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Ethics in Human Research

Chapter Summary

When participants volunteer to participate in research studies, they are doing the researcher a huge favour. Generally, researchers should be considerate and not waste people's time, be prepared, take up only as much time as is essential, respect **privacy**, and seek permission. Given that, the researcher has to ensure they are taking steps to protect their participants from harm as a result of their participation. The key to identifying ethical issues in research is to take the position of a participant and view the study through their perspective.

Staff and students of Canadian universities, many research organizations, and members of most 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 proposals or plans to advisory bodies, which evaluate it based on ethical guidelines. For social scientists, the major issues centre on the following key issues: gaining appropriate and informed consent, respecting individual privacy and confidentiality, awareness of the power dimension in the relationship between the researcher and research participants, and ensuring that the research objectives are clearly specified and do not overstep the bounds of the project's main focus. This chapter discusses the preparation and submission of ethical protocols for review by REBs. The procedures involve a clear statement as to the purpose of the research, identity of the researcher, properly formatted consent forms, and requirements of the participants.

There are five basic principles of research ethics:

- Principle 1: Researchers must have respect for human dignity and respect the persons, groups, and organizations who participate in their research. This includes keeping safe participant personal information, **confidentiality**, and **privacy**; respecting free and informed consent (via the **consent form** or **plain language statement**); vulnerable persons; justice and inclusiveness; and balancing harms (minimizing) and benefits (maximizing).
- 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.
- Principle 3: The potential benefits of the research must substantially outweigh the potential harm to participants.

- Principle 4: Research participants must be capable of making a voluntary and informed decision (consent) to participate (including freedom to withdraw their participation).
- Principle 5: Research is a public activity, conducted openly and accountable both to the researcher's community and to the participants in the research.

A goal as researchers is to minimize the power differential between the researcher and the participants, though there remains a power dynamic.

Given the personal nature of much qualitative data, REBs impose strict guidelines for qualitative researchers who are doing research involving human participants. Most professional associations have codes of ethics to guide their members. In 2010, the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2)* was passed by the Interagency Panel on Research Ethics. The interagency panel includes CIHR, SSHRC, and NSERC. An update to the *TCPS2* was made in 2014. As a result, most universities and professional organizations have adopted the *TCPS2* guidelines. All research involving human participants taking place at universities must be approved by the REBs to ensure their ethical compliance.

CIHR, NSERC, and SSHRC have developed separate ethics guidelines for research about Aboriginal peoples and other vulnerable groups. Researchers should engage with Aboriginal communities as collectivities—that is, as entities representing their members. The *TCPS2* provides additional guidelines involving decolonizing research, equity, equitable treatment of Indigenous researchers, opportunity not obligation, partnerships with Indigenous peoples, *Gus-wen-tah* and joint exploration, and joint exploration of knowledge opportunities. The *United Nations Declaration on the Rights of Indigenous Peoples* recognizes that Indigenous peoples have ownership of their cultural practices, artefacts, and knowledge. Research that includes cultural and intellectual property, the Indigenous community may have legal claim. As Canada is a signatory to this convention, researchers must abide by this.

The use of secondary data is also creating increased confusion requiring ethical criteria. According to the *TCPS2*, “secondary use refers to the use in research of information originally collected for a purpose other than the current research process.” In most provinces, as long as the datasets have been anonymized, researchers are free to analyze their data provided that it meets a number of criteria.

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

Key Terms

Confidentiality A concept that signifies that the information provided by participants in a research project will remain anonymous and not attributed to them in any way. The goal of researchers is to present research results in a way that maintains the anonymity of all respondents while ensuring that data released publicly cannot be used to identify any individual or group involved in the research project. (p. 191)

Consent form A consent form is a requirement for conducting research involving human participants. The form should describe who you are, how you accessed the person's name, why you are

doing your research and what the research will require from the person, whose permission you are seeking. A consent form concludes with information about what the participant should do if they have any questions or concerns. (p. 182)

Decolonizing research Research designed to correct the historic tendency of marginalizing, disadvantaging, and harming Indigenous persons in the research process. It has long been acknowledged that many widely used research practices are embedded in a Western, racist way of thinking. The decolonization movement in research recognizes the history of abuse experienced by Indigenous persons at the hands of researchers. Today, we work together with Indigenous Peoples to recognize and centralize their voices in all research. (p. 201)

Equity A concept that encourages researchers to consider their participants as equals in the research process. This means treating participants with respect and listening to their requests and concerns. (p. 201)

Ethics An honourable code of behavior in research. It is also the concept that encourages researchers to “do the right thing” with regard to the treatment of their participants. This means treating participants with respect and dignity, and treating the information they provide with the utmost confidentiality and care. Almost all professional organizations have a code of ethics, outlining what constitutes acceptable conduct in the field. (p. 181)

Gus-wen-tah A Haudenosaunee word referring to two-row Wampum belt to signify that an agreement between two parties has been made. The concept recognizes that research involving Indigenous Peoples must be reciprocal, and that researchers and Indigenous participants must collaborate as equals on all research projects. It is also a way of recognizing the important contributions that Indigenous Peoples have made and will make in research on health, culture, society, and other concerns. (p. 202)

Informed consent Consent given by potential participants based upon a clear appreciation and understanding of the facts, implications, and consequences of an action. To give informed consent, the individual concerned must have adequate reasoning faculties and be in possession of all relevant facts regarding the purpose and outcomes of the research project. (p. 182)

Joint exploration A way of conducting research that allows the participation of non-researchers as part of the research process. (p. 202)

Maximizing benefit The idea that any research conducted should maximize the benefits and minimize the harm to participants. While there is usually no benefit to an individual to participating in the study, once the research has been published and disseminated, the outcome should make elements of life for the group more positive than negative. (p. 191)

Minimizing harm The idea that all research must be conducted in a way that does not harm participants. If harm is a possible outcome, then researchers must provide participants with information regarding the potential for harm and the opportunity to not participate or to end their participation in any research project. Participants should not be physically, psychologically, or emotionally harmed as a result of participating in research. (p. 191)

Plain language statement Another term for a consent form. It is an effort made by researchers to explain the purpose and outcomes of a research project without using technical language or disciplinary jargon. The intent is to provide clear information and details about a research project so that the participant can decide whether or not to consent to participate. (p. 182)

Participant People who consent to participate or be researched. The term *participant* is used rather than *subject* because it implies a degree of cooperation and reminds the researcher that their research is dependent on the participation of the participants. (p. 189)

Privacy A concept that signifies that information about an individual research participant should never be shared. Individuals generally have the expectation that their information will be used for legitimate research purposes and will not be shared with others. Most provinces have legislation intended to ensure the privacy of its citizens. (p. 182)

Research Ethics Board (REB) A committee, usually consisting of research experts and sometimes graduate students and members of the public, that reads and reviews all proposed research projects at a university or institution. REBs are tasked with pointing out ethical errors or potential errors in research projects prior to the beginning of the research. The boards are meant to assist researchers in identifying ethical problems that might negatively affect the participant and/or researcher. Most members will have been trained in the *TCPS2* protocols. Every publicly funded university in Canada must have at least one research ethics board review. (p. 180)

Vulnerable person A term used to describe someone who, owing to such circumstances as diminished mental capacity or being under the age of consent (17 years of age or younger), is unable to provide consent to participate in research projects. (p. 190)

Study Questions

Scroll down for answers.

1. What are the basic ethical issues concerning social science research?
2. What information needs to be included in a consent form?
3. To what specifically is Principle 5 referring when it states that “research is a public activity, conducted openly and accountable both to the researcher’s community and to the participants in the research”?
4. What are the basic parameters within which researchers have to operate while conducting research in Aboriginal communities?
5. Elaborate on voluntariness and freedom to withdraw in relation to Principle 4.
6. What are the three agencies that make up the Interagency Panel on Research Ethics?
7. What is reflexivity? Why is it an important skill in conducting qualitative research?

8. Why don't researchers use the term "subjects" to describe people participating in studies?
9. What is the OCAP principle? How would you put it into practice?
10. What does the final report to the REB consist of?

Video Resources

The following two videos examine unethical studies with Canadian researchers and/or participants. Issues of informed consent, autonomy, power relations, and humanity are explicit throughout each video and provide an excellent basis for discussion.

1. The first is a series of CIA experiments known as MKUltra that used Canadian psychiatric patients as test subjects, in studies ranging from "psychic driving" treatments conducted while they slept to LSD administration.

The Fifth Estate (1980). *MKUltra* (21:20)

<https://www.cbc.ca/fifth/episodes/40-years-of-the-fifth-estate/mk-ultra>

2. The second video reviews decades of medical research and experimentation conducted on Aboriginal patients in tuberculosis hospitals in the 1940s and 1950s.

APTN (2017). *APTN Investigates: The Cure was Worse* (23:51)

<https://aptnnews.ca/2017/10/27/aptn-investigates-reliving-indian-and-inuit-tuberculosis-sanatoriums/>

Answers to Study Questions

1. The basic ethical issues concerning social science research are as follows:
 - Be considerate of the needs of the participants. Don't waste their time, and don't irritate or alienate them.
 - Be prepared. Make certain that the questions are relevant to the extent that they reflect the hypothesis—don't ask needless questions.
 - Share the results of the research with the participants.
 - Ensure that consent is obtained.
 - Be professional. Include a business card. (pp. 181–182)
2. The following information needs to be included in a consent form:
 - Purpose and background of the study
 - Procedures specifying the nature of the participant's involvement
 - The risks associated with participation in the research project
 - Information on how the participant's identity and privacy will be secured
 - Compensation for involvement in the research project
 - Researcher's contact information
 - Consent indicating degree of involvement and voluntary exit from the research project (pp. 182–186)
3. When Principle 5 states that “research is a public activity, conducted openly and accountable both to the researcher's community and to the participants in the research,” it's referring to the following:
 - The public aspect of research means that research participants, assistants, and support staff are afforded a greater degree of protection.
 - Public research is conducted in transparent fashion.
 - Public research is scrutinized by REBs and other institutional safeguards. (pp. 195–196)
4. Researchers have to operate within the following parameters while conducting research in Aboriginal communities:
 - Decolonizing research: Indigenous knowledge and beliefs should be included.
 - Equity: Participants must all be treated fairly and equally.
 - Equitable treatment of indigenous researchers: Community engagement in the research enterprise should be fostered.
 - From obligation to opportunity: Aboriginal researchers should be included in research dealing with Aboriginal affairs.
 - Partnership with Aboriginal peoples. Aboriginal scholars should be provided with management opportunities in the research project.
 - Aboriginal way of knowing: The relationship between Western and Aboriginal knowledge should be treated as equal.
 - Joint exploration of knowledge opportunities: Equitable research should be promoted. (pp. 201–203)

5. Voluntariness means that compliance on the part of research participants should never be sought under conditions of coercion and duress. The researcher must also be mindful concerning power imbalances. Freedom to withdraw means that if participants wish to withdraw involvement, they must not be pressured or coerced to continue it. (pp. 194–195)
6. The three agencies are:
 - CIHR: Canadian Institutes of Health Research
 - SSHRC: Social Science and Humanities Research Council of Canada
 - NSERC: Natural Sciences and Engineering Research Council of Canada (p. 186)
7. Reflexivity is a process in a qualitative research that refers to the understanding that the study of any social phenomena; or problem is always shaped by the researcher's personal experiences, biases, opinions, and outlook. There is no such thing as pure objectivity. We need to learn to be reflective in order to ensure the data collected is representative of the participants and not the researcher's own biases. (p. 198)
8. Participant implies a degree of cooperative activity on the part of those we study. It 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. (p. 189)
9. 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. Ensure that Indigenous communities be involved in *all* aspects of the research process, including the interpretation of data collected. (p. 202)
10. For minimal risk projects, there is a declaration that indicates that the researcher did not experience any problems interacting with study participants. For 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 data collection. (p. 205)