Thursday, June 20, 2019 – Campus Administration Sunroom

9:15am – 10:15am
Keynote
Dr. Vicky Bungay, Associate Professor | Canada Research Chair: Gender, Equity & Community Engagement; Associate Director: Strategic Initiatives, School of Nursing, UBC

10:30am – 12:00pm
Panel: Empowering Communities: Taking Their Research Back

Research 101: A process for reflecting local understandings of "ethical" and "respectful" in community-developed guidelines for research in Vancouver's Downtown Eastside

Scott Neufeld, Vanier Scholar, PhD Student, SFU Department of Psychology & Research Assistant, BC Centre on Substance Use
Nicolas Crier, Project Coordinator, Megaphone Speaker's Bureau, Cast Member/Co-Creator, Illicit: A Shadow Story, Co-Author, Research 101/A Manifesto for Ethical Research in the DTES
Samona Marsh, Secretary, Vancouver Area Network of Drug Users (VANDU) & Board Member, Canadian Association of People Who Use Drugs (CAPUD), Co-Author, Research 101/A Manifesto for Ethical Research in the DTES

Vancouver’s Downtown Eastside (DTES) neighborhood is a heavily-researched community. Many folks in the neighborhood feel they have been "researched to death", and that too often research benefits researchers disproportionately, leaving them and their fellow community members feeling exploited, misrepresented, and exhausted. This points to differences in the ways that researchers, and research ethics boards (REBs), think about "ethical" practice in this particular context of community-based research. How can researchers and REBs alike gain a better understanding of community member understandings of ethical and respectful research in the context of the DTES? In early 2018, with funding and support from Simon Fraser University and DTES NGO "Hives for Humanity", we developed a series of six weekly workshops called “Research 101”. These workshops brought together approximately 13 representatives from peer-based organizations in the DTES (including people with lived experience of sex work, colonial trauma, criminalization for substance use, and both positive and negative experiences with research) to create space for community members themselves to discuss the pitfalls and potential of research in their neighborhood and to empower them to develop their own local guidelines for ethical research in the DTES. Research 101 workshop discussions were summarized in a co-authored “Manifesto for ethical research in the Downtown Eastside” that serves as a resource to both empower community organizations to develop more equitable partnerships with researchers and also help researchers ground their work in locally developed ethical principles of researcher transparency, community-based ethical review, empowering peer researchers in meaningful research roles, and taking
seriously the need for reciprocity in the research exchange. Our ongoing work includes building consensus for these guidelines within the community and institutionalizing the principles of the manifesto in local universities’ procedures for ethical review of research in the DTES. Furthermore, our process could be replicated elsewhere.

Nicolas Crier We will present along with Scott Nuefeld on a 2018 series of workshops called RESEARCH 101 and the resulting publication called A Manifesto for Ethical Research in the DTES

**Shannon Waters, Clinical Assistant Professor, School of Population and Public Health, UBC**

"Without us, all the crops would rot in the fields": Addressing systemic vulnerabilities of migrant agricultural workers through research

**Amy Cohen, Anthropology Professor, Okanagan College**

This presentation will examine the unique vulnerabilities of migrant agricultural workers in the Okanagan Valley and throughout Canada, and suggest best practices for researchers who wish to engage with migrant agricultural workers to address some of these challenges.

**1:30pm – 2:30pm**

**Taking Care of Each Other: First Nations Engagement in Ethics Review at First Nations Health Authority**

**Namaste Marsden, BA, LLB, Manager, Research and Knowledge Exchange, FNHA**

First Nations Health Authority (FNHA) recently celebrated its fifth year in service to communities. Its unique governance model, commitment to cultural safety and humility and transformation of health services to become more respectful and accessible for First Nations have helped it stand out as an innovative model for systems change. In the area of research and ethics the FNHA has been building capacity and engaging First Nations in defining self-determination in research through partnerships and initiatives at local, regional and provincial levels. FNHA also aligns with Indigenous led initiatives at the national and international levels. This brief talk will update participants on initiatives FNHA has taken in this shared space to transform how research is implemented in accordance with the Seven Directives which are Nation and community formed principles that guide FNHA’s service delivery mandate.

**CULTURAL SAFETY TRAINING**

**Laurie Harding, MSW, BA, Integration Lead, San’yas Indigenous Cultural Safety Program, Indigenous Health, PHSA**

**Nancy Laliberte**

What’s the Harm? Research Ethics Board’s Responsibilities in Reconciliation Racism and stereotyping towards Indigenous people are deeply embedded in the social fabric of Canadian society. Due to the structural and systemic nature of Indigenous specific racism, it often becomes normalized within our
social systems and institutions. In this age of truth and reconciliation, both the federal and BC provincial
governments have adopted and are moving toward implementing the United Nations Declaration on the
Rights of Indigenous Peoples and the 94 Calls to Action of the Truth and Reconciliation Commission. We
suggest these pivotal documents can be utilized as accountability frameworks for meaningful change,
especially in the area of systemic racism, toward reconciliation.

2:30pm – 4:00pm
Panel: Creative Practice/Applying Exemptions

Research Ethics Review in Art + Design Settings: A view into the grey zone between practice and research Synopsis

Dr. Lois Klassen, Research Ethics Board Coordinator, Emily Carr University of Art and Design
Dr. Jamie Hilder, Independent Artist and Instructor, Faculty of Culture + Community, Jake Kerr Faculty of Graduate Studies, Emily Carr University of Art and Design

Reviewers from a research ethics board that primarily reviews proposals from artists and designers become very familiar with the TCPS2’s creative practice exemption, as well as other exemptions that may apply to creative research methods. This presentation will briefly review how art and design research, including research-creation methods, are approached by the research ethics board of Emily Carr University of Art + Design. Whereas the participation of humans in art and design research presents unique potential benefits, expertise in the disciplinary contexts for art and design methods is required by REBs. This presentation will emphasize the level of judgement required in interpreting TCPS2 guidelines surrounding creative methods.

Exemptions to the Rule: Creatively Engaged, Ethically Complex Sharing three different research projects undertaken by students

Dr. Lynn Fels, Associate Professor, Faculty of Education, SFU
Denise Kenney, Associate Professor, Interdisciplinary Performance, UBCO

Lynn will speak to the ethical tensions and creative challenges that researchers encounter when engaged in research in the arts.

Dialogical and Social Art Practice Artists are always in conversation with their communities; they enter the discourse through their art. This is true for all art genres and practices. Questions are explored and resolved within the art, not prior to it, and considering and navigating ethical relationships throughout the creative engagement is fundamental to all art production methodologies. Various case studies in Kenney’s dialogical performance and social art practice will be discussed to explore just how nuanced and project-specific these considerations are.
4:15pm – 5:15pm

Dr. Jeannette Armstrong, Canada Research Chair (Tier2) in Okanagan Indigenous Knowledge and Philosophy; Professor, Indigenous Studies, UBCO

Friday, June 21, 2019

9:15am – 10:15am
KEYNOTE
Dr. M-J Milloy, Canopy Growth Professor of Cannabis Science UBC

The legalization of adult non-medical cannabis use in October 2017 is the biggest change in Canada's policies on psychoactive substances for decades. One aspect of the repeal of cannabis prohibition is the implementation of a new regulatory framework for research into cannabis. Along with increased funding from governments and industry, these regulatory changes have sparked a new interest in determining the harms and possible benefits of cannabis use, both non-medical and medical, on the health and wellbeing of Canadians. In his presentation, Dr. Milloy will briefly summarize emerging research into cannabis use by people living with substance use disorders and the possible use of cannabis as an intervention in the ongoing opioid overdose crisis. He will focus on the interrelated scientific, regulatory and ethical challenges of conducting observational and experimental research into cannabis use among people at risk of overdose.

10:30am – 11:45am
Panel: Innovations to Informed Consent

Zach Camozzi, Sessional Faculty, Emily Carr University of Art and Design

Re-designing assent for participatory design research with grade 5 students The Health Design Lab, a research and design centre at Emily Carr University, has been engaged in participatory design with Kenneth Gordon Maplewood School, a private K-12 school that serves children with learning differences. Started as an inquiry into how objects might augment the learning of grade school students. Now, in its tenth year, it supports and creates opportunities for faculty, masters and undergraduate research. This presentation shares materials that challenge the existing format of assent for this ongoing collaboration. It suggests that designers should be applying their skills to the consent process and questions the effectiveness of predetermined templates.
Dr. Kristie Westerlaken, Manager, Research Ethics Board, BC Cancer

BC Cancer recently developed a new informed consent form with the goal of ensuring all current regulatory and ethical requirements are met, but also with the intent that the document is clear and concise so that participants are actually informed about the study. I'll discuss the process of how the document was developed.

Dr. Suzanne Vercauteren, Director BC Children’s Hospital BioBank

Multimedia e-consenting platform for biobanking and other research BC Children’s Hospital Biobank (BCCHB) is a valuable resource to local, national and international investigators, providing high-quality patient samples with corresponding de-identified clinical data for their research. Before patients participate, patient or parental/guardian consent is obtained, a process that informs the patient of the goal, risks and benefits of the BioBank, among other information. In addition, children age 7 years and older partake in an assent process in which the children are informed about the research and their permission to participate is requested. Informed consent is important to achieve ethical standards and maintaining participant and public trust. The current consent process for the BCCHB consists of a traditional 11 page paper form with few visual aids. Feedback received through our patient and public engagement initiatives indicates that there is room for improvement in the traditional consent process. Modernizing consent for research through the use of readily available electronic devices may facilitate the consent process while also improving comprehension and engagement of pediatric participants. Initial work by the privacy officer of PHSA has shown that electronic consent is safe and adheres to all privacy standards. This project will adapt existing BCCHB consent forms to an interactive electronic format, with multilingual options. Our multidisciplinary team, including biobank specialist, ethicist, patient experience scientist, privacy/regulatory expert and a bio-informatician, will provide input throughout the development process. In addition, patient/family representatives will advise on all stages of the project, pilot the consent tool and provide input from the end-user’s perspective. Participant satisfaction and user experience will be assessed after implementation. The standard template for e-consent resulting from this project will not only be used for the BioBank consent process but will also be available to all PHSA investigators, for use in their study specific research.

11:45am – 12:15pm
Research Ethics BC Harmonization Update
Terri Fleming, Unit Director Research Ethics BC
Paola Pinto Vidal, Research Ethics BC Navigator

Research Ethics BC is moving into a new phase after joining the family of operating units under the BC AHSN. In this short presentation, we will highlight some of the achievements of the recent past and present some of the strategic areas under development for research ethics in the province of BC.
1:15pm-1:45pm
Update from the Secretariat on Responsible Conduct of Research
Hanan Abdel-Akher, Senior Policy Analyst, Secretariat on Responsible Conduct of Research

During this session, Hanan Abdel-Akher will present highlights of the latest changes to the second edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans

1:45pm – 2:45pm
Panel: Community Engagement/Participant Feedback

Dr. Rachelle Hole, Associate Professor, School of Social Work; Director, Centre for Inclusion and Citizenship, UBCO

Considerations for Integrating a Patient-Oriented Approach into Ethical Reviews
Brittney La Pietra, SFU Research Navigator, Fraser Centre
Sarah Flann, Research Ethics and Regulatory Specialist, Department of Evaluation and Research Services, Fraser Health

CIHR’s SPOR (Strategy for Patient-Oriented Research) is a national initiative to close the gap between researchers and knowledge users in the health care sector by expanding the patient role beyond participant, embedding them directly within research teams as partners. An integral piece of the patient-oriented research (POR) approach is ensuring information generated by research teams is relevant and usable by knowledge users, and translating that knowledge back to the community or individuals impacted by the research in a meaningful way. Using local examples, we will explore the REB’s role in ensuring the ethical conduct of patient-oriented research (POR) and discuss how the core principles of POR could inform ethical reviews to improve the quality of research overall.