

ARECCI ETHICS GUIDELINE TOOL

A pRoject Ethics Community Consensus Initiative (ARECCI) developed the *ARECCI Ethics Guideline Tool* to help project teams consider the ethical implications of quality improvement projects, evaluation projects, needs assessments, knowledge transfer, and health innovations. The following six questions and related statements help project teams make decisions to protect people and their information. This tool should be used along with the *ARECCI Ethics Screening Tool* to identify the ethical risks, to consider how to mitigate them, and to determine the appropriate type of ethics review.

This is a fillable PDF. Save this document for distribution to your team members or when requesting a [Second Opinion Review](#).

PROJECT TITLE

1. HOW WILL THE KNOWLEDGE GAINED IN THE PROJECT BE USEFUL?

POINTS TO CONSIDER

- What is the problem, issue or situation that you are addressing?
- What is the context of the project, problem or issue?
- How will you use the information?
- With whom will you share the results and how will you do this?
- How will you report results that are negative or unfavourable?
- What relevant literature, best practices or sources have you consulted?

Describe what you hope to find out or to improve by doing this project.

Describe who will benefit from this project and how they will benefit. When thinking about benefits, consider patients, clients, providers, families, employees, service providers and the organization.

Describe to whom you will communicate the results and how you will do that.

Describe how you will communicate negative findings or if you discover behavior or actions that adversely affect people or your organization.

2. HOW WILL THE DESCRIBED METHOD OR APPROACH IN THE PROJECT GENERATE THE DESIRED KNOWLEDGE?

POINTS TO CONSIDER

- What method or strategy will you use and why is it appropriate for your project considering the type of data, the populations, the context, timeline and resources?
- How will you collect and analyze the data?
- How will you know when you have obtained enough data?
- Do you need to consult with someone who has expertise in certain areas? For example, if you are doing statistical analyses, have you consulted someone knowledgeable in statistics? If you are using focus groups or surveys, have you consulted someone knowledgeable in those methods? Have you consulted anyone who has expertise in engaging with the population of data in your project?

**We use the word “data”, but your team might use the word “information”. They are interchangeable for ARECCI’s purpose, so use whichever one is most appropriate for your context.*

Describe your approach, method or strategy and how it will result in the desired knowledge.

Describe your plan for data collection and analysis.

3. HOW WILL YOU ENSURE THAT THE PARTICIPANT (OR DATA) SELECTION PROCESS IN THE PROJECT IS FAIR AND APPROPRIATE?

POINTS TO CONSIDER

- How will you choose the participants or the data?
- Will you exclude anybody or any group that might have seemed appropriate for your project? If yes, why will you exclude them?
- How will you ensure that you are not overburdening anybody or group (e.g., marginalized groups, cultural groups, people with a particular disease or disorder, staff, management, community members)?
- How many participants or how much data will you use in your project?
- What sampling strategy will you use for obtaining participants or data?
- How will you recruit participants to the project? Will the people recruiting participants have training in privacy and confidentiality?

Describe who your participants will be or the data elements that you will be using.

Describe how you will recruit potential participants or how you will obtain the data elements from existing documents..

Identify who you will be excluding or what data you will exclude and why this is appropriate for your project.

4. HOW WILL YOU MAXIMIZE BENEFITS AND MINIMIZE OR MITIGATE THE ETHICAL RISKS IN THE PROJECT?

POINTS TO CONSIDER

- How will your organization and participants benefit from the project?
- What are the risks identified by the *ARECCI Ethics Screening Tool* and how will you minimize and mitigate them?
- What are the risks of not doing this project?
- Will your organization tolerate the risks that remain in your project?

Describe the benefits to participants and to your organization.

Describe the ethical risks for participants and for your organization. Explain how you will minimize (decrease the number) and mitigate them (decrease the severity of those risks that remain).

Justify the remaining risks.

5. HOW WILL THE RIGHTS OF INDIVIDUALS, COMMUNITIES AND POPULATIONS BE RESPECTED IN THE PROJECT?

POINTS TO CONSIDER

- How will you protect the privacy of participants when collecting data?
- How will you maintain confidentiality when using or reporting the data?
- What are cultural interpretations of privacy and confidentiality that you may need to consider?
- Will you be collecting the least amount of data needed to complete the project? Will you be collecting only the “need to know”, rather than the “nice to know”?
- Who will have access to the data and in what form? How will you ensure that only the fewest number of people necessary see the data?
- Will you be following your organization’s policies or other relevant policies or legislation to protect people and their information (e.g., Freedom of Information and Privacy Act, Health Information Act, Ownership, Control, Access and Possession Act)?
- How will you deal with data security if any is being transferred across regional, provincial, national, or international boundaries?
- How will you ensure unintentional identifiability when reporting results to participants, or giving presentations or writing for publication?

NOTE: If your project involves individually identifying health information, please ensure that you are meeting the applicable legal obligations in your jurisdiction. For example, you may need a privacy impact assessment in some circumstances.

Describe how you will ensure privacy when collecting data.

Describe how you will maintain confidentiality when using the data or when communicating the results.

Describe how you will retain, store, secure and destroy the data.

6. WILL INFORMED CONSENT BE NEEDED IN THE PROJECT?

POINTS TO CONSIDER

- How will you ensure that participants are not feeling any undue influence or pressure to participate (e.g., manager/staff, service provider/client, health care provider/patient, faculty member/student)?
- How will you inform participants about the project, especially their role and anticipated risks?
- How will you inform participants if risks arise during the project?
- Why is your approach to consent (e.g., signed, verbal, implied, other) appropriate for the project?
- How will people know that they can withdraw from the project at any time?
- How will you ensure that you will use an appropriate level of language in the consent process? Will there be a need to consider health literacy?
- How will you know that any honoraria or other forms of compensation will be fair or appropriate?
- Do you or other team members have a conflict of interest with any aspect of this project?

Describe how you will inform participants about the ethical risks of the project.

Describe what type of consent process you will use for your project. If expressed consent is needed, how will you obtain that?

Describe how you will minimize and mitigate the risk that people will feel pressured into participating.



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