



*National Homelessness
Initiative*

*Initiative nationale
pour les sans-abri*

**ETHICAL GUIDELINES
FOR
CONDUCTING RESEARCH
INVOLVING HOMELESS PEOPLE**

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of Canada

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SECTION 1: INTRODUCTION

Any review of the literature on social research will highlight the significance of ethics in research and also the complexity of identifying and addressing ethical issues during the course of research. The key concern? All research involving human subjects has the potential of being exploitative and damaging, even when the intent is to benefit those who are being investigated.

These Guidelines build on and complement the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* which describes the policies of the Medical Research Council, the Natural Sciences and Engineering Research Council, and the Social Sciences and Humanities Research Council (available at <http://www.nserc.ca/programs/ethics/english/policy.htm>), and they are intended to minimize harm and ensure that the rights, privacy, confidentiality and well-being of homeless participants are fully respected.

For the purpose of these Guidelines, “homelessness research” is defined as any systematic investigation designed to develop or contribute to knowledge about homelessness. These Guidelines apply primarily to qualitative research (e.g. interviews, focus groups, consultations, etc.) and to independent researchers (consultants, academics, students, etc.) as well as community organizations contributing or hosting research activities.

SECTION 2: BASIC PRINCIPLES

Below are a set of basic principles intended to guide researchers’ actions in conducting research involving homeless people.

In keeping with the spirit of the *Tri-Council Policy Statement*, the overarching principle that will guide research is **the principle of respect of human dignity**. This principle highlights two important imperatives. First, “it is unacceptable to treat persons solely as a means (mere objects or things) because doing so fails to respect their intrinsic human dignity” (*Tri-Council Policy Statement*, p. 1.5). Second, the principle “aspires to protecting the multiple and interdependent interests of the person from bodily to psychological to cultural integrity” (*Tri-Council Policy Statement*, p. 1.5).”

The above basic principle provides the foundation for **10** further ethical principles which, when taken together, provide a framework to guide and evoke thoughtful actions in conducting research. In particular circumstances more than one of these principles may apply at the same time, and when they do, conflicts between them frequently arise. Researchers must weigh all the principles and circumstances involved to reach a defensible and reasoned conclusion. The following principles refer to the rights of the participants and the obligations of the researcher.

ETHICAL PRINCIPLES

1. Participants are honestly and comprehensively informed about the homelessness research study they are taking part in.
2. Participants have the right to make free and informed consent about participating in the homelessness research study.
3. All research procedures protect the interest of homeless people, and respect the descriptions of their traditions, customs and values.

4. Participants' privacy will be protected before, during and after their participation.
5. All information provided by participants will remain confidential at all times.
6. Participants are treated with fairness and equity.
7. Researchers ensure foreseeable harm do not outweigh anticipated benefits for research subjects.
8. Researchers avoid, prevent or minimize harm to others.
9. Researchers conform to these accepted ethical guidelines.
10. It is essential the design of homelessness research studies take into account any relevant ethical Guidelines.

SECTION 3: GUIDELINES FOR ENSURING WELL-BEING OF HOMELESS PEOPLE

PRINCIPLES

- The researcher takes all reasonable precautions to ensure participants are in no way directly harmed or adversely affected as a result of their participation in the study. Researchers have no special rights to intrude on a person's privacy nor to abandon respect for an individual's values.
- In devising a homelessness research process and procedure, it is essential researchers follow these ethical Guidelines and the *Tri-Council Policy Statement*.
- Researchers are responsible for ensuring that all research assistants and student investigators involved with the research know of and comply with these Guidelines and the *Tri-Council Policy Statement*.
- Researchers who are supervising research assistants and student investigators have the obligation to treat them with the same respect as colleagues and study participants, including ensuring good working conditions and providing fair remuneration for work.
- When homeless or formerly homeless people work as research assistants, researchers are expected to take necessary steps to protect their privacy, and treat them equally and fairly.

PRACTICE

During Recruitment

1. Every attempt is made to inform participants of the themes and subjects of the discussion as well as the time, location and language of the interview or focus group.
2. Invitations indicate participation is entirely voluntary, and participants have the right to withdraw from the study and withhold information at any time without affecting their use of services or need for assistance.
3. Participants are told there will be a staff person designated by the host agency at the time of the interview or focus group to provide advice, if needed.
4. Researchers must consider the host agency's own research procedures and guidelines in working with homeless people. Researchers must ascertain whether or not they exist, and whether or not they are congruent.
5. It is the responsibility of the researcher to ensure anonymity of participants; ideally researchers don't know the participants or have direct dealings with them. The prime consideration is to avoid any real or perceived conflicts among participants that their participation may affect access to services. It is also

necessary to avoid any potential discomfort about disclosures to a person in a position of authority or on whom the participant may need to rely for assistance.

During Interviewing/Focus Groups

1. Participants are informed again if they find the subject matter distressing and would like to leave the interview or focus group, that there is a staff person available from the host agency to discuss these issues or a phone number they can call for help.
2. The introduction clearly states the risks involved in participating in the study, including the consequences involved in revealing personal information on matters pertaining to personal or public safety (for example, under the Ontario Child and Family Services Act there is an obligation for the public, including professionals who work with children, to report any situation where one becomes aware of a child in need of protection to a children's aid society). Since reporting incidents of harm overrides confidentiality, these incidents have to be considered on an individual basis, and a decision reached in consultation with a professional (social worker, counselor, etc.) who works directly with the participant. **Potential conflicts should always be brought to the attention of the National Secretariat on Homelessness.**
3. Participants who may have impairments that limit understanding and/or communication to the extent they are unable to give informed written consent. In these cases, it is therefore essential that permission is obtained from a family member or other responsible adults, such as a caregiver or guardian, before proceeding with the research.
4. Participants will be instructed not to share what others in the focus group say with outside individuals.
5. Informed written consent is obtained from participants after they are informed of their rights as well as the risks and benefits of their participation.
6. In cases where written consent cannot be used, as for instance with recorded telephone interviews or where the subjects are illiterate, informed oral consent is obtained by documenting on the consent form.
7. Researchers offer all participants the right to freely abstain from, enter into, or withdraw from the study on the basis of a fully informed personal decision.
8. Researchers or designated staff person from host agency check in with participants who become angry or distressed during an interview or focus group if they wish to postpone the interview or focus group or withdraw from the research.
9. Assurances to the length of the interview or focus group are honored or in the event of a discussion running over time, participants have the right to leave.
10. Interviews or focus groups will take place where participants feel most comfortable and familiar, and where both the participant and the researcher feel safe.

Technical

1. Researchers are explicit about their name, affiliation, role and position during recruitment and during interviewing or focus group.
2. Introduction of participants will be on a first name basis only or given pseudonym.
3. The recruitment and introduction informs participants of the purpose and objectives of the interview or focus group discussion; the procedures to be followed, including an estimate of the time commitment of participants, language of the research; the duration and frequency of involvement; the description of

- compensation; the recording of interview or session, and; the presence of an observer.
4. Informed consent forms must be written clearly and concisely as possible without distorting the nature of the research being undertaken (see Appendix 1). The language used must be appropriate to the participants and their cultural background.

SECTION 4: OBSERVATION OF INTERVIEWS OR FOCUS GROUPS

PRINCIPLES

- Researchers fully inform participants about being observed and give the opportunity to decline to be interviewed, or to withdraw at any stage during the interview or focus group, because of any concerns they may have about being observed.
- Researchers take into account that being observed may alter people's behavior and affect the quality of the research. The researcher must take all necessary actions to minimize the observer effect on the project as a whole.

PRACTICE

A. During Recruitment

1. If an observer is present, it is the responsibility of the researcher to inform observers fully about their ethical responsibility towards participants.
2. It is the responsibility of the researcher to ensure anonymity of participants; ideally observers **do not** include people who participants are likely to know, or have direct dealings with. The prime consideration is to avoid any real or perceived conflicts among participants that their participation may affect access to services. It is also necessary to avoid any potential discomfort about disclosures to a person in a position of authority or on whom the participant may need to rely for assistance. In these situations, the researcher can ask recognizable observers to immediately leave the "observation room" to protect anonymity and recognition. This guarantee is passed onto participants by fully introducing observers (name, who they work for and what they do) before the study begins.
3. The researcher informs participants about the nature of observation at recruitment, giving participants the option of not participating in the interview or focus group.

B. During Interviewing/Focus Group

1. During the welcome, the researcher again informs participants about the observer and why they are present (e.g. interested in participants' point of view) and what they will do (e.g. take notes).
2. The researcher reassures participants about the confidentiality of their responses and personal details, unless this cannot be guaranteed (e.g. reporting any situation where one becomes aware of a child in need of protection to a children's aid society) in which case participants are fully informed of this.

Technical

1. It is good practice to ensure observers only observe some of the interviews or focus groups participants—ideally no more than half —so the researcher can assess the observer effect and interpret the interview or focus group responses with more confidence. Where this is difficult to achieve, the researcher is mindful of the observer effect on the responses given, when interpreting the data.
2. Extra consideration about observers is given when a subject matter is considered sensitive (e.g. eliciting responses to questions about substance abuse or sexual abuse). In these circumstances, researchers should consider excluding observers from observation.
3. The researcher advises observers, prior to attending, of how best to ensure participants' well being and minimize the observer effect. Researchers consider style of clothing, where the observer sits, and the role and responsibility of the observer.

SECTION 5: PRIMARY DATA¹ AND TAPING AND VIDEO RECORDING

PRINCIPLES

- Researchers take reasonable steps to preserve the confidentiality of participants, their families, and other associated individuals.
- Researcher/research agency is responsible for securing all primary data (transcripts, audio tapes, video tapes).
- Researchers own the primary data.
- Researchers and the National Secretariat on Homelessness own the final report.

PRACTICE

A. During Recruitment and During Interviewing or Focus Group

1. Researchers are required to sign an Oath of Confidentiality with the host agencies they are working with (see Appendix 2).
2. Participants' identities remain anonymous.
3. Participants are told at recruitment and at the beginning of the discussion, tape or video recording will be used. Recording must not be used where any participant objects.
4. The researchers are responsible for retaining on file the primary data and evidence of written consent by participants in the study for a minimum of one year.

B. Researcher's Right to the Primary Data

1. The researcher or research agency can allow any individual access to the primary data once all safeguards described below are put in place.

¹ Primary data is original information (e.g. field notes, interview transcripts, video tapes, audio tapes, diaries, questionnaires, etc.) collected from observations, interviews, focus groups and surveys directly by the researcher.

2. Audio and video recording must not be allowed out of the hands of the researcher carrying out the study unless explicit permission has previously been obtained from all the participants involved.
3. When such permission is obtained, the researcher must ensure that participants are given as much relevant information as possible about the future use of the primary data, in particular:
 - to whom they are to be given;
 - to whom they are likely to be shown; and
 - for what purposes they are likely to be used.
4. Transcripts or verbatim comments must be anonymous before they are handed to any individual or included in research reports.
5. If the primary data is to change after participants have given their permission for its release, then the researcher will have to obtain written permission from each participant for further release, giving full details as to the new uses of the data.
6. If any part of an audio or video recording is to be played the researcher must ensure no references be made to the identity of participants involved without their prior permission.

SECTION 6: FEEDBACK

1. Participants and other involved parties are periodically informed of findings and provided with the final report.
2. Thank you letters are received by participants and host agencies.
3. Participants and other involved parties have information on how to contact the researcher. They are made aware they are able to provide feedback within a certain period after the research is completed.

SECTION 7: REVIEW SESSION

All researchers can request to participate in a review session with the National Secretariat on Homelessness to go through the Guidelines: the role of the researcher; method of obtaining informed consent; confidentiality and anonymity; body language and clothing; compensating participants; recording and taking down notes; protocol pertaining to personal or public safety; and, procedures for providing participants, National Secretariat on Homelessness and other key stakeholders feedback and final report.

APPENDIX 1: POINTS TO INCLUDE IN AN INFORMED CONSENT FORM

A. *Name (s), affiliation (s), and means of contacting the principal researcher(s).* This person may be contacted for any reason.

B. *Subject matter or goal of the study, and an outline of benefits.*

C. Description, in clear, very simple (non-technical) language of *what participation will involve* including:

- i) the questions to be answered and tasks to be done;
- ii) duration and frequency of participant's involvement;
- iii) the time, date and location;
- iv) clearly and fully spell out all the potential risks and/or discomforts when requesting informed consent; and
- v) if applicable, the name and the role of observer.

D. *Define homelessness and at risk of homelessness, and ask if it applies to participants.*

E. *Some important points to include in the consent form, if applicable:*

- Participation is entirely voluntary.
- The research is video or audio taped, and an explanation as to why this is necessary.
- Identity will be anonymous.
- Participants will make up a name or provide first name or initials.
- Participants can choose not to answer any question or they can stop the interview any time.
- Participation doesn't affect their use or need of services in any way.
- Interview will be kept anonymous.
- Participants have an obligation to respect the privacy of the other members of the group by not disclosing any personal information that they share during the focus group discussion.

F. *Description of compensation participants will receive.*

G. *Describe the protocol in place for counseling.*

H. *Access to final report.*

I. *Ask if participants have any questions about the study and what's expected of them.*

J. *Ask if participants agree or disagree to participate in the research study.*

K. *"I will sign my name to indicate that I have agreed to participate as set out above, and I will only provide my initials or first name. (We are not asking you to sign your full name so your identity can be kept confidential and anonymous)."*

Date

Researcher

Participant's initials or first name

L. *Questions, concerns or complaints about the research or researcher are sent to the National Secretariat on Homelessness (name and telephone number).*

M. *Provide business card or coordinates of the researcher.*

N. *A copy of the consent form must be left with the participant.*

APPENDIX 2: OATH OF CONFIDENTIALITY

Title of research study and short description:

Organization name:

Principal researcher name:

CONFIDENTIALITY AGREEMENT

As a member of the research team, I understand that I may have access to confidential information about study participants. By signing this statement, I am indicating my understanding of my responsibilities to maintain confidentiality and agree to the following:

- * I understand that names and any other identifying information about study participants are completely confidential.
- * I agree not to divulge, publish, or otherwise make known to unauthorized persons or to the public any information obtained in the course of this research study that could identify the persons who participated in the study.
- * I understand that I am not to read information and records concerning study participants, or any other confidential documents, nor ask questions of study participants for my own personal information but only to the extent and for the purpose of performing my assigned duties on this research study.
- * I understand that a breach of confidentiality may include a termination of the study.
- * I agree to notify the National Secretariat on Homelessness immediately should I become aware of an actual breach of confidentiality or a situation, which could potentially result in a breach, whether this is on my part or on the part of another person.

Signature of Principal Researcher Date Printed Name

Signature of Executive Director (of host agency) Date Printed Name