CAREB-ACCER 2016 National Conference and AGM
Concurrent Breakout Sessions

Thursday, May 26, 2016 – 1:30pm to 2:45pm

HALIBURTON ROOM – Upper Level

1. Managing Risk While in the Field: Negotiating Safety During Episodes of Gun Violence

Marta-Marika Urbanik, PhD Candidate and Instructor in the Department of Sociology at the University of Alberta

Moderator: Catherine Paquet, *CAREB Board Member; Director, Office of Research Ethics and Integrity, University of Ottawa*

Urban ethnographers are usually well aware of the risks associated with their research, even prior to entering the field. Decisions to proceed with the research are generally based upon weighing the value of what can be learned from researching disadvantaged groups and areas, against the potential risks to their safety while in the field. Sometimes however, communities undergo extreme changes in their level of safety, requiring an immediate reassessment of dangers associated with the research. Ethnographic research in Canada's oldest and largest social housing project – Regent Park – during a period of mass neighborhood change and amidst a flurry of gun violence, illuminates the difficulties facing ethics boards, and researchers in assessing, and responding to, high risk of potential violence.

HUMBER ROOM – Upper Level

2. Balancing Support and Overprotection in Research: Exploring Supported Entrepreneurship at Common Ground Co-operative

Courtney Bishop, Behaviour Consultant, Hamilton Brant Behaviour Services
Jennifer Hope, Executive Director, Common Ground Co-operative
Jennifer Li, Associate Professor of Accounting, Brock University
Frances Owen, Professor, Department of Child & Youth Studies and Centre for Applied Disability Studies, Brock University
Anne Readhead, PhD candidate, Child & Youth Studies, Brock University
Lisa Whittingham, MA Candidate, Brock University

Moderator: Delilah Ofosu-Barko, *CAREB Co-VP (Acting), Research Operations Manager, Trillium Health Partners*

Common Ground Co-operative is an innovative social service agency that supports five social enterprises in which the non-share-capital partners are adults who have developmental disabilities. The agency exists at the nexus of social service and social enterprise in its approach to supported entrepreneurship. The community-university research team will discuss strategies used in case study and social return on investment research to focus on the experience of partners while providing mechanisms for their support during data collection. Strengths and limitations of the research model and the balance between protection and overprotection in research and practice with persons who have intellectual and developmental disabilities will be discussed in the context of the United Nations on the Rights of Persons with Disabilities right to employment and participation and the TCPS2 research principles of Respect for Persons, Concern for Welfare, and Justice.

KINGSWAY ROOM – Upper Level

3. Model Review: A Discussion of Case Study and Framework to Enhance Research Ethics Review of Research Involving Gender Non-Conforming, Queer, and Trans* Youth

E. Sarah Bennett, Manager, Office of Research Ethics at Simon Fraser University
Holly Longstaff, Partner of the Engage Associates Consulting Group and Ethicist for the BC Cancer Agency REB

Moderator: E. Sarah Bennett, *Manager, Office of Research Ethics at Simon Fraser University*

The break out workshop will provide learning opportunities for REB members, support staff, and other interested participants to examine gender-related issues associated with the review of REB applications. Our session will be framed by ethics education resources produced by the CIHR Ethics Office. We will begin with a presentation to address relevant aspects of TCPS2 (2014) and provincial and federal regulatory issues followed by audience generated workshop deliberations.

In 2014, the CIHR Ethics Office launched the Ethics Education Workbook, which consists of a Knowledge-to-Action/Ethics framework, and a series of scenarios where an ethics lens is applied and discussed. The original case studies included in the resource were built around each of the four themes of CIHR funded health research and address a range of issues from new vaccines to surgical robots. Case studies are also regularly added over time to ensure the continued relevance of the materials to the research community. One of the most recently constructed cases addresses research with gender non-conforming, queer, and transgender youth.

The aim of this case is to raise awareness of ethics issues related to antiquated notions of parental consent and unfair barriers to research participation, among other things. Some may suggest that respectful research relationships, collaboration, and engagement with gender non-conforming, queer, and transgender youth is best guided by the new "distinct community" inclusion in TCPS2 (2014) chapter 9. However, others may warn about the various unintended consequences of exceptionalizing these studies, which could lead to increased REB paternalism, unwarranted bureaucracy, and participant disenfranchisement. We will work together with workshop participants to identify the most significant ethics issues to negotiate when reviewing this type of research and discuss the various ways in which our community can help to support study teams and participants involved in this research domain.

BALLROOM – Lower Level

4. Secretariat on Responsible Conduct of Research/Panel on Research Ethics

Susan Zimmerman, Executive Director of the Secretariat on Responsible Conduct of Research (SRCR)

Moderator: Susan Babcock, *CAREB Secretary, Executive Director (Acting), Research Ethics Office, University of Alberta*

The Secretariat on RCR will describe recent and current activities relating to proposed changes to the TCPS 2 having to do with population and public health researcher and clinical trials; consideration of TCPS 2 guidance with respect to ethics review of research involving cell lines (and more generally, all secondary cell use); and educational initiatives aimed at research participants.

CALEDON ROOM – Upper Level

5. Drugs, Ethics, and Research

Dario Kuzmanovic, Project Lead, www.drugsCBRethics.com and Director of Research Integrity at the University of California, Riverside, USA; Member of the Joint Centre for Bioethics (JCB) at University of Toronto
Peggy Millson, Professor Emeritus in the Dalla Lana School of Public Health, University of Toronto; Physician with a specialty in Public Health and Preventive Medicine

Moderator: Shane Kimber, *Department of Medicine, University of Alberta; Chair, Health Research Ethics Board (Biomedical Panel), University of Alberta*

While ethical guidelines for conducting community-based research (CBR) have proliferated, few publications address ethical research with people who use drugs. We conducted peer-reviewed and grey literature searches for substance use, CBR, and ethics. The thematic summaries from the scoping review and over 20 consultations with people who use drugs informed the development of the community resource. This scoping review and community resource complement recent social sciences and humanities research focused on the experiences of participants, researchers, and other stakeholders in CBR. We recommend a re-focus on the hard task of engaging participants and development of pragmatic ethical guidelines for researchers conducting studies with diverse communities of people who use drugs.

OAKVILLE ROOM – Upper Level

6. Facilitators and Barriers to Engaging in Health Research

Presenter: Sean B. Rourke, Clinical Neuropsychologist and Scientist at St. Michael's Hospital, Professor of Psychiatry at the University of Toronto and Scientific and Executive Director of the Ontario Ministry of Health AIDS Bureau-funded Ontario HIV Treatment Network

Moderator: Rachel Zand, CAREB-ACCER Past President (2013-2015); *Director, Office of Research Ethics, University of Toronto*

This session will focus on the social determinants of health and the community-based research contexts which affect the engagement and participation in health research in HIV/AIDS.

CAREB ACCER

Friday, May 27, 2016 -3:30pm to 5:00pm

BALLROOM – Lower Level

1. Is This Research or Not?

Don Flaming, Manager, ARECCI
Marie Pinard, Manager, Quality Management, The Hospital for Sick Children, Toronto, ON

Moderator: Brenda Sawatzky-Girling, *REB Member, Western Institutional Review Board (WIRB); PhD Candidate, University of British Columbia*

Non-research projects, such as quality improvement, program evaluation, needs assessment and knowledge transfer might resemble research because the same populations, designs, methods and statistical analyses are used. Although non-research projects may present similar ethical risks to participants, the TCPS2 explicitly states that they should not be reviewed by a Research Ethics Board (REB) as they are outside the REB's scope.

However, determining the difference between research and non-research is becoming increasingly difficult.

To assist professionals who conduct non-research projects and to reduce the burden on the REB by diverting the project's review, A pRoject Ethics Community Consensus Initiative (ARECCI) developed an open-access, online decision-making support tool: the Ethics Screening Tool. This tool can identify the need for appropriate ethical oversight for non-research projects.

In this breakout session, the presentation and discussion will be framed using questions from the Ethics Screening Tool. The use of the Tool in both health and non-health sectors will be touched upon, as well as the uptake processes used in both.

In addition to the case studies presented, audience participants will be invited to share their own experiences with projects that blur the lines between research and non-research, and the ethics oversight which might be applicable.

OAKVILLE ROOM – Upper Level

2. Researching Self-Injury Online: Ethical Challenges and Practical Solutions

Yukari Seko, University of Guelph

Moderator: Diana Raymond-Watts, *CAREB Board Member, North York General Hospital*

The anonymous and boundary-spanning nature of the Internet has provided researchers with the potential to access hard-to-reach population, such as youth engaging in non-suicidal self-injury (NSSI), the purposeful damaging of body tissue without suicidal intent. Given that adolescents and young adults report a higher NSSI rate and Internet usage than any other age groups, and that individuals who self-injure may use the Internet more frequently than those who do not, recent NSSI studies have greatly benefited from emergent online venues. Internet-based tools provide researchers with a convenient means to recruit participants, conduct naturalistic observation, and implement case studies and large-scale surveys. Researching NSSI via the Internet, however,

raises several ethical concerns regarding confidentiality, anonymity, data security and potential risks. Drawing on a series of Internet-based studies we have conducted at the Self-Injury and eMental Health Lab and the Centre for Addiction and Mental Health, and extant literature, this presentation discusses ethical challenges pertinent to online NSSI research, along with lessons learned and practical solutions we have developed thus far. This presentation will also draw on our recent interview study with REB members in Ontario regarding ethical challenges they are facing when reviewing Internet research. Some of the key ethical concerns and demands for updated national framework in the age of "digital scholarship" will be presented and discussed.

CALEDON ROOM – Upper Level

3. Whose Data? Who Participates? Who Decides?: Respecting the Rights of Human Participants and Other Research Contributors

Michelle K. McGinn, Professor and Associate Dean of Research and International Initiatives Member of the Brock University Social Science Research Ethics Board

Moderator: Delilah Ofosu-Barko, *CAREB Co-VP (Acting), Research Operations Manager, Trillium Health Partners*

Respecting and protecting human participants in research is a central concern in the field of research ethics. In the Canadian context, the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (*TCPS2*, 2014) provides definitions of research and of human participants, and presents principles and considerations to guide researchers and research ethics boards. Specifically, the *TCPS2* emphasizes "the treatment of persons involved in research directly as participants and those who are participants because their data or human biological materials…are used in research" (p. 6). There is also an acknowledgement that, "in some cases, research may involve interaction with individuals who are not themselves the focus of the research" (p. 14) and "are not considered participants" (p. 15), such as authorized personnel who provide access to available information. As well, research about a particular individual may rely upon information from third-party individuals. The *TCPS2* provides guidance and support for researchers and research ethics boards with respect to protecting the rights of human participants in research, but redirects researchers elsewhere in fulfilling their obligations to protect the rights of other research contributors.

This interactive workshop will explore what constitutes participation in research and the responsibilities of researchers and research ethics boards to respect individuals who are or are not recognized as human participants. Case illustrations will be drawn from a range of research traditions (e.g., autoethnography, living theory, evaluation, participatory research, and critical research) to introduce considerations related to (a) public, private, and personal information; and (b) social relations and power dynamics among researchers, human participants, and others. The session will be geared toward generating recommendations for researchers, research ethics boards, and the Interagency Panel on Research Ethics.

HALIBURTON ROOM – Upper Level

4. Turning Statements on Ethics and Research Data Management into Best Practices

Chuck Humphrey, Director of the Portage Network
Susan Babcock, Executive Director (Acting), Research Ethics Office, University of Alberta

Moderator: Susan Babcock, *CAREB Secretary, Executive Director (Acting), Research Ethics Office, University of Alberta*

The Tri-Agency Statement on Digital Data Management identifies expectations and responsibilities for the management of research data. Furthermore, a recent workshop for VPs Research organized by Research Data Canada and University of Alberta resulted in a statement of research data management principles. Both of these statements contain comments about ethics and data management without reference to actual practices. This presentation addresses the implementation of best practices to support the intent of these statements

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KINGSWAY ROOM – Upper Level

5. CIHR Ethics Policy Project - Patient Engagement in Research

Geneviève Dubois-Flynn, Manager, CIHR Ethics Office
Nicolas Fernandez, Professor at the Center for Applied Pedagogy in the Health Sciences of the Faculty of Medicine at the Université de Montréal
Michael McDonald, Professor Emeritus of Applied Ethics, W. Maurice Young Centre for Applied Ethics, Faculty of Medicine, University of British Columbia
Don Willison, Associate Professor and Interim Associate Director of Clinical Epidemiology and Health Care Research at the Institute of Health Policy Management and Evaluation, in the Dalla Lana School of Public Health, University of Toronto

Moderator: Shane Kimber, *Department of Medicine, University of Alberta; Chair, Health Research Ethics Board (Biomedical Panel), University of Alberta*

Draft Session Objectives:

- Raise awareness of patient engagement in research as partners.
- Introduce the new CIHR Ethics Policy project.
- Catalyze interaction and dialogue with panel and the audience on practical experiences of patient engagement in research, practical ethical issues arising, and gaps in ethics guidance.

Panel Members:

- Nicolas Fernandez, Genevieve Dubois-Flynn: speakers
- Don Willison, Michael McDonald: discussants

Speakers:

1) Nicolas:
   - Types of patient engagement as partners in research (distinct from patients as research participants/subjects) during the research lifecycle.
   - Potential benefits of including patients on a research team.
   - Potential ethics issues that can arise.

2) Genevieve:
   - High-level overview of the Strategy for Patient-Oriented Research (SPOR) and the Patient Engagement Framework
   - Relevant international initiatives; and
   - The CIHR ethics policy project.

3) Michael as a discussant
   - Type of knowledge that REB members would like to learn from patients involved in research projects.
   - Ways in which such knowledge may help REBs improve ethics review and oversight processes.

4) Don as a discussant
   - Ethics questions relevant to REBs that review research protocols with patients as co-partners.
   - The role of REBs in the ongoing monitoring of such research projects.

Format:

1) Formal presentations: 60 minutes
   - Speakers: present for 10-12 minutes each
     After each presentation, opportunity for the audience to ask for clarification (if need be)
   - Discussants: present for 10-12 minutes each
2) General discussion with the audience based on pre-identified questions: 30 minutes
   - How would the REBs' risk assessment differ when patients are engaged in research (e.g., clinical trials) as collaborators?
   - What are the ethics implications of patients as data collectors on the research team?
   - What are the gaps in ethics guidance for REBs in this area?

Post-session:

A survey for a broader consultation with CAREB members could be conducted.