

Research involving humans is premised on a fundamental moral commitment to advancing human welfare, knowledge and understanding. As a research intensive institution, McMaster and its affiliated hospitals share this commitment to the promotion of responsible research.

We welcome your ideas, and feedback. Contact us at (szalak@mcmaster.ca or 905 525-9140 Ext. 26117).

RESEARCH FROM THE PARTICIPANT'S PERSPECTIVE

A group of Toronto health researchers experiencing difficulty recruiting Portuguese Canadian participants conducted a qualitative study to investigate research involvement from the participants' perspectives. Paula Barata and her colleagues conducted focus groups in which they introduced a mildly invasive fictional health study and used role play between the focus group moderators to explore Portuguese Canadian and Caribbean Canadian participants' concerns about recruitment and written consent.

The researchers discovered that building rapport throughout the research process (e.g., from recruitment to data collection to dissemination) is necessary to overcome general misconceptions and mistrust of research. Both immigrant groups identified a general lack of information regarding the research and genuinely wanted to receive more. Having clearly written participant information letters (translated when necessary) was appreciated and praised by participants. Both groups wanted and appreciated an opportunity to not only ask questions but found it useful to do so in group contexts. The authors advised that while similarities were found between the groups, it was important to further explore subtle cultural differences. This study underscored the importance of core ethical themes such as justice and inclusiveness (Tri-Council Policy Statement – pg. i 6) by ensuring that individuals and groups are not discriminated against or excluded from benefiting from advances in research.

Reference: Barata PC, Gucciardi E, Ahmad F, Stewart DE (2006) Cross-cultural perspectives on research participation and informed consent. *SOCIAL SCIENCE AND MEDICINE* (62) 479-490.

UNPACKING THE CIHR ABORIGINAL GUIDELINES

The Aboriginal Guidelines, designed in conjunction with the Canadian Institutes of Health Research (CIHR) and its Institute of Aboriginal Peoples' Health, were created to assist CIHR funded health researchers conducting studies with urban or rural Aboriginal people. "The Guidelines will assist in developing research partnerships that will facilitate and encourage mutually beneficial and culturally competent research".

<http://www.cihr-irsc.gc.ca/e/29134.html>

This brief document begins with background on and the rationale for the guidelines as well as the key ethical principles on Aboriginal health research. The process and procedures section, presented as an algorithm, walks the researcher through the research process from the concept development phase to ethics submission and dissemination of findings. A very useful feature of the guidelines is the sample research agreement found in the appendix. The research agreement will be a key document particularly when conducting community-based participatory research (CBPR). It is expected that these guidelines will be referenced in the upcoming second edition of the Tri-Council Policy Statement.

JOINT CENTRE FOR BIOETHICS WEBCASTS

REB CONTACTS:

McMaster Research Ethics Board (MREB)

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Hamilton Health Sciences / McMaster Faculty of Health Sciences Research Ethics Board (HHS/FHS REB)

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St. Joseph's Healthcare Hamilton, Research Ethics Board (SJHH)

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Dr. Raelene Rathbone, Chair
Dr. Astrid Petrich, Vice Chair
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Are you interested in attending the Joint Centre for Bioethics's presentations but can't manage the time for a trip to Toronto? You and your students can watch simultaneous web cast presentations as a remote participant and have the opportunity to send in your questions to the moderator. Register by going to the ePresence server at <http://epresence.ehealthinnovation.org/epresence>. You will need to obtain a login and password. Then mark the web cast on your calendars and log on 5 minutes before the scheduled broadcast.

Archived Presentations for use in teaching: More than 15 previous web cast presentations have been archived and are available for viewing at any time. Presentations address both clinical ethics and research ethics and include "Critical Issues in Community-Based Participatory Research Ethics," and "Challenges for Research During a Public Health Emergency: Learning from SARS". This term's series ended in June and resumes in September.

TIP: Links to these web casts can be put on course syllabi to add variety to standard print sources on research ethics.

NEED HELP WITH ETHICS?

Are you are preparing an application for human ethics review and have questions about the process? Help is a phone call or email away.

For assistance with submissions to the **McMaster Research Ethics Board (MREB) related to non-medical research** contact Karen Szala-Meneok or Michael Wilson (See the "REB CONTACTS" column in this newsletter for their contact information). The monthly MREB monthly ethics drop-in consultations will begin again in August, but you can contact the ethics office at any time to ask for advice or look over a draft of your application.

For assistance with submissions to the **HHS/FHS REB and /or SJHH REB** please contact the research ethics officer, Alison van Nie or the REB Coordinators, Deborah Mazzetti (HHS/FHS), or Leigh Mahan (SJHH) who will be happy to assist you with the process and answer your questions (See the "REB CONTACTS" column in this newsletter for their contact information).

COURSE APPLICATIONS FOR THE FALL TERM

Will you be teaching a course (non-health science) that requires students to conduct a research project with humans to develop their research skills?

Projects may be carried out by individual students, small groups or as a single class project. If you are designing this type of research course, consult the following link to the MREB Website to find course application forms and guidelines. Course approvals are valid for three years before having to resubmit.

<http://www.mcmaster.ca/ors/ethics/download/course%20guidelines.doc>

Renewal of Course-based Applications: If you received ethics clearance more than three years ago, you are required to submit a new application and supporting materials. Questions about submitting course applications to the MREB can be directed to Michael Wilson (X23142) or Karen Szala-Meneok (26117).

For Faculty of Health Sciences courses: please contact Alison van Nie (X 22057) vanniea@mcmaster.ca for specific requirements.