Human Participants Review Committee Guidelines for Conducting Research with People who are Homeless

Preamble

York University has formulated policies for conduct of research involving human participants. This policy applies to all Faculties and the Libraries of the University. This policy is intended to serve as joint protection for the researcher, the study participant and the University in order to ensure attention to various rights and responsibilities of the respective parties to the research endeavour. The Human Participants Review Committee (HPRC) is responsible for ensuring that research involving human participants is consistent with the guidelines set by the University.

The Senate of York University affirms that researchers must respect the safety, welfare, and dignity of human participants in their research and treat them equally, fairly, and not as a means to an end. The University values the academic freedom of its researchers, and the ethics review process shall not unfairly censor researchers who support unorthodox views. However, academic freedom is complemented by the requirement to respect the rights of human participants. The University's principal reference is the Tri-Council (SSHRC, NSERC, CIHR) Policy Statement (TCPS): Ethical Conduct For Research Involving Humans.

The following guidelines for conducting research with people who are homeless have been developed in acknowledgement of the need for continuing interpretation and refinement of applicable policies to account for changes in research methods, contexts and cultures. Guidelines for conducting homelessness research have been developed in recognition that: a) people who are homeless are by definition a marginalized population that routinely experiences exploitation, and thus are in need of special considerations, and that b) certain sub-populations of the homeless (street youth, the mentally ill, for instance) may present special challenges for research and as a consequence require added protections. These guidelines have been developed in an effort to not only protect human participants, but to ensure that research with people who are homeless is conducted in a respectful manner that recognizes the special circumstances endured by people without housing. The following guidelines are in place to ensure respectful encounters with people who are homeless, minimize risk to research participants and are in keeping with the cardinal principles of ethics in research.

These guidelines complement and build on those outlined by *York University's Human Participants Review Committee*, the <u>*Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*</u>, and the Government of Canada's *Ethical Guidelines for Conducting Research Involving Homeless People* (2004).





Who Should Use These Guidelines?

The "Guidelines for Conducting Research with People who are Homeless" are to be used by all York University faculty, adjunct faculty, visiting scholars, students or anyone else associated with York University or acting on the University's behalf, and who is conducting homelessness research that involves human participants. It is also recommended that faculty members supervising anyone conducting such research (including students) make sure that such persons are fully aware of, and have reviewed these guidelines.

SECTION 1: Defining Homelessness Research

For the purpose of these Guidelines, "homelessness research" is defined as any systematic investigation that directly involves people who are homeless as research participants. This may also include research focusing on the institutions that research participants may encounter preceding, during or after their experience of homelessness. Homelessness research involving human participants may include interviews, surveys, focus groups, medical research, clinical trials, as well as photography, filming or audio recording with or of people who are homeless. Research may be funded or unfunded.

Homelessness is defined as an extreme form of poverty characterized by the instability of housing and the inadequacy of income, health care and social supports¹. People defined as homeless include those who are absolutely homeless (i.e. temporary, intermittent or ongoing), as well as those who are at risk of homelessness (underhoused). The absolutely homeless may be living in shelters, outdoors in public or semi-public spaces, with friends or relatives ('couch surfing'). Those 'at risk' of homelessness may be precariously housed, living in hotels, rooming houses or apartments, and transitional housing, but who may potentially lose their housing for a wide range of reasons, including (but not limited to) eviction, inadequate income, because they are fleeing violence, etc.

The term "Homeless Service Providers" refers to agencies, services or personnel employed by such agencies who work with people who are homeless and/or underhoused.

SECTION 2: Basic Principles

Researchers must strive to ensure that the physical, social and psychological well-being of homeless research participants is not adversely affected by their participation. In conducting research with people who are homeless, researchers should be guided by the following principles. These basic principles emphasize the importance of respectful encounters with a vulnerable population, and provide a framework for conducting research and refer to the rights of the participants and the obligations of the researcher.

1. In keeping with the spirit of the Tri-Council Policy Statement, it is imperative that research be conducted with respect for human dignity. The rights, welfare and dignity of the research

¹ Stephen Gaetz (2009) Definition of Homelessness. The Homeless Hub (www.homelesshub.ca/Topics/Homelessness-176.aspx)





participant are paramount and therefore necessarily take precedence over the requirements of research.

- 2. Research with people who are homeless must be conducted in a non-judgmental way. Marginalized populations such as people who are homeless characteristically experience discrimination and social exclusion. This is often compounded by racism, sexism, homophobia and other forms of discrimination. Researchers must not contribute to the marginalization of homeless persons through acting in a way that is judgemental regarding a person's appearance, strategies for making money or personal habits, for instance. Though none of us are free of biases, we must strive to avoid judgemental actions, which include any comments or behaviours that are intended to express disapproval based on moral or personal biases. The exceptions to this are when there is a clear or immanent threat of danger to the researcher, the research subject or a third party.
- 3. People who are homeless typically lack access to private space, and live much of their lives in the public realm. Researchers do not have special rights or privileges to intrude into the lives of people who are homeless simply because they are in public spaces such as parks, streets or sidewalks. The right of people who are homeless to privacy and security must be respected at all times and this right must be reflected in recruitment methods and research methodology.
- 4. Researchers should recognize that many people who are homeless have experienced difficult lives characterized by violence, abuse and trauma. While one must be careful not to generalize, it is estimated that up to a third of adults who are homeless experience some form of mental illness, and that rates of depression and suicide are much higher amongst people who are homeless than the general population. Researchers working with people who are homeless must consider the fact that many people they encounter may be suffering from some form of mental illness, trauma, distress or depression.
- 5. Researchers should be aware of issues of diversity, and how these impact on homelessness. The distinctions and differences that we see in the rest of society and the discrimination and prejudice that result are also seen within the homeless population. In this sense, many individuals who are homeless may be marginalized in multiple ways; not only because they are homeless, but also because they are visible minorities, women, sexual minorities, have a disability, are Aboriginal, etc. Some minority groups are overrepresented amongst people who are homeless (sexual minority youth, Aboriginal people, people with disabilities, for example).
- 6. Research involving people who are homeless must be conducted in recognition of the special ethical issues that may be associated with specific sub-populations.

SECTION 3: Guidelines for Working with People Who are Homeless

Research that contributes to our understanding of the causes and consequences of homelessness is important. The purpose of research guidelines is to ensure that the researcher takes all reasonable precautions to minimize the risk of harm to those participating in studies. The following guidelines outline key considerations and practices that apply to those who conduct research with people who are homeless.





- **Research must follow HPRC Policies and Guidelines**. All research with people who are homeless conducted by faculty, adjunct faculty, visiting scholars, students or anyone else associated with York University or acting on the University's behalf, must be approved by HPRC in accordance with York University policies, procedures and guidelines for conducting research involving human participants. Students who plan to conduct research with people who are homeless must be under the supervision of a supervisor/supervisory committee at York University. Guidelines for faculty can be found at: <u>http://www.research.yorku.ca</u>, and for graduate students at: <u>http://www.yorku.ca/grads/policies/ethics.html</u>.
- Research practices should be conducted in ways that minimize distress for homeless research participants. It will not always be possible for the researcher to make a determination regarding the mental health and wellbeing of someone they are interviewing, regardless of whether he or she is homeless. Nevertheless, when conducting research, one must consider that some research topics, questions and activities may be extremely distressing for people who are homeless (for example, inquiries into experiences of sexual abuse, loss or trauma). While such areas of research are not prohibited, researchers should be sensitive to the potentially stressful impact of their activities, monitor the research participants' responses, and ensure that necessary supports are in place should research questions, the research experience and / or the conduct of the researcher lead to episodes of distress.

Supports may include ensuring that the research participant has access to, and is made aware of, counselling and supports after the research encounter. Ideally this information should be provided both prior to, and at the conclusion of, the research encounter. Where the research encounter occurs outside of an agency or facility where there is counselling support, it is strongly recommended that the researcher not only make arrangements for, and inform the subject of the availability of such supports, but be able to provide the person access to such supports – including paying for transportation if necessary.

- Researchers engaging in arts-based approaches must consider the long term implications of capturing and presenting images of people who have experienced homelessness. While maintaining the confidentiality of research participants is important, this is not always possible when participants are photographed or filmed. The privacy of people who are homeless must be respected, particularly because their access to private space is limited. People photographed in public spaces may not wish their identity be broadly revealed, for a number of reasons. At the same time, it is important to consider that public images of homelessness may outlast the actual time an individual is homeless, and that many individuals may not approve of a public and permanent record of their homeless experience. It is therefore important that individuals who are homeless give consent for capturing their image, and that this consent is based upon a clear understanding of what the images will be used for, where they will be displayed and for how long.
- Researchers must consider the implications of discovery/discussion of criminal acts or potentially criminal behaviour. Because of their extreme poverty and situational factors associated with street life, many people who are homeless engage in illegal and/or quasi-legal activities in order to survive. This may include the consumption and sale of illegal substances, theft and other petty crime, involvement in the sex trade, and violations under Ontario's Safe





Streets Act. In the course of conducting research, participants may reveal details about their involvement in such activities. This raises several issues for the researcher to consider.

Researchers must make clear to the participant that they cannot provide absolute assurances of confidentiality (for instance, a researcher and their records may be subpoenaed in a court case). At the same time, researchers should be aware that they are not required to divulge information they obtain from a research participant to a police officer, except in cases where the officer in question suspects that a crime is under way at the time of the request.

• Researchers must not assume the role of counsellor or therapist. It is important for researchers to remember that in most cases they are not trained counsellors or therapists, and should not assume this role vis a vis the research subjects. It is also worth noting that in working with marginalized populations, researchers may experience distress themselves when confronted with the difficult life circumstances of the research subjects.

SECTION 4: Guidelines for Working with Young People Who are Homeless

Conducting research with minors (whether homeless or not) raises a number of questions regarding informed consent, parental involvement, and a consideration of developmental issues.

HPRC has established guidelines for research involving minor age participants, under the age of 18:

- 1. For minimal risk research involving participants 16 years of age and older, parental consent is not required;
- 2. For more than minimal risk research involving participants 16 17 years of age, parental consent may be required;
- 3. For participants under the age of 16, parental consent is required.

The following guidelines address considerations for conducting research with young people who are homeless.

4.1 Research with Street Youth

Young people who are homeless, often referred to as 'street youth', are defined as people who are homeless who are under the age of 25. Conducting research with street youth under the age of 18 presents a series of challenges in terms of obtaining informed consent, especially if there is an expectation that parental consent is required. This is because many if not most street youth do not live with, or have positive relations with parents or caregivers. In fact, it is safe to say that a sizeable percentage of street youth do not have any contact with birth parents whatsoever, and are not currently in the care of any adults2.

² It should be noted that in some instances young people living in youth shelters and who are street involved may in fact be "crown wards". If the researcher becomes aware that the street youth in question has a legal guardian (such as a CAS worker) with whom the youth is regularly in contact, the researcher must, according to HPRC guidelines for research involving minor age participants ,obtain consent from the legal guardian.





HPRC recognizes the importance of conducting research with street youth, while at the same time acknowledging the challenges that such research presents within the context of the application of research ethics policy and guidelines. Therefore, HPRC outlines special considerations required if research is to be conducted with homeless youth under the age of 18 without the usual practice of obtaining parental consent. This includes more than minimal risk research with 16 and 17 year olds, and research with young people under the age of 16.

Where there is no parent, it is the responsibility of the researcher to act in the best interests of the young person. Where there is a conflict between responsibility towards the youth and the objectives of the research, the interests of the youth come first.

To summarize, researchers may conduct research with street youth under the age of 18 without parental consent if the following conditions are met:

- The young person who is homeless gives his/her consent.
- Counselling services and supports for youth participants are arranged beforehand and are accessible following the research encounter. Ideally such supports should be provided by homeless community service providers with expertise working with this population.
- Research participants must be informed of the availability of such supports, and provided with information about how to access such supports, prior to the engaging in research.
- If interviews and research are conducted in settings where such supports are not provided "on site", the researcher must make an attempt to provide the young person with access to such service, including arranging transportation where necessary.
- In obtaining HPRC ethics approval, the researcher must clearly demonstrate the procedures put in place to offer protection to research participants under the age of 18.

4.2 Street Youth under 16 years of age and the Obligation to Report

Considerations for conducting research with street youth under 18 years of age continue to apply when the research participants are under the age of 16. However, there are some important additional factors to consider. Under the Ontario Child and Family Services Act there is an obligation for the public, including professionals who work with children, to report to the Children's Aid Society any situation involving a child under the age of 16 in need of protection (if research is being conducted in jurisdictions outside of Ontario, the researcher must familiarize themselves with relevant laws and obligations).

Section 72(1)(11) of the Act outlines the duty to report, which states the following:

72. (1) Despite the provisions of any other Act, if a person, including a person who performs professional or official duties with respect to children, has reasonable grounds to suspect one of the following, the person shall forthwith report the suspicion and the information on which it is based to a society:





11. The child has been abandoned, the child's parent has died or is unavailable to exercise his or her custodial rights over the child and has not made adequate provision for the child's care and custody, or the child is in a residential placement and the parent refuses or is unable or unwilling to resume the child's care and custody.

While it is open to interpretation whether conducting research is performing professional or official duties with respect to children, the guiding principle of the researcher should be to act in the best interests of the child. York University's HPRC takes the position that the researcher is not in every case obligated to report a homeless youth to the CAS3.

If, however, the researcher determines the child is in need of protection because he or she does not have access to emergency street youth services and supports, is being exploited, or is in danger, there is an obligation to report. Reporting incidents of harm overrides concerns regarding confidentiality, and researchers are expected to inform a research subject of this fact when / if they become aware of the participant's age.

In considering the decision to report a child under 16 to the Children's Aid Society, it is important for the researcher to be aware that:

- many homeless youth may have problematic relationships with CAS, may not want their involvement, and a decision to report them may drive them further underground;
- a decision to report may jeopardise the relationship between the young person and the agency where the research is taking place;
- research participants may decline to give researchers their real last name, or information regarding where they are is staying. In this case, the information collected by the researcher may be unlikely to assist the Society in locating the child.

It is therefore advised that researchers who wish to make a report to the Children's Aid Society do so in consultation with staff from street youth serving agencies who are working directly with the youth in Question 4. Ideally, these scenarios should be discussed by the researcher and the host agency prior to the commencement of research, and a plan of action should be put in place.

Conclusion

The preceding guidelines have been established to provide direction and procedures for conducting research with people who are homeless. The goal is not to prescribe specific methods or methodologies, but rather to ensure that research with people who are homeless is conducted in a respectful manner with minimum risk of harm to the participants.

⁴ This is consistent with the Government of Canada's ethics review protocols as outlined in the *Ethical Guidelines for Conducting Research Involving Homeless People* (2004).





 $^{^{3}}$ The exceptions are when the researcher: a) is simultaneously working in a professional capacity at a street youth agency as an employee or volunteer, b) has a professional designation that obligates them to take specific actions (such as a physician or nurse), or c) is working in partnership with a street youth serving agency to conduct the research.

If the guidelines are unclear, or if you have specific questions, please contact Alison Collins-Mrakas, Senior Manager and Policy Advisor, Research Ethics, Office of Research Ethics, Fifth Floor, York Research Tower, York University at 416-736-5914 or <u>acollins@yorku.ca</u>.



