Participant Rights and Tips for Engagement in University-based Research

General Information:

- Social research is an important component of how we learn about ourselves and the people around us. The information that is collected in a research study about social groups helps us to advocate for positive changes and improved practices regarding how we interact and treat each other.
- Not all research has a positive effect on us though. Depending on who is conducting the research, some groups who historically have experienced marginalization, oppression, or violence may find that information collected about them is used against them. For example, research findings may be used to justify surveillance of particular groups.

University-based Research:

- Because research may be harmful to particular groups, all research that sets out to collect information from people must be reviewed by an ethics board before it begins. The purpose of these Research Ethics Boards (REB's) is to protect people who take part in research. The REB's goal is to make sure that university-based research follows national research guidelines that are intended to protect research participants; the benefits of the new knowledge gained from doing the research must outweigh any potential harms to the participants.
- One example of a national set of research guidelines aimed at protecting research participants are the 2010 Tri-Council Policy Statement (TCPS2). In the spirit of protecting research participants, these guidelines provide information for participants on how to take part in research while staying safe and free of harm.

Your Rights as a Research Participant:

- If you choose to take part in research, your participation should always be voluntary. Before making your decision to offer your FREE and INFORMED CONSENT, you have the right to ask the researchers these questions, and any others that you feel are important:
    - How the study originated and what the purpose of the study is;
    - Who to contact if you have questions or issues;
    - Who benefits from the study;
    - How the study will be conducted;
    - What the risks and benefits to participating are;
    - What is required of you in terms of time commitments, information you will need to provide, how that information will be used, who has access to it, and how information will be stored and destroyed;
    - How to withdraw your consent to participate in the study;

    - How the findings from the study will be shared and who will have access to this information[1]

  You have the right to make a decision about your participation based on **your own free will.** In other words, there should not be any negative consequences for saying "no", or any major benefits if you say "yes".

- You have the right to **privacy**. This means that if you agree to participate in an interview for example, the researcher must make sure that it takes place in an environment that is safe and does not stigmatize or harm you in any way. Most social researchers meet participants at times and locations of their choosing.

- You have the right to know whether information about you will be **confidential**. Unlike the relationship between a doctor and a patient, the relationship between a researcher and a participant is not privileged. This means that it is not legally protected; in other words, if a researcher is called on by the courts to disclose information about you, they are not obligated to protect you. Having said this, some researchers will offer you **unlimited confidentiality** which means that even if they are faced with demands from the courts to disclose information about you, they will not. Other researchers will **limit confidentiality** which means that if they are faced with demands from the courts to disclose information about you, they will.

Tips for Participating in University-based Research Studies:

Ask researchers questions about their studies, like the ones listed in the 'Your Rights as a Research Participant' section above. This will help you in making a decision about participation. You may also:

- Ask why the researcher is approaching you to participate and what information they are hoping to collect, and how.

- Ask the researcher what s/he stands to gain personally and professionally from conducting the study.

- Ask the researcher who else is on the research team.

- Ask the researcher about their background and how they have contributed to your cause or identity group etc. Their answer should provide you with information regarding the level of commitment and investment that they have in your community.

- Ask researchers for a copy of their studies and information about how the study is funded. This will bring insight into whose interests are being considered, and who makes decisions about the research (i.e. how it is made available and to whom)

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[1] This is not an exhaustive list

- Ask about your privacy and the level of confidentiality the researcher is offering you.

- Ask for **consent forms**. Get copies of any consent forms and take time to read them before signing or agreeing to participate. Sometimes projects are advertised through flyers that promote all of the benefits or monetary gain one can expect from participation but do not discuss risks and other details. The most pertinent information that you will need to make a decision about participation for University-based research will be on the consent forms and not on promotional flyers. Please note that if you are asked to sign a consent form with your real name your participation is not anonymous.

- Ask about compensation and when it will be provided to you and under what conditions.

- Ask about the process for withdrawal from the study.

- Ask about publication of the research results

For More Information:

See Wigmore Criteria, a test for confidentiality http://www.sfu.ca/~palys/Wigmore.html

See TCPC2, Canada's national standards for research with human subjects http://www.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf

See "Research Ethics: A Guide for Community Organizations" http://bccec.files.wordpress.com/2007/12/community_research_-guidelines_feb2006_draft_.pdf

See Tips for Individuals Participating in Community-based Research http://bccec.files.wordpress.com/2007/12/research_participation_tips_feb2006.pdf

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

See also Palys and Lowman's: "What's Been Did and What's Been Hid: Reflections on TCPS2" http://www.sfu.ca/~palys/PalysLowmanCommentsOnTCPS2-2011.pdf

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