

Panel 1: Indigenous Research Governance

The Kahnawake Schools Diabetes Prevention Program Code of Research Ethics: An Indigenous Approach to Ethical Health Research - Treena Delormier, Kaylia Marquis

In 1994, in the Kanien'kehá:ka (Mohawk) community of Kahnawake, a research project was initiated to address the high prevalence of type 2 diabetes in the community. Using a health promotion approach, schoolchildren would be supported to improve physical activity and nutrition for the primary prevention of type 2 diabetes, and participatory research would examine the impact of the intervention. At the outset of the research, it became clear that guidelines were needed to ensure that the self-determination, responsibilities, and values of the Kahnawake people would be respected. After an 8-month process involving the community and research partners committing to an understanding of each others distinct obligations and responsibilities in research, the Kahnawake Schools Diabetes Prevention Program Code of Research Ethics was complete. The Code was one of the first Indigenous community research ethics codes elaborated in Canada and served as a model for the chapter on Research Involving the First Nations, Inuit and Métis Peoples of Canada in the initial Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. In our presentation we will discuss the participatory process that guided the Code's development, we will describe the Indigenous principles and values that are represented in the code, and in the practices it supports. We will review the two revisions of the Code and provide examples for how research is approved in practices and some of the challenges to using the code.

Anishinaabek Research Ethics and Governance – Lorrilee McGregor

The Manitoulin Anishinaabek Research Review Committee (MARRC) serves seven First Nation communities on Manitoulin Island. Fed up with unethical research practices, the communities gathered to develop *Guidelines for Ethical Aboriginal Research*. For the past 20 years, the committee has supported research governance through ethics reviews, capacity building, policy development, and research conferences. This presentation will describe what research governance looks like in practice.

Guidelines for Research with Aboriginal Women – Suzy Basile

These guidelines are intended to help manage the many research proposals received and make informed decisions on whether or not to become involved in those projects. The guidelines also outline an approach that will help establish a transparent, equal and mutually respectful relationship between the researchers and the Aboriginal women concerned.

Panel 2: Urban Community-Led Research Governance

The Jane Finch Community Research Partnership – Abena Offeh-Gyimah, Farwa Arshad

In this presentation, we will discuss our training modules, *Tools for Conducting Research in Jane and Finch Community*; the Jane Finch Research Collection, which is a digital repository for past research and scholarship about the neighbourhood, and the *Principles for Conducting Research in Jane Finch* document. These projects are committed to protecting residents of the Jane Finch community from harm caused by research; while educating researchers to adopt ethical and equitable research methods that move beyond harmful objectification and stigmatization of the Jane Finch community.

Research 101: A Manifest for Ethical Research in the Downtown Eastside - Jule Chapman, Nicholas Crier, Scott Neufeld

Co-authors of the groundbreaking resource publication known as Research 101: *A Manifesto for Ethical Research in the Downtown Eastside*, will present as a group on the history of the Research 101 project, the writing and publication of the Manifesto, and sharing how the next steps towards their collective vision of building a Community Research Ethics Workshop in the Downtown Eastside has taught them some valuable lessons, and how the process even inspired a documentary film.

Research 102: Meaningful Activist Research in Treaty 6 Territory – Rylan Kafara

Research 102 was created in late 2019 and early 2020 during a series of workshops with city-centre residents, activists, and workers from harm-reduction centres, social organizations, and academic institutions in city-centre Edmonton. The purpose of *Research 102* was to help ensure a collaborative and mutually beneficial research process for everyone involved in a city-centre project. This presentation explains that research process, guided by the “five spokes of the research wheel”, and how *Research 102* was used in projects since the onset of the COVID-19 pandemic.

Speaker Bios

Aianóhon Kaylia Marquis is Kanien'kehá:ka (Mohawk) from the Kahnawà:ke Mohawk Territory, and has been the Network Manager for the Tahatikonhsontóntie' Québec Network Environment for Indigenous Health Research since its inception. She has a background in psychology, project management, and entrepreneurship. She has most recently worked delivering projects for community and grassroots organizations related to environment protection, food security, social entrepreneurship, and early childhood education.

Dr. Treena Wasonti:io Delormier is Kanien'kehá:ka, and a member of the Wolf Clan from the Kahnawà:ke Mohawk Territory. An Associate Professor at McGill University's School of Human Nutrition, she is also serving as the Associate Director of McGill's Centre for Indigenous Peoples' Nutrition and Environment (CINE). Her research focuses on the food and nutrition of Indigenous peoples, as well as health promotion interventions that address the social determinants of health underlying the health inequities in Indigenous populations, particularly in the context of colonialism. Dr Delormier's research approaches employ qualitative methodologies, with a focus on Indigenous and community-based methodologies. She is dedicated to building capacity in Indigenous health research through mentoring and training students, as well as community researchers.

Lorrilee McGregor is an Anishinaabe from Whitefish River First Nation. She is an Assistant Professor at the Northern Ontario School of Medicine where she teaches about Indigenous peoples' health. Dr. McGregor has been a member of the Manitoulin Anishinaabek Research Review Committee since 2002.

Suzy Basile comes from the Atikamekw community of Wemotaci, Quebec, Canada. She is professor at the School of Indigenous Studies of UQAT, at the Val-d'Or campus. In 2017, she set up a Research Laboratory on Indigenous Women Issues – Mikwatisiw and since January 1st, 2020 holds a Canada Research Chair on Indigenous Women Issues. She developed the Guidelines for Research with Aboriginal Women for Quebec Native Women Association published in 2012.

Abena Offeh-Gyimah is a writer, a researcher, and an advocate for an indigenous food sovereignty system. She's worked at Black Creek Community Farm as a coordinator for the youth farming program, with Building Roots as an urban gardener coordinator, with North York Community House as a Strong Neighborhood Coordinator, and currently the project lead with the Jane Finch Community Research Partnership which focuses on respectful and ethical research relationships for Jane and Finch. Her food business, Adda Blooms, seeks to work with small scale farmers to bring ancestral foods worldwide. Her blog, <https://abenaoffehgyimah.com/>, seeks to explore the intersections between food, culture, and equity.

Farwa Arshad is a 4th year student at York University majoring in Global Health and specializing in health policy, management, and systems. She works for the Jane Finch Community Research Partnership as a community research associate and is currently working on establishing an open-access community-based repository containing academic articles on the Jane Finch community. She is also involved in the York University community as the president

of the Global Health Students' Association, the representative body for the Global Health degree program, and as the careers coordinator for her faculty-associated colleges.

Jule Chapman is one of the research 101 CREW members and has been living in the Downtown Eastside (DTES) for the past 20 yrs. She is an outreach worker as well as a student journalist who is working with a magazine called Megaphone Magazine.

Nicolas Crier is a peer leader in Vancouver's Downtown Eastside community. He works with a number of initiative/progressive initiatives, including: Storytelling & Community Networking Liaison @ Megaphone Magazine, Peer co-lead Writer and Research Assistant with the UBC Transformative Health and Justice Research Cluster, Lived Experience Strategic Advisor with BC Mental Health and Substance Use Services, and Peer Responder/Outreach staff at the PHS Mobile Overdose Prevention Unit. He also attends a Continuing Studies course through Simon Fraser University called Community Capacity Building. In all he does, he sends love to his 11 year old son, Money.

Scott Neufeld is a Lecturer in Community Psychology at Brock University and a PhD candidate in Social Psychology at Simon Fraser University. His community-based and qualitative research seeks to broaden and deepen understanding of substance-use related stigma and exclusion to address these issues more robustly. This has taken many forms but has included collaborative work in Vancouver's Downtown Eastside to develop grassroots guidelines for conducting ethical and respectful research with people who use drugs (<http://bit.ly/R101Manifesto>) and a comprehensive review of substance use-focused anti-stigma campaigns from across Canada (bit.ly/FIRST-antistigma). Check out more of Scott's research interests and writing [here](#).

Rylan Kafara is a long-time city-centre worker, volunteer, and activist. Currently, he is a PhD candidate in the Faculty of Kinesiology, Sport, and Recreation at the University of Alberta. He is studying the ways city-centre residents use care, creativity, and connection to navigate houselessness.