above). This research has been approved by the [name of REB] Research Ethics Board at [name of university]. If you have any concerns or complaints about this project you may contact the Human Ethics Secretariat at [phone number of REB secretary], or by email at [email address of REB].

Participant's signature

Date

Researcher's signature

Date

I am interested in obtaining a summary of the findings from this research project:

No ()

Yes (): If yes, how would you like to receive the results?

By email () Please provide email address: _____

By surface mail () Please provide mailing address:

¹This section is directly quoted from the University of Manitoba as is part of section D. 2010. *Human Subject Research Ethics Protocol Submissions (Ft. Garry Campus) Guidelines and Checklist for Submissions & Reviews*. http://umanitoba.ca/research/ors/ethics/human_ethics_REB_forms_guidelines.html

A personal card issued by your institution, stating your position (e.g., PhD student) and contact details is an effective introduction to participants (see Figure 9.2). When you give these cards to participants, they can feel more assured of your identity and purpose and confident that you are willing to allow them to verify who you are. This action, which shows prospective participants that you wish to act ethically and do the right thing by them, usually wins their attention and cooperation quickly. Further information, such as the contact information for the REB, can be placed on the reverse side of the card.



Figure 9.2 • A sample card

Formal Ethical Review of Research

Simply being considerate is not enough. The ethics of all research involving human participants has become a major area of discussion and policy review. Most professional associations, such as the Canadian Sociological Association and the Canadian Association of Social Workers, have devised codes of ethics to guide their members. Read the code of ethics for the professional association related to your intended occupation. These ethical codes are usually available online.

In 2010, the second edition of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2)* was passed by the Canadian Institutes of Health Research (CIHR), Social Sciences and Humanities Research Council of Canada (SSHRC), and the Natural Sciences and Engineering Research Council of Canada (NSERC), collectively known as the Interagency Panel on Research Ethics (PRE), the first major update of the original *TCPS* of 1998. Several changes were made to the *TCPS2* in 2014 (PRE, 2014). The purpose of the *TCPS* is “to create a uniform . . . ethics policy for research and a policy that would set the highest common standard for governing the academic or learned research done through these three primary funding agencies” (Kirby, 2007, p. 8). Under the new policy, any research that is funded by CIHR, NSERC, or SSHRC must adhere to these guidelines (*TCPS2*, 2014). As a result, universities in Canada, along with many professional organizations, have adopted these new regulations within their existing ethical framework. One of the conditions of obtaining ethical approval is that researchers (professors and students) must complete an online Course of Research Ethics (CORE) before their application to the REB may be considered. This course takes four to six hours to complete and reviews and tests prospective researchers about their knowledge of ethical research practices.

Following a number of excesses perpetrated by some overzealous or unscrupulous researchers in various fields, procedures have been instituted in

all post-secondary institutions for the careful ethical scrutiny of research proposals by REBs prior to the commencement of the research and before funding is approved or passed on to the researchers. First instituted to guide medical research, ethical review is now required for all research involving human participants. The fundamental principles are stated in the *TCPS2* (2014). This document outlines ethics for Canadian research involving humans. REBs use the principles in this statement to guide their consideration of research proposals. All universities now require all research involving humans, including most sociological, psychological, business management, marketing, science, education, and oral history research, to be evaluated by an ethics committee. This includes both funded and unfunded research. Ethical considerations are important and becoming more complicated as more professional organizations adopt their own ethical guidelines and as the provinces have introduced their own, which has added to confusion among researchers. The remainder of this chapter outlines some of the major ethical considerations and is guided primarily by the *TCPS2*. Students are encouraged to also consult the REB guidelines within their own institution, their professional association, and their provincial legislation on privacy and protection of information for details about ethical guidelines.

CASE STUDY

Some Examples of Unethical Research

Not so long ago, researchers paid very little attention to the health and well-being of participants of their research. Canada has a long history of conducting questionable and even criminal experiments against its people. Canada's Indigenous Peoples were subject to many cruel, violent, and downright criminal experiments. In the 1940s and 1950s, several research studies subjected Indigenous children and adults to various inhumane living conditions to conduct scientific and medical studies. In one study, Indigenous children living in Norway House, Cross Lake, God's Lake Mine, Rossville, and The Pas in northern Manitoba were intentionally starved to give scientists a chance to examine the effects of malnutrition on growth and development patterns (Mosby, 2013). In subsequent studies, Indigenous children living on reserves in British Columbia, Alberta, Ontario, and Nova Scotia were refused proper diet and supplements to replicate the Manitoba study (Livingstone & Weber, 2013). Historian Ian Mosby (2013), discovered that scientists, with the help of the Canadian government, had allowed children in several remote Manitoba reserves to starve because they were the "perfect test subjects," meaning that they were not given the opportunity to provide any consent to participating in the study and lacked the political power to question the ethics of the study in the first place, and that because of the racist attitudes held by most Canadians at the time, their poor

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living conditions would continue to go ignored. The scientists “rationalized” the unethical treatment by suggesting that the sacrifices of a few children would lead to significant benefits to the health of future children. Instead, their studies have become part of a massive catalogue of abuse, colonization, and genocide inflicted on Indigenous Peoples within Canada that were encouraged and supported by the Canadian government. In June 2015, the Truth and Reconciliation Commission of Canada (2015) released its long-awaited report on the effects of residential school system on the lives of Indigenous Peoples in Canada. Among its recommendations is recognition of the harm that has been done towards Indigenous Peoples.

The Stanford Prison Experiment, the Milgram Study, and the Tuskegee Study are other infamous examples of questionable ethical practices that students should learn more about. Lest students think ethical practices are less likely to be ignored today, however, the following recent examples shed light on the extent of this problem. Recently, medical ethicists have begun to question a widespread practice among industrialized nations to “offshore” clinical trials. By offshoring these studies, researchers do not have to abide by the more stringent ethical standards imposed on them by professional organizations and regulatory bodies in their own countries or jurisdictions. In 2008, more than 6400 clinical trials were being conducted outside the United States, where funding for these trials originated (Gonzales, 2010). In the 10-year period between 2000 and 2009, over 58,000 drug trials (Bartlett & Steele, 2010) were being conducted in overseas jurisdictions with lighter restrictions on ethical regulations. In countries with less rigid ethical guidelines, it is easier for researchers to conduct studies without requiring informed consent about the true nature of the study or potential risks to participants. An exposé by Bartlett and Steele revealed that many of the participants in such studies believed they were being treated for a disease and were unaware they were part of a clinical trial. Death is not an uncommon event in some of these trials. In New Delhi, in 2010, 49 babies died in a 30-month period during a trial of blood-pressure medication, while in a one-year period in 2008, seven babies died in Argentina after participating in a trial of a pneumonia vaccine. These are just two incidences of extreme abuse and ethical practices in recent medical trials. We must be vigilant in our research practices to ensure that future participants are not harmed by our research.

Basic Principles of Research Ethics

The following principles of research ethics summarize the concerns most REBs focus on in evaluating research proposals.

Principle 1: Researchers must treat with dignity and respect the persons, groups, and organizations who participate in their research

According to the *TCPS2* (2014) guidelines, these issues involve respect for persons, concern for social welfare, and social justice.

People have feelings, orientations, cultures, rights to privacy, and rights to control their lives and information about themselves. The rights of people are greater than the researcher's "need to know." However important you think your research is, you must place participants' well-being first. Sensitivity to others is very important but especially in social science research, where it is precisely that sensitivity that may open new insights into the nature of social situations. You are asking people, "What is it like to be you? What is your perspective on this? How do you respond to this or that situation?" In order to "hear" their responses, you need both to ask sensitive questions and to listen very sensitively to their responses.

Following current discussion of ethics in human research, we refer to people who consent to be researched as "participants," rather than "subjects," for several reasons. First, the term "participant" implies a degree of cooperative activity on the part of those we study. Participants are not passive subjects but cooperate with us in our research. It is important to remember that without the cooperation of participants, we will not get our data. This helps to remind us of our dependence on them and to enhance our respect for them. Remembering that you are dealing with people, not objects, will help you to retain the levels of respect and concern appropriate to humans.

"Participants" is also a useful term because it encompasses groups, corporations, organizations, and neighbourhoods as well as persons. All participants have rights, needs for privacy, and a claim on our respect.

The respect accorded to participants extends to treating the information they provide with great care and not violating their privacy. One way of protecting your informants is to mask their identity by never recording names, by changing the names on your files and using fictitious names in your reports, by assigning numerical codes, and by referring only to grouped data (that is, not to Tom Brown's score individually but to the average score of "young males" in response to a particular question). You can mask the locality of your research by not naming the municipality or organization in which the research was done.

If you are promising participants that you will protect their identities (which is the most common case), your REB will wish to know how you will accomplish this (e.g., de-identifying records and reports of information with codes, keeping records locked in a secure place, encrypting computer data files, etc.).

After gaining permission, you must retain sufficient information, including letters of invitation or recruitment, consent forms, and data, to prove that you actually did what you proposed to do and were given ethical clearance to do so. This is necessary to defend yourself against the possible charge of forging your data and to be prepared for an audit by your REB.

Personal information and privacy

In most social science research, there is no need to collect information that identifies individual participants. Researchers seldom need facts that can identify individual participants to others. However, if you plan to gather and publish such information, you must know the relevant law regarding privacy. Most provinces and territories have passed privacy legislation that binds researchers to protect

their participants' personal information. The *Canadian Charter of Rights and Freedoms* also has provisions protecting the privacy and rights of individuals. It is a good idea to become familiar with the privacy legislation in your province. The *TCPS2* also contains general guidelines about protecting individual privacy. Personal information includes information given to the researcher by the participant. It may be answers provided to survey questions or in interviews. It may be health information from physicians' records or academic grades from school. Regardless of the source, "personal information" identifies individuals and must be kept from public viewing at all times.

Depending on the relevant privacy principles, there can be additional restrictions on the collection, use, and disclosure of a type of personal information known as "sensitive information." Sensitive information may include information or an opinion about an individual's race, ethnicity, sexual orientation, criminal record, religious beliefs and affiliations, philosophical beliefs, health information, political opinions, and membership in political parties, trade unions, and professional associations. "Health information" is information or an opinion about an individual's health or disabilities, their health service usage or intended use, personal information they give to health services, and personal information they give when arranging the donation of their body parts.

Before gathering personal information, always consult an expert in privacy regulations. If you research within a government department or private firm, talk to the privacy officer. If you research as a consultant or with a volunteer organization, seek advice from a lawyer. Most universities have units that will provide advice to researchers about privacy laws. Be familiar with the privacy legislation of your province. Otherwise, you may compromise participants' rights and break the law.

The following list contains some guiding ethical principles researchers must abide by as they conduct their studies on human participants.

- **Respect for human dignity:** Researchers must maintain the physical, social, religious, familial, community, linguistic, and cultural integrity of all participants.
- **Respect for free and informed consent:** Participants must be fully informed about the purpose and intended results of the research project prior to signing a consent form. They must not be coerced into participating by any means. Consent, according to the *TCPS2* (2014), is an ongoing process (p. 7). Any changes to data collection protocols must be approved by REBs and participants must be informed and allowed to leave the study.
- **Respect for vulnerable persons:** The *TCPS2* (2014) reminds us that "some people may be incapable of exercising autonomy because of youth, cognitive impairment, other mental health issues or illness" (p. 6). Researchers must take special care in studying these participants. This usually means obtaining consent from parents/guardians or primary caregivers.

- **Respect for privacy and confidentiality:** Privacy is a fundamental right and is protected in various legislative documents both provincially and nationally. Participant information must be kept in secure locations and not shared for purposes outside the intended research. Published documents must remove any identifying information that may compromise the privacy and confidentiality of research participants. The *TCPS2* (2014) outlines various types of directly and indirectly identifiable information (p. 58–9).
- **Respect for justice and inclusiveness:** There is a history of excluding participants from research on the basis of their age, language, ability, gender, race, religion, ethnicity, sexual orientation, and ability. The *TCPS2* identifies this kind of exclusion as injustice. The *TCPS2* (2014) warns us, however, “that particular individuals, groups or communities should neither bear an unfair share of the direct burdens of participating in research, nor should they be unfairly excluded from the potential benefits of participation” (p. 49). This issue is particularly important when considering research with First Nations, Métis, and Inuit peoples, as discussed later in this chapter.
- **Balancing harms and benefits:** Participants in any social science research should not expect to receive any personal benefit. Benefits from most of our research are based on advancement of our understanding of a particular topic or problem and thus are social benefits. Participation in research should not result in harm to participants. Your REB will determine whether or not your research project meets the criteria of low harm.
- **Minimizing harm:** It is the researcher’s duty to avoid, prevent, or minimize harm to participants. To minimize harm, research projects should recruit the smallest number of participants and subject them to the smallest number of tests needed to achieve valid data. Minimal risk is defined by the *TCPS2* (2014) as “research in which the probability and magnitude of possible harms implied by participation in research is no greater than those encountered by participants in those aspects of their everyday life that relate to the research” (p. 21). This relatively vague definition may make it difficult for new researchers to determine whether or not their project constitutes “minimal” risk to participants. This is one of the reasons why an independent REB is needed to assess all research.
- **Maximizing benefits:** In most research, the participant receives no direct benefit from participating in the study. The benefit usually occurs in the published research that helps to advance knowledge in a particular field or discipline. Incentives given to participants, if any, should be minimal and not cause undue influence. For instance, giving a low-income mother \$1000 to have her child participate in an untested vaccine study may be too high an incentive, given her economic position. The *TCPS2* takes no position supporting or rejecting the use of incentives.

Principle 2: Research must be based on knowledge of the work of others in the area and be conducted and/or supervised by persons qualified to do the work who have the necessary facilities to ensure the safety of participants

It is unethical to rush into the field to collect data before doing a literature review to learn what has been done before, what is known, and what questions remain in the field of study you propose. It is also usually a great help to see how others have tackled the problem you propose to study. It is unethical to carry out poorly designed research since, at the very least, people's time is wasted and, at worst, misleading results might be declared. It is also unethical to unnecessarily replicate studies (unless the purpose is to corroborate evidence) because it is a waste of research funds and the participants' time and goodwill. It is likely that any research you do as a student will need to be cleared by your professor and a thesis/dissertation committee, in addition to an REB.

While many of the skills required for social science research are similar to the ordinary skills of human interaction, their use in research requires careful supervision, particularly when students are learning how to research. In one of the co-authors' experience on an REB, the most problematic research proposals have come from researchers who were just being introduced to the skills of social science research. New researchers require close assistance from their supervisors, who should not allow them to choose sensitive topics that are more appropriate for experienced researchers.

Supervision is also required because in the process of interviewing someone, you may uncover problems that are beyond your ability to resolve—a difficult domestic situation, a deeply troubled person, or some other such circumstance. You are probably not trained as a counsellor or family therapist, or in other helping skills, and hence you have no business trying to solve these problems. You should carry a list of qualified social workers, counsellors, or medical practitioners to whom you can refer people in need. These specialists must be contacted prior to your data collection to ensure they are qualified to assist your participants should they experience ill effects. You may have to report a particularly serious situation to the police or a social worker, especially if the participant is a minor or under institutional care. However, you are only there to collect information relevant to your research project; you are not a helping agent. Your abilities and responsibilities are quite limited. Discuss these issues with the person responsible for your research, or your professor, or your supervisor.

Principle 3: The potential benefits of a research project must substantially outweigh the potential harm to participants

Again, discuss these issues with the person responsible for your research, or your professor, or your supervisor. Your REB can also provide input on these issues. REBs are there to weigh the promised benefits of a project against its potential to harm participants and also to ensure the collection of relevant data. Although researchers have a responsibility to minimize harm, the role of the researcher is different from the role of the therapist or helper. Confusion between therapy and research often leads to serious ethical dilemmas.

Principle 4: Participants in research must be able to make a voluntary, informed decision to participate

Consent

The decision to participate must be based on knowledge of what will be involved, what will be demanded in terms of time, activity, and topics covered, what risks are likely, and where to lodge a complaint should that become necessary. This information is usually provided by means of a consent form like the sample in Figure 9.1, otherwise referred to as a plain language statement. Potential participants must understand such information. This may require translation, careful wording in everyday language, and avoiding the disciplinary jargon that researchers use for efficient communication with each other but that leaves the layperson bewildered.

Written consent from the participant is required in almost all instances of research where humans are participants. Increasingly, REBs are requiring researchers conducting online surveys and self-administered surveys to have all participants sign consent forms. According to the *TCPS2* (2014) consent is assumed when the actions of the participant—such as the return of a completed online survey—indicate consent (p. 46). In these cases, a consent form is not strictly required. Kitchin (2007) agrees with this assessment, given the extreme difficulties in identifying and contacting potential participants on the internet, especially for those researchers conducting a content analysis of blogs, online forums, and discussion groups. When in doubt, however, it is always better to err on the side of caution and collect signed consent forms when possible.

The consent forms are always stored in locked filing cabinets in secure offices. They may be stored for a period of up to seven years (depending on the provincial legislation). These consent forms are always stored separately from the data collected. As a good organizational strategy, consent forms should be separated from surveys, audio or video data, and research notes as soon as the information is collected. That way, if data were compromised, it would not be possible for persons other than the researcher to connect the information collected with specific individuals.

Usually, the risks and discomforts involved in social science research are minimal. However, there are risks that need to be carefully examined. The most important issue here is the risk of the disclosure of information that might be damaging to a person. It is not possible for you to promise absolute confidentiality to the people you interview. There is always a chance that direct quotes may identify individuals. It is your duty to inform all participants of this, no matter how remote the chance. You could be subpoenaed for results if they have a bearing on a court case. Your files are open to searches under the freedom of information legislation current in your province. Before embarking on a project in which this might happen, ask yourself, “How would I deal with it?”

Gaining informed consent poses particular problems for some forms of social research. One such example is public behaviour. This does not usually require consent. Some research is little more than having a conversation with someone. However, that conversation may have proceeded differently if the

participant in the research had known the intent of the conversation. In such a case, it would be ethically correct to inform the participant that their responses and opinions will be used in research, but such information might destroy the validity of the research. REBs now assist researchers to resolve some of these ethical issues.

Another issue related to discomfort and risk involves asking questions about sensitive areas. Topics may be sensitive because they are public issues, politically sensitive, or personally painful. For example, interviewing parents a few months after the death of their child from sudden infant death syndrome might be important in understanding the grief process following such a death, but it might be too disruptive to the parents and in fact could affect (positively or negatively) the very process you intended to study.

Voluntariness

While rarely an issue in social science research, it is important never to coerce compliance by offering overly enticing rewards for participation, such as large sums of money or holidays in the sun. At most, participants may receive reimbursement for expenses or some small compensation for the time they give. Most research-funding bodies do not allow for large incentives. CIHR, NSERC, and SSHRC do allow for some compensation but not excessive amounts. It is almost always more acceptable to offer children and youth gift certificates (e.g., to a movie or a bookstore) rather than cash. For some participants, however, cash incentives are not appropriate. In recent research one of the co-authors of this book has participated in, research participants often refused the \$50 incentive for an interview lasting two to five hours. The argument made was that the families wished that the research would contribute to changes in policy and practice and that this would be “reward enough.” However, it is not ethical for interviewers to allow the participant to refuse (given issues related to bookkeeping and fairness). In these incidents, we advised the interviewers to indicate that participants were not permitted to reject the incentive but that they could suggest that the cash be donated to a charity of their choice.

In some cases of social science research, the investigator may be in a position of power over the participant (e.g., parent/child, professor/student, employer/employee, supervisor/subordinate, parole officer/parolee). When this is the case, particular care must be taken in securing consent. In some cases, it may be impossible to get free consent, and the research may have to be abandoned. In other cases, a neutral third party may be able to secure the consent. Further, an interviewer wearing a lab coat or a clerical collar while conducting an interview may be playing on a symbol of authority to gain the participant’s acquiescence. The style of clothing to wear while conducting an interview needs to be considered in terms of the power relations between interviewer and interviewee. The *TCPS2* (2014) advises that “consent should be judged from the perspective of prospective participants, since the individuals being recruited may feel constrained to follow the wishes of those who have some form of control over them” (p. 26). This has to do with issues of trust and dependency. Students who do not wish to participate in research (for course credit, which is common

in some disciplines) conducted by their professors, for example, should be given reasonable alternative projects for credit should they wish to opt out of the study. Physicians and nurses should not be involved in the primary health care of their research participants for similar reasons.

However, in most social science research, the most powerful figure is likely to be the participant, who can just walk away, refuse to answer, or give a “safe” or misleading answer. This imbalance of power is central to maintaining the public’s trust in participating in scientific research.

Freedom to withdraw

Participants in your research must not only be free to consent to participating at the outset, they must also be reminded that they are free to withdraw at any time without penalty and “need not offer any reason for doing so” (*TCPS2*, 2014, p. 27). This can be very frustrating to researchers, but it is not ethical to pressure participants to complete interviews and questionnaires or to stay for the completion of the experiment. To do otherwise violates the rights and freedom of the participant. Arguing or pleading with participants that their withdrawal will waste your time, threaten your grade in a subject, hold up your degree, necessitate another interview with someone else, or render invalid the questionnaire constitutes pressure and is therefore unethical. Students should bear this in mind when constructing consent forms and approaching potential participants. This also needs to be a consideration throughout the entire data collection exercise.

Principle 5: Research is a public activity, conducted openly and accountable both to the researcher’s community and to the participants in the research

Research is a public activity conducted to increase our knowledge of some aspect of the universe. Its very public nature is one of the strengths of knowledge generated by research. Recall the definition of science in Chapter 2. This public nature of research also helps to keep researchers honest and affords a level of protection to participants.

This applies to research teams and covers the rights of co-researchers and assistants. It is important that all researchers and staff involved be as fully informed as possible so that they know what they are part of, what their role in the project is, what the overall goal is, and what procedures are involved. Keeping co-workers and subordinates in the dark is dangerous, inconsiderate, a waste of their input, and unethical. Imagine how you would feel if after working on some aspect of a project, you discovered that its overall goal or basic technique violated your sense of right and wrong. The *TCPS2* (2014) indicates that the principal researcher is ultimately responsible for the actions of her co-researchers, interviewers, and assistants (p. 25).

The research ethics boards at most post-secondary institutions have representatives from a variety of disciplines—from medicine, law, and religion, for example—and from the wider community to provide a public forum for assessing the ethical considerations in specific research projects. As we said in the

In Focus

A Note on Power Dynamics

Although our goal as researchers is to minimize the power differential between the researcher and the participant, there remains a power dynamic. By power dynamic, we mean that the act of conducting research automatically places the researcher in a position of power over the participant. For instance, when preparing the research report, the researcher has the power to identify what quotes are used and who is quoted. The researcher has the power to identify and even determine the issues that are most significant or important and which ones are the least important. They even can choose to leave out issues that they feel are insignificant. Even the act of interviewing has power related to it. An unstructured interview, where the goal is to let the participant identify the issues and direct the flow of conversation, has power attached to it. The researcher still has the authority as “the expert” and the participant provides information.

Even the most seasoned researcher cannot change the way participants perceive their role and contribution to research. We can mitigate some of the issues that cause this power imbalance. We can allow, even in the most structured of interviews, for participants to ask us questions and to add further detail. We encourage participants not to answer any question that they feel is unnecessary or inappropriate, or reveals too much personal information. We give participants the right to end the interview at any time without question or consequence. Good researchers also provide participants with a “sneak preview” of the final report and will allow them to make suggestions or changes to their answers. By including the participant in these aspects of the research process, we respect and value the contributions they make and we can reduce some of the power the researcher has to determine the outcome of the project.

introduction to this chapter, all research involving humans, organizations, and corporations requires the scrutiny and approval of an REB. Much of the research in social science does not raise life-and-death issues; however, many proposals require important advice, caution, or redesign to protect either the researcher or the participants, or both.

Special Ethical Issues in Qualitative and Secondary Data Research

Qualitative research often brings researchers and participants into close contact and creates a need for the interests of both to be balanced. Researchers can improve the lives of participants if they have access to such data, and they need support in their efforts. Because participants provide researchers with personal data, they need to be protected from infringements on their privacy. Research

ethics boards consider a number of issues as they seek to support the interests of both participants and researchers.

First, the close and sometimes extended contact between researchers and participants can change researcher/participant relationships and compromise the original conditions under which studies receive ethics approval, especially in relation to questions of authority and trust. REBs require formal relationships between researchers and participants based on clear explanations by researchers and the official consent of participants. During in-depth interviews and participant observation, you and your participants develop a rapport and personal trust, and the relationship can become less formal and more personal. Eventually, participants may reveal personal secrets, trusting you to remain silent. Such confidences are often of little consequence, but participants may confide personal information that will force you to make difficult choices. They may reveal facts that you as a researcher are obliged to report—for example, that they are victims of abuse or perpetrators of crimes. In such situations, you would be faced with a conflict of trust. Either you betray the trust of your participant, or you betray your professional and ethical obligations.

Similarly, in-depth interviews about sensitive issues may stimulate memories that participants find upsetting. REBs often require that researchers make provisions for referring participants to counselling agencies should they have such problems. It is not ethical for you to conduct an interview or series of interviews that leave respondents upset, with nothing in place to meet their need.

Given the personal nature of much qualitative data, REBs seek to protect participants' privacy. You must obtain permission from participants if you wish to quote them in reports. It is acceptable, as long as the participant's consent is obtained, to identify certain people as sources. This may involve quotations that can be attributed to upper management at some organizations, to politicians, and to experts. The issue is that these kinds of identity disclosures are not used very often, and when they are, they are used sparingly. The general practice is to assign pseudonyms to all participants in publications and research reports. Researchers must also take steps to de-identify data—that is, they must remove all references to the identities of participants from tapes and transcripts, such as names and unique characteristics. Lastly, REBs oblige researchers to keep data in secure places, such as locked filing cabinets and encrypted computer files that only they and their supervisors can access. You must have such places ready before collecting data and should officially notify participants in your explanatory statement that you have made such arrangements to protect their data.

REBs also have concerns about observational studies. University and college students must obtain permission from their REB for most observational research. This includes observations of public events such as church services and concerts, and of some online activities where individuals have a presumption that “participants and observers will accord the proceedings some degree of privacy” (*TCPS2*, 2014, p. 145). When observation focuses on specific organizations, groups, or individuals, REBs require that researchers obtain permission from the intended participants. Therefore, if you wish to observe a local

CASE STUDY

Reflexivity

When reading qualitative research, you might see a new word, “reflexivity.” Reflexivity is a process in qualitative research, particularly in feminist methodology, that refers to the understanding that the study of any social phenomenon or problem is always shaped by the researcher’s personal experiences, biases, opinions, and outlook. It is not possible for human beings to be entirely “objective” about any subject that involves human interaction or behaviour. We “filter” our observations through the cultural, historical, social, and religious mindsets that shape our personal identity. For this reason, social science research, particularly for postmodernists and feminists, cannot be objective or value-free. We can, as researchers, however, reduce the amount of personal bias and opinion that shapes our interpretation of the qualitative data we collect. It is difficult, but becoming aware of our own personal biases, assumptions, and preferences is important as we examine the data and begin to make sense of it. This process is called reflexivity.

It is difficult for some people to learn to be reflexive because we are so enmeshed in our own lives. One analogy is a fish swimming in a fish bowl. The fish knows it is in water but it doesn’t appreciate the water it is swimming in until it is removed from the fish bowl. Culture and social situations are very similar. As human beings, we “think” we are aware of our biases, but until something happens that makes us aware of how culture, history, the things we learn, the people we spend time with, and the things we read all influence our outlook, it can be difficult to be reflexive. For some people, travelling to distant places to learn different cultures is one way to become more reflexive. It’s like moving your fish into a new fish tank. Being exposed to different cultures, societies, languages, and histories can help us better understand our biases and appreciate differences. For others, simply reading about different cultures or learning a new language can encourage important shifts in the way we think that will help us to begin to appreciate differences in culture or opinion.

Regardless of how you come to realize your own biases, recognizing that not everyone thinks the same thoughts or values the same things as you do and that these differences are based on history, culture, religion, language, and social context is a major step towards reflexivity.

political group or an order of nuns, or monitor an internet chat room, your REB may not give approval until the potential participants supply their written permission. If researchers plan to conduct observation studies on premises that are privately owned or have restricted entry, researchers are obliged by their REBs to obtain permission to enter the premises from owners or caretakers. Hence, if you wish to enter factories to observe workers, convention centres to

observe visitors, or nightclubs to observe patrons, your REB will require letters of permission from owners or managers. Most research done in shopping centres also requires permission from the manager of the complex.

There are some exceptions to the rules around consent and observation. According to Article 10.3 of *TCPS2* (2014), in situations where those participating have no reasonable expectation of privacy, the researcher must submit a document to his or her REB articulating the need for an exception to informed consent (p. 145). This applies in public places where

- the research does not involve any intervention staged by the researcher or direct interaction with the individuals or groups;
- individuals or groups targeted for observation have no reasonable expectation of privacy; and
- any dissemination of research results does not allow identification of specific individuals (*TCPS2*, 2014, p. 16).

Generally, covertness in all research is unethical unless it is necessary for the research to have scientific validity, the researchers are able to accurately define the extent of the covertness, no alternatives exist, participants are not exposed to any increased harm by the covertness of the project, researchers make immediate disclosures to participants, participants are able to withdraw their data, and the research will not bring notoriety to the research community.

In Focus

Falsifying Data

Falsifying data and results is another unethical practice that, sadly, has been getting lots of media attention lately. One high profile study was featured in the premier interdisciplinary journal, *Science*. In 2014, scientists Michael LaCour, a PhD student in psychology, and his supervisor, Dr Donald Green at Columbia University, published what appeared to be a very important paper. They found that negative opinions on same-sex marriage could be reversed with a simple but short face-to-face conversation between a LGBTTTQ canvasser and a potential voter (Wanjek, 2016). Imagine how more accepting society could be of all kinds of differences if all it took was a short conversation! Naturally, everyone wanted the “recipe” or the transcript of the discussion points. Unfortunately, LaCour could neither produce the transcript nor the data that he supposedly analyzed for his PhD thesis and for the published paper. The journal later retracted the study in 2015 when the results were deemed to be fabricated.

It is worth noting that not only was the article retracted with great fanfare, but the lead author, Michael LaCour, had his new job as a professor at Princeton University rescinded. Dr Green has now changed his research practices to provide more scrutiny in regards to his students’ work. Falsifying data is not only unethical and damaging to your discipline, it can cost you your job!

Should you wish to consult archives, your REB will require that you obtain permission from the legal custodians. You would also be obliged to inform the custodians of how you intend to use the material and not to use it for any other purpose.

The use of secondary data is also creating increasing confusion regarding ethical requirements. According to the *TCPS2*, “secondary use refers to the use in research of information originally collected for a purpose other than the current research purpose” (2014, p. 64). For instance, one of the co-authors of this book had a student who wanted to survey victims of crime regarding their satisfaction with Victim Services. A database containing contact information and victimization reports was available to this researcher. But since the database was not originally collected for research purposes, the researcher had to contact each individual and obtain permission for the data to be used in the study. More commonly, issues arise from the use of health and tax records for research purposes. There are valid reasons for analyzing this type of information. First, it lowers the research burden on society; the less researchers must “bother” the public to participate in research, the less burden is placed on society. The information contained in such databases may not be readily available to participants. For instance, medical diagnoses and related test results may not be known to the potential participant—but they are readily available in such databases to which the researcher may obtain access.

Under most provincial jurisdictions, as long as the datasets have been anonymized (all identifying personal information has been stripped from the database), researchers are free to analyze their data provided that all of the following apply:

- identifiable information is essential to the research;
- the use of identifiable information without participants’ consent is unlikely to adversely affect the welfare of individuals to whom the information relates;
- the researchers will take appropriate measures to protect the privacy of individuals and to safeguard the identifiable information;
- the researchers will comply with any known preferences previously expressed by individuals about any use of their information;
- it is impossible or impracticable to seek consent from individuals to whom the information relates; and
- the researchers have obtained any other necessary permission for secondary use of information for research purposes (*TCPS2*, 2014, p. 64).

Research with Indigenous Peoples

CIHR, NSERC, and SSHRC have developed special ethics guidelines for research about Indigenous Peoples and have devoted an entire chapter in the *TCPS2* to its discussion. Indigenous Peoples have been the subject of extensive research, but much of the historical work done with them has not benefitted them. Much of this research has been conducted by outsiders who have neglected to use methods that appropriately recognize the multiple cultures, languages, religions, and

traditions of this diverse people. As a result of these injustices, many Indigenous Peoples are rightly suspicious and distrusting of research, particularly the kind that appears to have no communal benefit.

Like other participants, Indigenous Peoples are subject to the same types of protections we discussed earlier. The difference is that when working with Indigenous Peoples, there is recognition of the harm that has been done to them in the past by ill-intentioned researchers, and recognition that their unique culture, way of life, and contribution to Canada must be acknowledged to best protect their interests when participating in research. The following are some guidelines identified by McNaughton and Rock (2003) and augmented by more recent information from the *TCPS2*.

1. **Decolonizing research:** Current research on Indigenous Peoples should include “Indigenous knowledge, traditions, beliefs and values”; adhere “to Indigenous protocols at all stages”; involve Elders and Indigenous researchers; involve partnership at all stages of research design; and use “Indigenous methodologies as appropriate to local traditions and the subject being addressed” (McNaughton & Rock, 2003, p. 15). Research practices should incorporate their unique worldview that extends “to the interconnection between humans and the natural world” and includes “obligations to maintain, and pass on to future generations, knowledge received from ancestors as well as innovations devised in the present generation” (*TCPS2*, 2014, p. 113).
2. **Equity:** All participants should be treated fairly and equally by researchers. In the past, “abuses stemming from research have included: misappropriation of sacred songs, stories and artefacts; devaluing of Indigenous peoples’ knowledge as primitive or superstitious; violation of community norms regarding the use of human tissue and remains; failure to share data and resulting benefits; and dissemination of information that has misrepresented or stigmatized entire communities” (*TCPS2*, 2014, p. 113). To ensure this does not happen again, researchers should ensure that their research will be relevant to the community. Access to data and results by the participants is imperative in terms of the development of community programs and services as a result of research.
3. **Equitable treatment of Indigenous researchers:** Indigenous Peoples should be represented on grant adjudication committees; the merit of non-academic contributions should be considered; Indigenous researchers should be identified as such in projects. Community engagement in the research process is essential as an ethical practice in research with this group. Research should also “support capacity building through enhancement of the skills of community personnel in research methods, project management and ethical review and oversight” (*TCPS2*, 2014, p. 129). This point is related to number 4, which follows.
4. **From obligation to opportunity:** This involves moving beyond the post-colonial critique that has defined much research on Indigenous Peoples

in Canada. Recognition of the rights and self-worth of Indigenous Peoples can help our society move forward. Research on Indigenous Peoples that incorporates opportunity for Indigenous researchers and common research goals may be a first step in social justice. One of the best ways to accomplish this is to apply collaborative and participatory approaches in research and data collection with communities. Another way forward is to mentor Indigenous students in conducting research for their bachelor's, master's, and doctoral studies. If this is not possible, employing assistants and translators from the community also assists in capacity-building.

5. **Partnership with Indigenous Peoples:** Several communities have adopted their own ethics code, based on consultations around the First Nations Regional Longitudinal Health Survey. Known as OCAP, it is based on community ownership of data collected, control over this data, access to data, and “possession of research processes affecting participant communities” (*TCPS2*, 2014, p. 122). SSHRC, NSERC, and CIHR have all created special advisory bodies that oversee research for and about Indigenous Peoples. The idea is to give “Aboriginal [*sic*] scholars and other Aboriginal knowledge-keepers full responsibility for management of research” on Indigenous issues (McNaughton & Rock, 2003, p. 17). In practice, Indigenous communities should be involved in all aspects of the research process, especially when the welfare of entire communities is affected. Indigenous communities must be directly involved when data collection occurs on First Nations, Métis, or Inuit land; when recruitment criteria includes “Indigenous” identity of potential participants; and when cultural heritage or traditional knowledge are the topics of study. The community must also be consulted in the interpretation of data collected in such studies (*TCPS2*, 2014).
6. ***Gus-wen-tah* and joint exploration:** This term refers to the Indigenous way of knowing. *Gus-wen-tah* is also referred to as the Two Row Wampum, “a treaty to express the rightful relationship between the Haudenosaunee (leadership of the nations) and European nations” (McNaughton & Rock, 2003, p. 18). The relationship between “Western knowledge” and the “Indigenous way of knowing” should be equal. Today, the Indigenous way of knowing is not primary in Canadian society. Researchers should work to place the Indigenous way of knowing on an equal footing. This also means the researcher must be knowledgeable and respectful of the cultures in the communities where studies take place. Practices that are acceptable in one community may not be in another.
7. **Joint exploration of knowledge opportunities:** Using the *Gus-wen-tah* may be a way to promote equitable research in the social sciences and humanities.

Researchers must always exercise integrity in adhering to the preceding guidelines. These guidelines already have practical support in protocols developed by the *TCPS2* with respect to research with Indigenous communities. Researchers should engage with Indigenous communities as “collectivities”—

that is, as entities representing their members. It is always necessary to negotiate formal participation and consent with Indigenous communities through their representative bodies (usually band councils and chiefs). As when engaging with individual participants, researchers usually must obtain written consent. However, this may not always be the right/ethical thing to do for some research involving Indigenous Peoples. According to the *TCPS2* (2014), “written signed consent may be perceived as an attempt to legalize or formalize the consent process and therefore may be interpreted by the participant as a lack of trust on the part of the researcher. In these cases, oral consent or verbal agreement(s)” may be substituted in lieu of a signed consent form (p. 46). Research ethics boards usually require that negotiations of this type occur in face-to-face situations. By doing so, researchers observe the guideline of equality. And as they do with any other potential participants, researchers must also respect the right of Indigenous communities to refuse their approaches, especially since Indigenous Peoples have been the subject of many dubious research projects over the past two centuries.

When consent is obtained, researchers must accept the role of “guest” in their “host” Indigenous communities, thereby showing respect and observing reciprocity. Indigenous communities must make the final decisions about the design and conduct of all stages of the research. Communities are then able to retain project ownership, ensure receipt of benefits, protect themselves against exploitation, and preserve their voices and cultural viewpoints in the findings.

For example, communities and researchers must collaborate in the first stage—the formulation of research goals. In order not to perpetuate the exploitive researcher/participant relationships of the past, we must take care to negotiate topics pertinent to each community’s needs. Researchers must also present frequent progress reports in formats and language that host communities deem appropriate. This responsibility maintains and respects the partnership and ensures that projects remain true to agreements.

Communities should also participate in decisions about methodology, particularly with respect to issues of cultural sensitivity. For example, a community can stipulate that questionnaires be written in its first language or that the researcher should not interview members of their opposite sex.

Communities may also impose guidelines on the administration of research. A community may ask a researcher to only recruit research assistants from among its members. It may also require a researcher to respect the secrecy of certain knowledge such as that involving sacred ceremonies or songs. A community may also stipulate that findings be presented in its own language and only in the context of its anticipated benefits.

Researchers should respect the knowledge of Indigenous peoples—that is, their interpretations and viewpoints of the world. Indigenous knowledge always takes precedence over that of other cultures, and researchers must acknowledge this in analysis and reporting. If a community attaches special meaning to certain wildlife on its land, researchers must respect this knowledge and, if the community consents, make it a context of their findings. This protocol supports the guideline of equality.

In Focus

Ethical Dilemmas in Research

Sometimes, despite our best efforts and planning, the research process does not go smoothly. Events happen and sometimes researchers uncover unethical situations themselves. Although this does not happen very often, we should be prepared in the event that it does. For example, we may unintentionally discover unethical practices at a business, learn about a criminal event, or discover abuse of vulnerable people. What are we to do in these situations? First, if you are a student, report the situation immediately to your supervisor/professor. They are better trained in dealing with these situations. If you are a researcher, faculty member, or other employed person at a post-secondary institution, report the incident/issue to the research ethics board. The REB will have methods in place to assist you in navigating the situation and determining which, if any, authorities ought to be contacted. This is a legal requirement, and a statement indicating the REB will be contacted when ethical questions arise ought to be included in the consent form (as we discussed above).

Second, seek advice from knowledgeable sources. Do not discuss the issue with your colleagues, friends, or family. Confidentiality remains important, especially when the researcher thinks something is amiss. Everyone deserves the right to a fair hearing of accusations, so it is important that the researcher not disclose this information to anyone other than the REB and professors/supervisors.

Third, document all information. This will be helpful for authorities if additional details are necessary. Ensure that this documentation is kept in a secured place and not easily accessible to your colleagues, friends, or family. Ensure that identifying information is not attached to this documentation.

It is very likely that the authorities will make a decision, based on your report, to investigate the situation. After that, your involvement will likely be minimal. Some researchers have been asked to testify at criminal proceedings, but that happens very rarely. It is unlikely that you will ever uncover unethical or criminal behaviour during your career, but it is important that you understand the steps in reporting issues and protecting vulnerable populations from exploitation.

By entering into a formal contract with the Indigenous community, the researcher formalizes their partnership. In doing so, the researcher observes the guidelines of responsibility and equality. Such contracts should contain clauses on administrative matters. These may include project timetables, principles for project evaluation, methods of obtaining consent from individual members, ways of negotiating changes to research, payments to communities, and procedures for resolving disputes between communities and researchers.

Contracts should also have clauses regarding cultural sensitivities. These clauses may formalize agreement on a researcher's access to culturally sensitive materials, information, and places; the production of images in reports; and appropriate forms of interaction between the researcher and individuals.

There should also be clauses on matters of cultural and intellectual property. The *United Nations Declaration on the Rights of Indigenous Peoples* recognizes that Indigenous Peoples have ownership of their cultural practices, artefacts, and knowledge. For research that incorporates these possessions, communities have legal claims to intellectual property such as final reports, books, cinema, and sound recordings. Canada has signed this declaration, and we are bound by international law to obey it.

This is only a general description of the ethics of researching among Indigenous communities. Even the *TCPS2* acknowledges that its chapter on Indigenous peoples and research is a work in progress. You should look at the official documents on research ethics published by your university and from the major Indigenous associations, including the Assembly of First Nations, the Congress of Indigenous Peoples, the Métis National Council, and the Inuit Tapiriit Kanatami, for additional guidelines. In addition, the extensive discussion of these issues in *TCPS2* is a good starting point.

Ending the Research Project

As part of the process of strengthening our commitment to ethical research, ethics boards, funding agencies, and professional associations increasingly require researchers to provide all interested participants with a summary of the results of the research. The onus is on the researcher to provide participants with an easily understandable summary of the results. Simply giving participants a website address and asking them to monitor the site for results is not acceptable practice. Instead, the researchers are required to send the respondent, either by surface or email, a summary of results at the completion of the project. This task is usually accomplished by a statement and question at the end of the consent form. This question asks participants whether or not they would be interested in obtaining the results of the research. If they answer affirmatively, they are asked to provide their surface or email address for communication purposes. Remember, part of the ethical requirements of any research is to ensure that the identity of respondents remains anonymous. This is why it is important that the consent forms are kept in a secure, locked storage area and that names are not connected to any of the other data stored for the project.

Another project-ending exercise is to submit a final report to the REB. Unlike the lengthy and detailed reports submitted to funders, the REB final report consists of a single question. For projects with “minimal risk,” there is a declaration that indicates that the researcher did not experience any problems interacting with study participants. If the researcher has experienced an adverse event, he or she is required to provide details to the REB so they may be kept on file. For projects determined to be “more than minimal risk,” the researcher must provide a description of how the study was conducted and to identify any problems or issues that arose during the data collection. Again, this information is kept on file at the REB. In cases where extremely adverse events have occurred, REBs usually require the researcher to produce a detailed report called an adverse event form that identifies the nature of the adverse reaction, procedures taken to alleviate or

reduce the adverse action, and a detailed description of how the researcher plans to proceed (i.e., change research protocols or cancel the study).

Summary

For social scientists, the major ethical issues centre on gaining an appropriate form of informed consent, respecting individual privacy and confidentiality, being aware of the power dimension of the relationship between the researcher and the participants in research, and ensuring that the research procedures (variables selected, measurement used, sample selected, and design employed) are adequate to answer the questions being asked. Confidentiality is a particular problem, since it is necessary to keep original data in a readily retrievable form in order to prove that they really were collected, not faked. Further, your files can be subpoenaed if they are relevant to legal proceedings, and you would be liable to charges of withholding evidence if you refused to hand them over or to charges of destroying evidence if you obliterated your files. Therefore, it is not possible to guarantee absolute confidentiality to participants. You can promise to protect the privacy of participants and interviewees by assigning case numbers, changing names, and dealing with group-level data, but there are limits to all undertakings of confidentiality and anonymity.

You must remain aware that there are always ethical issues involved in doing research. As we mentioned in our discussion about respectful and ethical research, particularly with Indigenous Peoples, sometimes you need to discuss proposed research with others not as close to the research as you are so that you may become aware of these issues and can find a way to solve the problems. Some people think that only medical or biological research poses ethical issues. That would be true if social research were inconsequential, if it had no effect. But most social research *is* consequential and therefore does pose ethical issues regarding its consequences for those who participate.

The responsible researcher is considerate, does nothing to injure, harm, or disturb the participants, keeps data collected on individuals and groups secure, accurately records information, and reports the findings of the research in a public manner.

Key Terms

Confidentiality 191	Maximizing benefits 191
Decolonizing research 201	Minimizing harm 191
Equity 201	Plain language statement 182
Ethics 181	Privacy 182
Gus-wen-tah 202	Research ethics board (REB) 180
Informed consent 182	Vulnerable person 190
Joint exploration 202	

Questions for Review

1. Why is the ethical review of research necessary? Why is this something for which researchers need outside help in the form of a research ethics board (REB)?
2. List some of the ethical issues involved in social research. Read research reported in journals or newspapers and discuss with other students the issues you see. For example, would you like to have been a participant in the research? Why is it unethical to waste other people's time? Is it ethical to conduct poorly designed research? Is it ethical to conduct research in such a way that those following you find it harder to gain access to people for research?
3. Find out the procedures in your university, college, or other institution for the ethical review of research. Try filling out the required form for a piece of research you are considering.
4. Does your professional association have a code of ethics? If so, read it and compare it with the codes of two other professions.
5. What are some of the unique ethical considerations for researching Indigenous Peoples?
6. Define and describe the OCAP principle. How would you put it into practice?
7. What do researchers mean when they mention "decolonizing" research?
8. Who are vulnerable people? Why should researchers be concerned about them?
9. Identify some of the key components of an ethical study.
10. Discuss why researchers need to be concerned about the power that researchers have over their participants.
11. Why don't researchers use the term "subjects" to describe people participating in studies?
12. Compare and contrast some of the ethical issues in qualitative and quantitative research.
13. What is reflexivity? Why is it an important skill in conducting qualitative research?

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