# Ethics in Evaluation and Research

This handout provides information on privacy and confidentiality, collecting consent, and managing risk.

## Ethics in applied research

Conducting research in an ethical way involves:

1. Protecting participants privacy and confidentiality
2. Minimizing risk
3. Voluntary and informed consent

Most health and social science researchers in Canada abide by the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.* The second version (2010) of the Policy Statement includes a new chapter on qualitative research, which is often used in evaluations.

## Privacy and confidentiality

All research participants have a legal right to privacy. Elements of research involve invasion of the participant's privacy. When you ask about personal beliefs, they are disclosing what would normally be personal, private details of themselves to you (Newman, 1997).

Several legal acts protect the public's privacy, principally, the *Freedom of Information and Protection of Privacy Act* (FOIP Act), which governs public bodies, as well as Alberta's *Personal Information Protection Act* (PIPA), which applies to private businesses, non-profit organizations or professional regulatory organizations.

Privacy in evaluations is protected through anonymity and confidentiality. This involves separating the participants' names from their responses and not disclosing them to the public. Usually names are replaced by a code or ID number. It is important to consider that it may still be possible to identify unique people by their responses (e.g., small community survey with few visible minorities).

By ensuring and reassuring that the participant's personal information will be protected, they will be more likely to participate and respond truthfully. Codes of ethics and statements requiring privacy and confidentiality can also protect the researcher (e.g., demands to release the names of participants).

## Privacy and confidentiality

There are specific components of ***Freedom of Information and Protection of Privacy Act (FOIP Act)*** that relate to the collection and use of public information. In general, the public must be made aware of:

- "the specific legal authority for the collection of information" (i.e., who is collecting their information)
- "the specific purposes for which the information will be used"
- "the title, business address and telephone number of an official in the public body who can answer questions about the collection of personal information." (FOIP Guidelines and Practices, 2009, p. 321)

The Act also specifies:

- "…ensure that the minimum amount of personal information necessary to carry out the program or activity is collected." (p. 320)
- "…collect personal information directly from the individual the information is about except in certain limited circumstances." (p. 320)
- "The personal information in a system or program must be used only for the purpose for which it was collected or for a use consistent with that purpose." (p. 325)
- "There should be documented procedures for collecting, processing, accessing, transmitting, storing, and disposing of personal information." (p. 324)

*Note: The Government of Alberta has policies on storage of data as well as file retention schedules.

## Consent

Ethically, participants are required to provide voluntary, **informed consent** prior to participating in any research or evaluation project. Typical statements within a consent form include: (Newman, 1997)

- purpose, process, and duration of the project
- any potential risks
- guarantee of anonymity and/or confidentiality
- researcher's information and contact information for additional information
- indication that their participation is voluntary and they can withdraw at anytime
- information about benefits and compensation
- information about how to access results

Verbal consent is most commonly used in surveys. Signed consent is not usually required; however, you may consider signed consent if your participant:

- is a minor (i.e., parental consent with minor's assent)
- has a cognitive disability, or
- the information you are collecting is highly sensitive (Wilder Research, 2009)

Evaluators need to be aware of potential issues collecting consent, such as:

- difficulties with language or literacy
- cognitive disabilities
- indirect coercion (e.g., children, students, employees, funding recipients) (Newman, 1997)

In cases where you may be unsure if the participants are informed, a strategy may be to ensure you are using plain language and you may ask the participant to explain what you have told them back to you.

## Risk Management

Minimizing risk of harm to participants is an evaluator's legal and ethical responsibility. In addition to following ethical guidelines and legal acts, such as FOIP, there are three common ways to manage risk:

1. Threat and risk assessments:
    - Identifies potential risks, the likelihood of occurrence, and seriousness of consequences.
    - Conducting a threat or risk assessment would allow you to determine strategies for mitigating risks.
    - Since it is usually not possible to remove all forms of threat and risk, it could help to identify where you need to be prepared for addressing residual risk and potential consequences.

2. Privacy Impact Assessment (PIA) is described in the FOIP act as a way to ensure compliance with the act and considers broader privacy implications.
    - "The PIA is an exercise in which the public body identifies and addresses privacy risks that may arise in the course of its operations." (FOIP Guidelines and Practices, 2009, p. 328)
    - "A PIA provides documented assurance to the public body, to the Information and Privacy Commissioner and to the public that all privacy issues related to the initiative have been appropriately identified and addressed." (p. 328)
    - "Privacy impact assessments are not mandatory under the *FOIP Act* but are recommended for major projects that involve the collection, use or disclosure of personal information." (p. 329)

3. Ethical review: formal ethical review is undertaken by an ethics review board (ERB) or research ethics board (REB).
    - An ERB will review a research proposal to ensure the project has no or minimal risk to participants via: following ethical guidelines, including a sound methodology, and the researchers have the skills and resources to undertake what is proposed.
    - The Community Research Ethics Board of Alberta (CREBA)* is an example of a health-related ethical review board. They provide a free, online screening tool** to assist researchers and evaluators in determining if there is sufficient risk of harm associated with their project to warrant ethics review.

*http://www.ahfmr.ab.ca/creba/creba.php

**http://www.ahfmr.ab.ca/arecci/screening/14202/c40cd93b9959713fc9e356f91a8bfbf3

## Risk Management

4. Alberta Research Ethics Community Consensus Initiative (ARECCI) *** Network has developed two ethics decision-support guides to help leaders and organizations in their projects: the *ARECCI Guidelines for Quality Improvement and Evaluation Projects* and the *ARECCI Ethics Screening Tool.*

    - Whether the project is evaluation, quality improvement (QI), quality assurance (QA), or research, these decision-support guides help with integration of appropriate ethics considerations in projects to protect participants.
    - These decision-support guides will help you identify ethical considerations that needs to be incorporated in your project and will help you determine appropriate review requirements for your project.

***http://www.ahfmr.ab.ca/arecci/areccitools.php

## References

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (2010). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Retrieved from: http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf

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