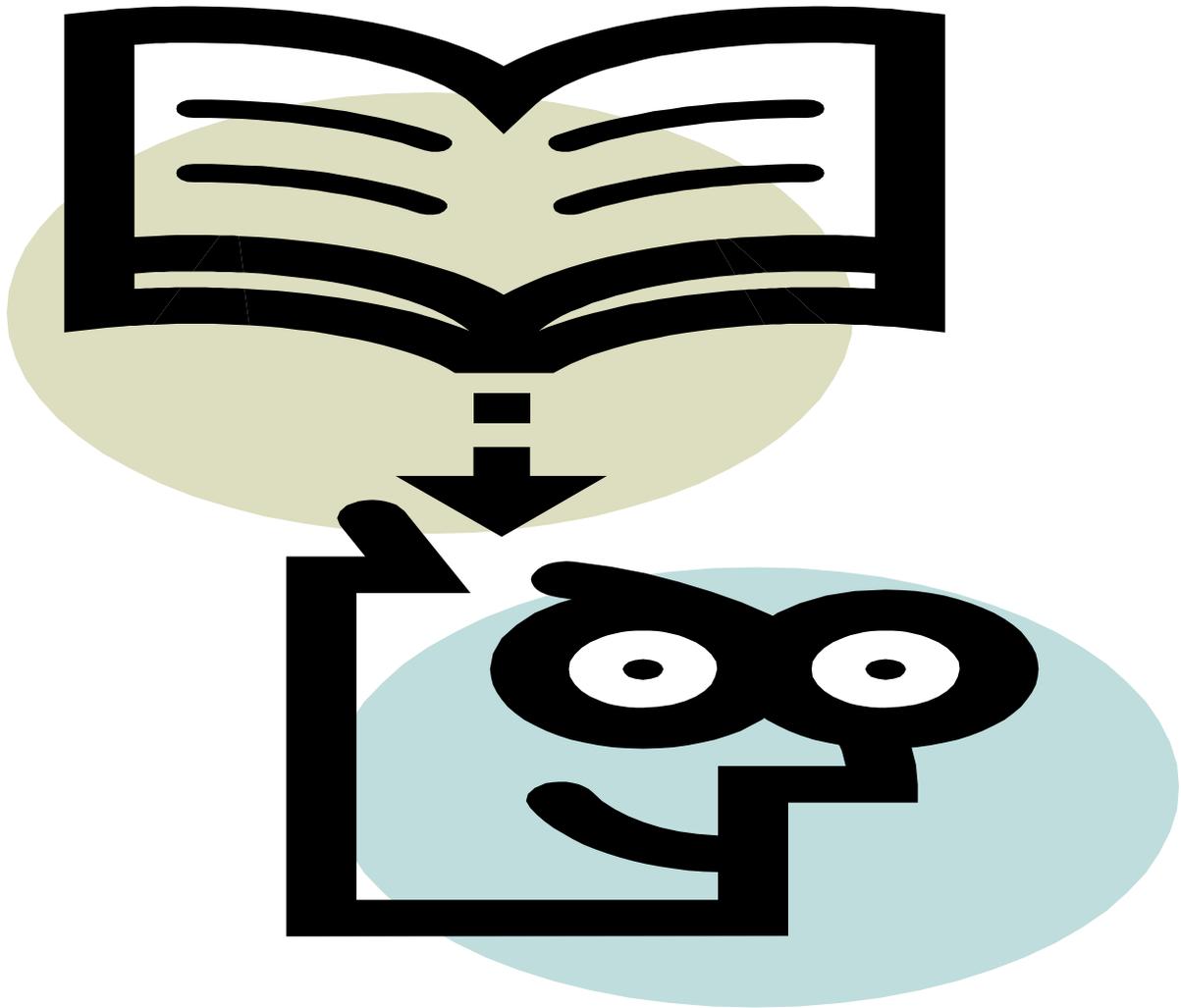# Research Ethics: A Guide for Community Organizations

Working Draft

Produced For PACE Society By
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"Our Social mandate is to understand all aspects of society not only as an end in itself, but also thereby to contribute to the development of a rational social policy" Palys 2003

Part One: The Context

Purpose:

As community based research becomes more prevalent within voluntary sectors, knowledge of research principles and ethics has become essential. There are three major reasons for this:

* First, we need to ensure are treated in accordance with established ethical principles when they are asked to participate in research;
* Second, to increase the quality of community based research/evaluation and thereby contribute to knowledge that will inform our service delivery and advocacy efforts;
* And third, it is important that community organizations become full partners in the production of that knowledge and play a central role in its discovery.

The research enterprise is a major contributor to social policy and our understanding of ourselves and the world around us. This document aims to share our knowledge around research ethics, to empower us in our work, and to reduce the potential harms that participation in research/evaluation has had on some impoverished and/or criminalized client populations by:

* Increasing organizational knowledge of research ethics and principles;
* Suggesting policy development and/or amendments to existing policies to increase participant knowledge and informed consent.

We also feel the need to make a strong argument for the necessity to make the Researcher-Participant relationship one of privilege. This would provide vulnerable populations with the level of confidentiality in a way that is free of fear and exploitation and that is necessary for their full participation in the production of knowledge.

Audience:

These guidelines are intended for groups that work with recipient populations that are impoverished, criminalized or otherwise socially marginalized or isolated. Groups that do not have philosophies of inclusion or asset mobilization built into their structures may have difficulty adopting these guidelines. For example, if a group is a youth serving organization and there are no youth representatives on their Board of Directors, on staff or involved in meaningful positions of influence with the organization, we recommend you read *Pathways: Real Options for Women out of*

Survival Sex available at: www.pace-society.ca, for some ideas on developing an inclusive organizational structure.

Background:

Over the past eleven years PACE Society has conducted research alone and in partnership. For the most part we have had positive research experiences due to the calibre and competence of researchers associated with our organization. Sex workers have shared their stories and details about their lives to enrich the community's understanding of sex work issues.

Some sex workers however, have shared experiences of a different sort. They have related instances where they have been paid to share personal information without full knowledge of what the data collection was for, or what impact their disclosures would have on them or the larger population of sex workers in relation to social policies, law enforcement and social stigma. They have expressed concern about not knowing where their personal information has ended up, who has control over the information or for how long their stories, photos, blood samples, affidavits, DNA and other sometimes identifying information would be used. Sex workers have even shared concerns about not being able to withdraw their contributions when they have felt unsafe or have their objections included in research reports.

Also, community organizations are required to conduct project evaluations, track the progress of project participants and measure outcomes most often without ethical review. This may not pose a threat to research and evaluation participants unless they are affiliated social groupings that are criminalized, like sex workers, 'racialized' or are otherwise undervalued by dominant cultures.

PACE Society saw the need to increase our collaboration with researchers and improve our working knowledge of research principles to better inform evaluation and research participants and obtain their investment in the research process. We are working toward providing opportunities for sex workers to make decisions about research involvement by ensuring the following information is shared:

- an overview of research and project goals and objectives;
- consent issues (duration, whether consent can be withdrawn);
- confidentiality and any limitations expressed or implied;
- risks and expectations and;
- compensation.

Academic Freedom

A. O. Lovejoy, a noted academic, maintains that "[universities are] the chief organized agency for the advancement of science and the canvasing of new ideas."

If this viewpoint is accepted, academic freedom can be defined as "the right of a worker in academic institutions to research and teach their beliefs without their livelihood being placed in jeopardy by those who disagree".[1] The Tri-Council Policy Statement further expresses that "These freedoms include freedom of inquiry and the right to disseminate the results thereof, freedom to challenge conventional thought, freedom from institutional censorship, and the privilege of conducting research on human subjects with public monies, trust and support"[2]. These freedoms set the climate for the academic pursuit of knowledge.

"Most defenders of academic freedom recognize that it is not an unlimited freedom"[3] and as such community groups interested in developing policies to protect and inform their recipient populations must walk this delicate balance. The goal of this document is to better protect research participants and increase collaboration, but not to violate the freedoms of researchers in the pursuit of knowledge. As organizations become increasingly more involved in the research process, taking on roles as co-investigators, the development of research policies or standards can serve as guidelines for collaboration. This will ensure that research partnerships can still be struck with researchers that may not share your organizations philosophies.

Ethical Concerns in Research

There are many sources to gather information on research ethics. A national set of guidelines that all Canadian universities must abide by is the Tri Council Policy Statement http://www.pre.ethics.gc.ca/english/index.cfm . Most research disciplines also have their own codes of ethics. Most share these basic principles:

- Ethical research should be conducted in a way that ensures all parties are free from harm and researchers are concerned with the safety of research participants that may experience heightened risks;

- Participants have the right to provide their free and informed consent at the onset of the relationship and researchers have an obligation to obtain this consent;

- Researchers must take steps to ensure that the privacy and confidentiality of participants is respected;

- Parties entering into research partnerships can anticipate and build in supports for participants. (For example, if a researcher is inquiring about life

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[1] Hewitt, John, "A Habit of Lies"- www.ahabitoflies.co.uk

[2] www.pre.ethics.gs.ca/english/policystatement

[3] "Academic Freedom," *International Encyclopedia of the Social Sciences* (Macmillan, 1968), I: 4–10.

histories that can be traumatic for some, the community organization and researcher can ensure that there exist post interview debriefing supports for participants).

► Researchers need to approach their research from a place of indifference in regards to the outcome and not engage in research that constitutes a clear conflict of interest.

Additional research principles speak to the researchers':

    ► **Respect** for participant autonomy and decision making;

    ► **Obligation** to increase the benefits to research participants and working to reduce harms associated with participation;

    ► **Commitment** to justice, which required fair participant selection and equal distribution of the benefits and burdens of research across participant samples.

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Part Two: Organizational Preparation

Know Your Organization:

Organizations can evaluate their interest and ability to conduct research with their recipient populations by having internal discussions about possible research topics, potential benefits and risks to participants.

Investigate: how your recipient populations are currently involved in your organization.

Does your organization have:

◆ Recipient involvement in operations and/or decision making within your organization, (Committees, Board of Directors, Staffing, peer projects);

◆ A general support structure for participants (that can be expanded to include supports during and after research);

◆ A mechanism for recipient contributions to organizational evaluation and review of research projects or other initiatives;

◆ Opportunities to hire a consultant for a workshop on research principles like: Research methods, Free and Informed Consent, Confidentiality and Privacy as they pertain to your membership.

Be Proactive:

➤ Explore the level of interest your organization's staff, volunteers and potential participants have in research;

➤ Assess your organization's resources (e.g. time, staffing and supports) that can be devoted to research activities;

➤ Work with your membership and recipient populations to develop research policies that will help your organization decide the circumstances in which research would or would not be conducted;

➤ Develop policies that serve to reduce the risks of research participation. For example: provide anonymity where possible, supports to participants for debriefing, and offer unlimited confidentiality;

➤ Ask for a research presentation to your organizations recipients/members, Board of Directors, staff and volunteers from any potential researcher;

➤ Cross reference potential research projects with your mandate-Does the goal of the research advance your organization's mission?

➤ When approached by external researchers wishing to partner, ask for a copy of the complete research proposal and read it over carefully.

**Part Three: Policy Development Areas**

Create Structure:

Organizations can develop policies in the following areas to increase clarity and reduce potential harms upon research participants.

> We have defined the following terms to best describe our understanding of research principles and our current realities. Feel free to read various books on the subject and choose terminology that works for your group.

Access and Recruitment describe the initial phase of contact between a researcher/evaluator and potential research participants.

Access:

Access is defined as external researchers wishing to enter into a partnership with your organization and/or recipients to conduct formal research or otherwise collect information for the public dissemination.
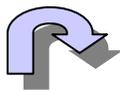
Policy Development Opportunity:
How does your group want to engage with external researchers? How can your organization support access to your population that recognize any safety requirements or special needs they may have?

Recruitment:

Recruitment is defined as your organization and its contractors (employees, peer workers or volunteers) engaging with its membership to connect external researchers with participants or to conduct internal research intended for public dissemination.

Policy Development Opportunity:
How will your group engage with its' members and inspire interest in research/evaluation participation without coercion?

Informed Consent:

Informed Consent is a principle that entitles potential research participants to be fully informed about research projects thus allowing individuals to make a free choice regarding their involvement.

Free and informed consent in research participation means that individuals decide whether they want to be involved in research based on their own values and priorities - no other issues should influence or sway their decision to participate.

Informed Consent has been achieved when the following has taken place:

1. Potential research participants have a **reasonable understanding** of expectations and risks associated with involvement;

2. Participants have been provided with **opportunities to ask questions** of the researcher and/or your organization and get responses to their concerns;

3. **Consent must be voluntary**. Organizations must steer away from asking individuals to fill out questionnaires etc. in exchange for a meal or other services;

4. Participants need to be **competent to give consent**. For example: it is argued that individuals who are chronically addicted to drugs may be less competent to give consent during withdrawal phases. Informed consent may be more readily achieved during periods after they have used or when they are 'well';

5. Consent may be documented in the form of a written agreement or it may be verbal. If documented, be sure to obtain a copy of the information sheet for the participants and agency's records. Do not sign anything you do not fully understand or feel uncomfortable signing.

As a guide, the following list expresses what participants are entitled to receive in order to make decisions about their participation:

1. Participants should be made aware of the purpose of the research in plain language (i.e., what is the researcher trying to prove and/or disprove; what do the researchers hope to accomplish?)

2. Any secondary or tertiary goals of the research must be revealed to the participant in a timely manner;

3. What limitations will be placed on the participants' confidentiality and what are the reasons for these limitations?

4. How will the data be kept? Will any initially identifiable data be made anonymous?

5. How will identifying information be used?

6. What are the researchers' affiliations, funding sources and whose interests are they serving?

7. What supports are in place for the participant during and after the research process?

8. What is the duration of the research and how long will participants be required to be a part of the process?

9. What are the activities and what is specifically required of participants?

10. Is there compensation available, how and when is it disbursed?

11. Do participants have to sign for or report monetary gifts or
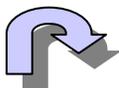
Policy Development Opportunity:

The above list of questions was developed by sex workers at PACE Society and reflects the <u>minimum</u> amount of information that is required by sex workers in order to support their decisions whether to participate in research. Work with your membership to add to this list if necessary.

Your organization may develop policies for how, when and how often to inform research participants about the purpose of the research, the type of information that is to be collected, format, compensation and risks.

Confidentiality:

Confidentiality has been defined as "discretion in keeping secret information"[4] or "ensuring that information is accessible only to those authorized to have access"[5]. The Tri-Council Policy Statement notes that "standards of privacy and confidentiality protect the access, control and dissemination of personal information"[6]. Thus, confidentiality is a core tenet of the researcher-participant relationship. Your organization may already have confidentiality policies that protect personal information and that govern how private information is collected, stored, transferred and destroyed.

The Wigmore Criteria:

The Wigmore Criteria is named after John Henry Wigmore (1863–1943) was an American legal educator and is best known for his work: *Treatise on Evidence* (4 vol., 1904; 3d ed., 10 vol., 1940).

The Wigmore Criteria are used to test whether relationships like the researcher-participant relationship should be one of privilege in Canada and the United States[7]. In privileged relationships like Lawyer-client, lawyers cannot be forced by the courts to betray confidences, agreements or share disclosures made to them by their clients in anything but the most extraordinary circumstances.

If researchers could offer absolute confidentiality to research participants, the disclosure of personal information or biological samples in that context would always by safe. Canada does not currently recognize the researcher-participant relationship as one of privilege for any researchers other than those from Statistics Canada. However, researchers can use the Wigmore Criteria that has been recognized by Canada's Supreme Court[8] in order to assert privilege in

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[4] Wordreference.com English Dictionary, 2005

[5] Dictionary.Labourlawtalk.com

[6] www.pre.ethics.gs.ca/english/policystatement

[7] Palys, Ted 2003, Research Decisions: Qualitative and Quantitative Perspectives(3rd Edition), Chapters 1,5

[8] Ibid Chapter 5, pg 95

the event of a request from the courts to disclose sources for which they have offered strict confidentiality.

Researchers who work with sex workers and other marginalized groups should know about The Wigmore Criteria and protect research participants by anticipating them in their research[9]. Doing so does not guarantee that the courts will agree, but the courts' record of protecting research participants in both the U.S. and Canada when the criteria are met is very strong.

The Wigmore Criteria Explained[10]
(Workshop provided by Professor Ted Palys to PACE Society 2005)

1. **The communications must originate in a confidence.**

   - The researcher and participant must have a common understanding that the interactions are confidential.
   - There must be a record of confidentiality and a mutual understanding of what confidentiality entails
   - Informed consent provides a description of confidentiality and the limits (if any).

2. **Confidentiality must be essential**. You would not participate in the research if confidentiality was not offered. The researcher should have a way of establishing this, and it should be written right into the research proposal.

3. **The relationship must be a relationship that the community values,** the community must recognize and support the researcher-participant relationship. There is a lot of evidence already that this is the case.

4. **Confidentiality must be balanced with court priorities**. A breach of confidentiality must cause far greater harm than keeping it secret in order for secrecy to be upheld in court. Palys and Lowman have reviewed a number of cases in Canada and the U.S. and they have concluded that "the only time confidentiality is not upheld is when innocence is at stake". In all other cases the agreement of confidentiality has been maintained.

Policy Development Opportunity:

A policy with regards to possible limits of your confidentiality policy should be developed to explain under what circumstances, if any; personal information will not be protected. Any research conducted by your organization needs to uphold your general confidentiality policies and expand them to the researcher-participant relationship. For example, your organization may limit confidentiality if someone discloses harm to self, harm to others, crimes that have been

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[9] Palys, T. and Lowman, J. (2000) *Ethical and Legal Strategies for Protecting Confidential Research Information.* Canadian Journal of Law and Society, 15(1), 39-80.

[10] For more information, see Palys, T. and Lowman, J. (2000)

committed or criminal intent. A research policy in regards to confidentiality can provide the basis for a full and frank discussion with researchers of how important confidentiality is and how they will work to protect it.

In research, as a rule, it is easier not to collect identifying information or to make data anonymous as soon as possible.

Note: This is why ethical review is important. Research Ethics Boards have a responsibility to weigh the benefits of research with the potential harms to society.

PACE Society works with individuals involved in sex work and in survival sex. Currently, activities associated with participation in sexual exchange are criminalized. For our organization, in keeping with our mandate, ethical review of research projects is essential however not always possible. As a community organization receiving government grants, we are often required to conduct project evaluation with our populations. Where ethical review is not possible, PACE Society in partnership with academic researchers and sex workers endeavour to conduct our own review to ensure that the benefits of research/evaluation outweigh the risks to individual participants or to sex workers as a social grouping.

Consider the development of policies in areas of Information Management with respect to privacy and confidentiality:

- **Ownership**: who owns research data;

- **Access:** who does the organization authorize to have contact with sensitive information;

- **Transference of Data:** How is data shared or moved;

- **Data Collection Methods:** In what ways will your organization collect information, what ways are prohibited;

- **Information Storage:** What format will information be in and how will it be secured;

- **Duration:** How long will information be kept;

- **Destruction:** How will information be destroyed, what are your approved methods of destruction?

Compensation:

If your organization compensates individuals for their participation in your programming, your group can then decide whether individuals will be paid or otherwise compensated for their involvement in research.
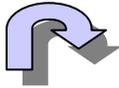
Policy Development Opportunity:

o How will participants be compensated;
o In what form are participants to be paid if monetary (cash or cheque);
o When are they paid/compensated;
o If monetary the income may be reportable (to provincial ministries or CRA);
o How will the compensation affect the principle of free and informed consent?

Something Else to Consider: When payment is offered to populations that are impoverished, the idea of free and informed consent appears compromised. Money or compensation will affect one's decision to participate. Does this mean that only the rich can participate in research?

Compensation to impoverished populations for participation can be handled like a booking fee. If individuals are paid first and they are made aware of their right to withdraw consent their participation will then be voluntary, free and informed. If they are paid after, they may feel like they are being held hostage or not free to end their participation.

Some individuals have noted that if they pay participants first, some will not stay long enough to finish their questionnaires or focus groups. Researchers and organizations will run that risk, as some individuals are motivated to participate in research solely for revenue. This in itself is a significant phenomenon. I have yet to meet anyone who makes a living from filling out questionnaires and if there is a high level of selective attrition, one may want to revise data collection methods and look at the external forces at play that may be statistically relevant.

Conflict of Interest:

Your organization may come across some instances where potential researcher(s) or research projects are in conflict with your mandate or philosophies. How will your organization work to resolve conflicts?

Consider the following:

o **A researcher's professional association(s):** Researchers with enforcement mandates conducting research with criminalized

populations may increase risk to participants. Prison guards conducting research among inmates may also pose a threat.

- o **How the researcher stands to personally benefit**: Some individuals obtain professional credentials through conducting research studies, others go on to write books based on their data collection. Ensure all personal benefits are disclosed and that no one party receives all the benefits or all the burdens.

- o **If the researcher is internal to your organization**: how will research activities affect the individuals' role? How will their role change? How will changes be communicated within the organization?

- o **Explore and understand power relationships**: Gender, class, race, profession, politics and other attributes may create power disparities and pose potential conflicts.

Create Understanding:

🌐 If your organization has decided to enter into a partnership to conduct research, a letter can be developed to make clear the intent of research and define the research relationship. This can increase understanding of research relationship, its potential outcomes as well as set parameters for research activities.

> **Letters of Understanding can include:**
>
> - Ownership and access to data information;
> - Data storage and destruction arrangements;
> - Limits to confidentiality (if any);
> - A recruitment or advertising strategy;
> - Strategies for free and informed consent, rights or privileges around peer review of research findings and ownership issues;
> - Issues of liability;
> - Insurance;
> - Support strategies for participants (compensation, travel, debriefing, follow up contact etc.);
> - Timeline and critical dates;
> - Publicity/ media involvement re: dissemination;
> - Consequences for Breach of contract.
>
> Note: The research outline/framework and/or data collection tools may be appended to the letter of agreement.

Seek External Support

It is important to talk about potential research projects with other organizations or experts.

Your organization may need to decide whether it will conduct research that has not been ethically reviewed. This decision can be based on the potential level of risk to participants if information about them was ever mishandled.

Research Ethics Board (REB's)

Research Ethics Boards are composed of elected professors at a university, some of whom have no field research experience; however they can serve as external support in university based research and are traditionally responsible for:

- Considering and protecting research participants;
- Ensuring participants have to and are able to consent to participation. (Consent can be written or verbal, by way of info sheets. Participants may also be asked to sign forms). Researchers and REB's should respect your wishes as to whether you are willing to sign forms or not.
- Understanding and weighing potential harms and put safeguards in place to reduce or eliminate them.

Ask Questions

When community organizations receive grant or contribution agreement revenue, some form of project evaluation is often necessary. Be sure to ask if there is an ethical review process within the funding body. If none exists, review the type of information that will be necessary to collect within your project. If you are required to collect any of the following data without an ethical review and policies that protect personal information, your research project or evaluation may be unethical and participants could be at risk:

- o Names;
- o Social Insurance Numbers;
- o Disclosure of any criminalized act;
- o Money issues as some institutions penalize people for earning money in underground economies;
- o Addresses;
- o Personal identifying traits, tattoos, photos;
- o Racial characteristics and/or profiling information;
- o Date of birth;
- o Criminal history specifics;
- o DNA, Blood work, health issues (HIV/HCV/ STI's) etc.

Recommendations:

- In order to better protect marginalized populations from potential harms associated with research participation we recommend a case goes forward to the Supreme Court of Canada requesting that the researcher-participant relationship become one of privilege under legislation, where absolute confidentiality can be offered to vulnerable populations.

- Community organizations need to be supported to increase their working knowledge of research principles to ensure project evaluation and community based research is conducted without undue harms to recipient populations.

- The mandates of some health authorities and enforcement bodies should be amended to ensure that the privacy and confidentiality of research participants are protected. Short of this recommendation, the principle of informed consent should be upheld allowing potential participants to be well informed of risks and permitted to withdraw consent from research projects that do not offer adequate protections.

- Individuals engaging in informal inquiry, collecting data for writing books or collecting photographs etc. among vulnerable populations for public consumption, should evaluate their methodologies based on research principles and be held to account for violations of confidentiality and informed consent.

- The ethical review of research projects that are community based should include representatives of the sample group that are not participating in the project. This would provide a level of inclusion, where individuals representing specific perspectives have opportunities to review findings.

- Research guidelines or policies developed at the community level aimed to protect participants cannot violate academic freedom. Community groups and individuals from displaced populations are encouraged to seek external and academic support in the development of standards.

Get More Information:

Here are just a few sources of information about research ethics, some of which have been cited in this document. Check the internet or your local library for more sources.

1. Canadian Institute for Health Research: www.cihr-irsc.gc.ca

2. Firehock, Karen, 2003, "Protocol and Guidelines for Ethical and Effective Research of Community Based Collaborative Processes" www.cbcrc.org/CBCresearch.

3. Palys, Ted and Lowman, John, 1999, "Informed Consent, Confidentiality and the Law: Implications of the Tri Council Policy Statement", http://www.sfu.ca/~palys/Conf&Law.html

4. Palys, Ted 2003, Research Decisions: Qualitative and Quantitative Perspectives(3rd Edition), Chapters 1 and 5

5. Tri Council Policy Statement: Ethical Conduct for Research Involving Humans, www.pre.ethics.gs.ca/english/policystatement

Acknowledgements: