

April 16, 2024

Indigenous Health Research Ethics in Clinical Research Symposium



Jack Poole Hall, Robert H. Lee Alumni Centre
University of British Columbia



Michael Smith
**Health
Research BC**
BC SUPPORT UNIT



This symposium brings Indigenous ways of knowing to health research and care.

We've invited trainees, researchers and leaders in research ethics to learn about innovative practices and solutions. We're building new relationships. We're also learning from established and emerging leaders in Indigenous research and research ethics. The symposium is hosted by the BC Network Environment for Indigenous Health Research (BC NEIHR) and the BC SUPPORT Unit.

“ **Whereas Indigenous ethics are a topic of intense dialogue, a pressing need exists to update ethics policy to align with community protocols actively engaged in reclaiming Indigenous knowledges in a context of self-determination. The pursuit of fundamental human rights, social justice and respect for human dignity, underscores ethical concepts and practice for Indigenous governance and must include Indigenous data sovereignty grounded in community distinctions-based research ethics. Each Indigenous community is unique, representing their distinctive cultures.** ”

– Dr. Jeffrey Reading, co-director, Centre for Collaborative Action on Indigenous Health Governance, Simon Fraser University

“ **Enacting Indigenous cultural safety (ICS) and respecting the right of communities to be self-determining in research leaves many research ethics board members uncertain about how to implement Chapter 9 and navigate tensions; consequently, ongoing ICS learning and understanding still needs to occur to uphold and advance Indigenous ethics and address policy to practice gaps. This gathering is an important opportunity for that learning, as it offers us a convening space to build relationships and co-create solutions.** ”

– Tara Erb, network coordinator, BC Network Environment for Indigenous Health Research

“ **This gathering represents an important milestone in the journey of engaging in relationship-building between Indigenous health researchers, trainees, and research ethics leaders in BC's health research ecosystem. By bridging the gap between Indigenous knowledge and existing clinical research ethics processes, we have an opportunity to enhance cultural safety in the system. This will help to transform clinical research ethics and improve Indigenous health outcomes.** ”

– Dr. Krista Stelkia, co-director, Centre for Collaborative Action on Indigenous Health Governance, Simon Fraser University

“ **We know inequities in the health research system continue to harm Indigenous peoples and communities. That's why the BC SUPPORT Unit partnered on this event that supports reconciliation in health research. I'm grateful to be part of this work that brings together Indigenous researchers and trainees with research ethics leaders to build the future of Indigenous health research in BC.** ”

– Monica Mamut, director, BC SUPPORT Unit





Mental wellness support

Cultural and mental wellness support is available for people in BC. Contact the following organizations for services online or by phone.

| Organization | Connect | Services |
|---|--|---|
| Tsow-Tun-Le-Lum Society | 1-888-403-3123 (toll-free) | Immediate crisis support available Monday to Friday 8 a.m. - 8 p.m., weekends 10 a.m. - 2 p.m. |
| First Nations and Inuit Hope for Wellness Help Line and On-line Counselling Service | 1-855-242-3310 (toll-free) www.hopeforwellness.ca | Immediate mental health counselling and crisis intervention to all Indigenous people across Canada. Connect with an online counsellor 24 hours a day, 7 days a week. |
| National Indian Residential School Crisis Line | 1-866-925-4419 (toll-free) | Emotional and crisis referral for former residential school students. Available 24 hours a day, 7 days a week. |
| Carrier Sekani Family Services | 1-800-889-6855 (toll-free) | Mental wellness counselling and addictions program, tele-health and primary health services for First Nations in BC. |
| KUU-Us Crisis Line Society | 1-250-723-4050 (adults/Elders) 1-250-723-2040 (youth) 1-800-588-8717 (toll-free) | Culturally safe help available 24 hours a day, 7 days a week. Crisis response services for adults, elders, and youth. |
| Métis Crisis Line | 1-833-MétisBC 1-833-638-4722 | Available 24 hours a day, 7 days per week. All crisis response personnel are certified and trained in Indigenous cultural safety bringing an understanding of Métis history and trauma. |
| FNHA mental wellness and counselling support through health benefits | 1-855-550-5454 | All mental wellness and counselling services require prior approval. Find a provider: https://bit.ly/FNHA-providers |

The objectives of this event are to:

1. Advance the engagement and understanding of Indigenous health research ethics in clinical practice.
2. Provide networking and convening spaces, and provide mentorship.
3. Support research talent development opportunities for Indigenous scholars, students, and early-career clinicians and researchers.





AGENDA

| Opening session | |
|-------------------------|--|
| 8:30 – 9:00 a.m. | Registration and breakfast |
| 9:00 – 9:30 a.m. | Opening prayer <ul style="list-style-type: none"> • Elder Glida Morgan • Elder Barbara Hulme |
| 9:30 – 10:00 a.m. | Welcoming remarks <ul style="list-style-type: none"> • Harley Eagle, Indigenous cultural safety and humility consultant • Dr. Jeffrey Reading, co-director, Centre for Collaborative Action on Indigenous Health Governance, Simon Fraser University • Dr. Krista Stelkia, co-director, Centre for Collaborative Action on Indigenous Health Governance, Simon Fraser University • Tara Erb, network coordinator, BC Network Environment for Indigenous Health Research • Dr. Stirling Bryan, chief scientific officer, Michael Smith Health Research BC • Gillian Corless, senior manager, Indigenous partnerships, Michael Smith Health Research BC • Michelle Buchholz, graphic recorder <p>Moderator: Mark Matthew, director, Indigenous health, Health Quality BC</p> |
| 10:00 – 10:30 a.m. | Keynote <ul style="list-style-type: none"> • Dr. Evan Adams, deputy chief medical officer, First Nations Health Authority |
| 10:30 – 10:45 a.m. | Wellness break |
| 10:45 – 11:30 a.m. | Plenary session: Advancing engagement and understanding of Indigenous health research ethics in clinical research <ul style="list-style-type: none"> • <i>Silent Genomes Project</i>: Dr. Jeffrey Reading, co-director, Centre for Collaborative Action on Indigenous Health Governance, Simon Fraser University • <i>Hishuk-ish tsawalk (everything is one, everything is connected): Using two-eyed seeing to optimize healthy early life trajectories for Indigenous Peoples</i>: Dr. Pablo Nepomnaschy, professor, faculty of health sciences, Simon Fraser University; Lynnette Lucas, director of health, department of health, Nuu-chah-nulth Tribal Council <p>Moderator: Mark Matthew, director, Indigenous health, Health Quality BC</p> |
| 11:30 a.m. – 12:30 p.m. | Lunch |



| Afternoon session | |
|-------------------|--|
| 12:30 – 1:30 p.m. | <p>Session 1: Building research relationships with Indigenous communities, collectives and organizations (ICCOS)</p> <ul style="list-style-type: none"> • Elder Dave Frank, co-lead of the Uut Uuštukyuu Society • Penina Harding, manager, Indigenous student empowerment, University of Northern British Columbia <p>Moderator: Elizabeth Hunter, research analyst, Centre for Collaborative Action on Indigenous Health Governance, Simon Fraser University</p> |
| 1:30 – 2:30 p.m. | <p>Session 2: Showcasing innovative models or case studies on existing Indigenous-led research</p> <ul style="list-style-type: none"> • Dr. Jeffrey Reading, co-director, Centre for Collaborative Action on Indigenous Health Governance, Simon Fraser University • Dr. Shannon Dames, professor, Vancouver Island University and Charsanaa Johnny, project coordinator, Kw'umut Lelum Foundation <p>Moderator: Taylor Atwater, Indigenous health research facilitator, Vancouver Coastal and Pacific Region, Centre for Collaborative Action on Indigenous Health Governance, Simon Fraser University</p> |
| 2:30 – 2:45 p.m. | <p>Wellness break</p> |
| 2:45 – 3:25 p.m. | <p>Session 3: Wise or promising practices and training the next generation (future thinking)</p> <ul style="list-style-type: none"> • Dr. Jessie King, assistant professor, University of Northern British Columbia (developed with Dr. Rheanna Robinson) and Tara Erb, network coordinator, BC Network Environment for Indigenous Health Research <p>Moderator: Keiten Brown, Indigenous health research associate, Centre for Collaborative Action on Indigenous Health Governance, Simon Fraser University</p> |
| 3:25 - 3:45 p.m. | <p>Session 4: Looking forward</p> <p>Moderator: Mark Matthew, director, Indigenous health, Health Quality BC</p> |
| 3:45 – 4:30 p.m. | <p>Closing remarks, reflections, closing prayer and dance</p> <ul style="list-style-type: none"> • Elder Glida Morgan • Elder Barbara Hulme • Mark Matthew, director, Indigenous health, Health Quality BC • Michelle Buchholz, graphic recorder • Dancers of Damelahamid • Compaigni V'ni Dansi group <p>Moderator: Mark Matthew, director, Indigenous health, Health Quality BC</p> |



BIOGRAPHIES



Evan *Tlesla* Adams is a Coast Salish physician from Tla'amin First Nation near Powell River, BC, Canada. Evan completed his medical doctorate at the University of Calgary and a residency in the Aboriginal family practice program at the University of British Columbia in Vancouver. Evan has a master of public health from Johns Hopkins University in Baltimore, Maryland. He was the deputy provincial health officer for BC (2012 –2014), the chief medical officer (CMO) of the First Nations Health Authority (FNHA) (2014 –2020), and then the deputy chief medical officer of First Nations and Inuit health branch, Indigenous Services Canada (2020 –2023). He has recently returned half-time to the FNHA as their deputy CMO and half-time to Simon Fraser University's new medical school as an acting associate dean.



Taylor Atwater is Stó:lō, from Semà:th First Nations with mixed ancestry. She has a background in clinical exercise physiology and is a graduate student at Simon Fraser University exploring First Nations communities' distinction-based approaches to health research ethics in BC. She is passionate about advancing the wellbeing of Indigenous Peoples, promoting cultural safety and humility, and exploring structural racism. She is currently employed with the BC Network Environment for Indigenous Health Research and the Centre for Collaborative Action on Indigenous Health Governance as an Indigenous health research facilitator for both the Vancouver and Fraser regions. Taylor lives on the unceded and occupied lands of the xʷməθkʷəy̓əm, Sḵw̓x̓ wú7mesh, and səliłwətał Nations.



Keiten Brown is a proud Secwépemc woman from Bonaparte First Nation. She holds a bachelor of science from the University of British Columbia, and is currently pursuing a master of science at Simon Fraser University. She holds over six years of experience working in Indigenous health. In her current role as an Indigenous health research associate at the Centre for Collaborative Action on Indigenous Health Governance, Keiten channels her passions for Indigenous Peoples health and wellness, art, traditional knowledge preservation, biodiversity and ecological health, decolonizing frameworks, social justice, and cultivating meaningful relationships.



Dr. Stirling Bryan is a first-generation settler with Scottish and English ancestry. He is university-based health economist with extensive experience of engagement with the policy and decision-making world. Stirling is professor in the school of population and public health at the University of British Columbia and senior scientist at the Centre for Clinical Epidemiology & Evaluation. Stirling is a strong advocate for, and practitioner of, patient-oriented research, and now partners with patients in all of his research activities. In 2021, he was appointed chief scientific officer for Michael Smith Health Research BC.





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Michelle Buchholz (she/her) is a proud Wet'suwet'en, Gitxsan woman. She holds a Master's of Public Policy from Simon Fraser University and wrote her capstone research on developing policies to address anti-Indigenous racism in health care. Michelle is the owner of Cassyex Consulting and much of her work is focused on graphic recording and graphic facilitation, though she is also an evaluator, policy analyst, qualitative researcher. As a visual practitioner, Michelle calls graphic recording a "witnessing," similar to how Wet'suwet'en people hire witnesses to have an oral record of governance within our feast halls.



Gillian Corless, senior manager of Indigenous partnerships with Michael Smith Health Research BC. Health Research BC is committed to reconciliation through increasing Indigenous self-determination within organizations and systems. She holds a MA from McGill University in community-based policy and planning and has held key roles in ethics, governance, and Indigenous community engagement in decision-making for more than 20 years. Gillian is a seventh-generation settler with Scottish, English and Irish ancestry. She now lives with her family on Neᓄwlélexm (Bowen Island), in the unceded, ancestral territory of the Sᓄwᓄwú7mesh (Squamish) Nation, and works in the traditional territories of the xʷməθkʷəy̓əm (Musqueam) Sᓄwᓄwú7mesh (Squamish), səliiwətał (Tsleil-Waututh) and Coast Salish peoples in BC.



Dr. Shannon Dames is a third-generation immigrant with mixed ancestry from Britain, Norway and Germany. She lives and serves as the innovation and nursing lead for The Roots to Thrive Society for psychedelic therapy. She's also a recipient of Michael Smith Health Research BC's Health Professional Investigator Award. Shannon is a professor at Vancouver Island University, which is situated on the unceded territory of the Stz'uminus and Snuneymuxw People. Her current work focuses on the development of innovative research infrastructure that promotes resilience and supports psychedelic service delivery and education development.



Harley Eagle is of Indigenous Dakota and Ojibway ancestry, originally from Saskatchewan. He has lived with his family at different times for over 25 years in Vancouver Island and is currently residing on the Island in the Traditional Territory of the K'ómoks Peoples. He is an Indigenous cultural safety and humility consultant who facilitates workshops and sessions that explore and build a foundation of understanding. This includes an Indigenous perspective on colonization, addressing systemic racism and trauma-informed practice. He also consults with many organizations across several societal sectors to strengthen their Indigenous cultural safety and humility capacity.





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Tara Erb is of mixed Moose Cree First Nation from Moose Factory and French European ancestry and grew up in Toronto, Ontario. She completed her bachelor and master of arts in sociology from the University of Victoria. Tara is currently completing her PhD in the faculty of health sciences at Simon Fraser University under the supervision of Dr. Krista Stelkia with a research focus on Indigenous cultural safety in research environments and structures, specifically ethics and ethical processes. Her research interests include Indigenous health and wellness, Indigenous cultural safety, anti-Indigenous racism and social theory. Currently, Tara is the network coordinator of the BC Network Environment for Indigenous Health Research residing as a guest on the territory of the Songhees, Esquimalt and W̱SÁNEĆ peoples.



Hičismi?a- Lighting The Way For Others (Dave Frank) was raised in Maaqtusiis, Dave belongs to families from ʕaaḥuusʔath, Qwatswii, and Keltmaht. Dave is a cultural leader and knowledge holder in Nuu-chah-nulth ḥaaḥaaḥuuli and travels widely to support healing requests. The incorporation of the Uut Uustukyuu Society realizes a vision nurtured for decades; to fully wake up healing modalities of the territory and increase access to these pathways for healing.



Penina Harding is a Secwépemc scholar from the Esk'etemc First Nation. At the University of Northern British Columbia she is a fourth-year PhD candidate in natural resources and environmental studies with a focus on Indigenous environmental planning. She is a part-time instructor in the school of planning and sustainability under the faculty of environment, and the manager of Indigenous student empowerment. She received a Social Sciences and Humanities Research Council Doctoral Fellowship (2022-25) and is a former recipient of the BC Network Environment for Indigenous Health Research Doctoral Scholarship (2020-21). She is a mother and Indigenous content creator on TikTok as @academic_aunty and on Instagram as @penina_and_her_phd.



Barbara Hulme is honoured as a founding member of the Métis Nation Greater Victoria. “Barb”, as she is affectionately known, is a mentor, a knowledge keeper and now, a trusted elder in the Métis community. Through teaching and mentorship at the University of Victoria, Barb supports Métis students at the First People’s House. Her mentorship is part of a much wider, more diverse effort, on Barb’s part, to improve the Métis community. She has also volunteered in her local Métis office as an administrator, historian, citizenship coordinator and genealogy advisor for more than 13 years.



BIOGRAPHIES



Elizabeth (Liz) Hunter is Stoney Nakoda from GoodStoney First Nation located in Mîñî Thîñî, Alberta. She currently resides as an uninvited guest on the unceded and occupied territories of the xʷməθkʷəy̓əm (Musqueam), Sk̓w̓x̓wú7mesh Úxwumixw (Squamish), səliiwətaʔt (Tsleil-Waututh) Nations. Liz is currently pursuing her undergraduate degree in health sciences with a minor in Indigenous studies at Simon Fraser University. She has over five years of experience working within Indigenous health organizations, most recently the First Nations Health Authority. Most recently, Liz became a certified doula grounded in Indigenous teachings and worldviews. Liz is passionate about exploring sleep, women's health, sustainability, biodiversity, disability, traditional food systems and Indigenous food sovereignty.



Charsanaa Johnny is an Afro-Indigenous member of Snuneymuxw First Nation. Born and raised in Seattle, Washington, Charsanaa relocated back to Snuneymuxw in 2015, where she currently resides as a mother of two. She's a student of the Master of Social Work program in Indigenous trauma and resiliency at the University of Toronto. Currently, she's a project coordinator with the Kw'umut Lelum Foundation. After moving to Nanaimo, she served as a youth leader with her Nation and provided project coordination within the greater Nanaimo community. She also worked as the health planner for Snuneymuxw Hulit Lelum (health centre).



Valarie Johnson ren skwest, Edward Johnson ren qé7tse ell Greta Johnson nee Daniels ren ki7ce. Te Eskét re st'7é7kwen. Secwepemcken. In November 2021, Valarie graduated from the University of British Columbia (UBC) Native Indigenous teacher education program with a bachelors in education, specializing in Indigenous knowledge. Following her graduation, she taught with School District #27 (Cariboo-Chilcotin) as a Secwépemc language teacher. Valarie is currently enrolled in a master of arts in curriculum studies program with UBC. She recently returned from Vancouver and relocated back to her home community, Esk'et (Alkali Lake), where she was hired as a curriculum specialist. Her focus as a research trainee and curriculum specialist is to develop a curriculum that nurtures and reflects the identity of the local Secwepemc culture and language. More specifically, Esk'etemc.



Jessie King, Hadiksm Gaax is Gitxaala / Git Lax M'oon through her mother and Grandmother with Irish and Scottish descent from her father. She's an assistant professor at the University of Northern British Columbia with research interests in Indigenous pedagogy, health, decolonization, Indigenization, philosophy and patriarchy. As an Indigenous scholar, Jessie seeks out interdisciplinary opportunities for critical discussions with the intent of nurturing relationships across academic silos in post secondary spaces. She is a grateful visitor to Lheidli T'enneh territories where she is raising her two children.



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Lynnette Lucas is the director of health for the Nuu-chah-nulth Tribal Council. Her primary focus is on health service delivery in these communities. One of Lynnette's goals is to integrate health research to enhance service delivery, while validating traditional Indigenous ways of knowing and being and supporting culturally safe practice for incoming providers.



Mark Matthew is director of Indigenous health with Health Quality BC. Mark currently lives on Tk'emlúps te Secwépemc (Kamloops) with his family. He grew up on the Simpcw First Nation reserve near Barriere, BC. He has observed how colonization affected his family, friends and community. Mark has worked extensively on Indigenous health initiatives. With Interior Health, he was the Aboriginal contracts advisor. Mark has also had several roles with the First Nations Health Authority, including community development liaison, acting director of community engagement, and manager of quality initiatives and partner relations. He has also supported the revision of the BC Health Quality Matrix and the BC's Standard on Cultural Safety and Humility.



Elder Glida Morgan is from the Tla'amin First Nation. Elder Glida is determined to bring healing light to our Indigenous People in her role as a front-line worker on Vancouver's downtown east side in the areas of family violence, mental wellness and women's health. Elder Glida has explored ways in which culture can be integrated into the health care plans for Indigenous people. Performing at community events across the lower mainland, Elder Glida is involved in a group that provides medicine in the form of songs for patients in palliative care through singing and drumming traditional songs.



Pablo Nepomnaschy is a professor in the faculty of health sciences at Simon Fraser University. He obtained his first degree in biology in his native country, Argentina, from the University of Patagonia. For his doctoral studies he moved to the United States of America, where he obtained a PhD in anthropology (biological) and natural resources and environment (ecology) from the University of Michigan. He then received post-doctoral training in epidemiology at the National Institute of Environmental Health Sciences, National Institutes of Health, USA.



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Dr. Jeffrey Reading is the co-director of the Centre for Collaborative Action on Indigenous Health Governance and the nominated principal applicant of the BC Network Environment for Indigenous Health Research. Jeff's broad interests public health research has brought attention to issues including, but not limited to, the social determinants of health, environmental issues including the provision of safe potable water, health promotion and disease prevention, heart health, diabetes, tobacco misuse and accessibility to health care among Aboriginal Canadians.



Dr. Rheanna Robinson is an Indigenous scholar and a member of the Manitoba Métis Federation. She is deeply committed to the discipline of First Nations studies and values the role of Indigenous knowledge within higher learning and what this knowledge offers the world. Her research interests include Indigenous disability studies, Indigenous education, Indigenous theory, methods, and Indigenous-led community-based research.



Quʔušinʔaqsa- Raven Woman (Erin Ryding) is a mamał̓i / white settler, raised in čišaaʔath̓ and Hupacasath̓ ɥaaɥaaɥuuł̓i and belongs to families from Scotland, Wales, England and ʕaaɥuusʔath̓ (Ahousesht). Moving always towards collective healing, she is currently the co-lead of the Uut Uuštukyuu Indigenous Healing Society, beside Elder Dave Frank.



Dr. Krista Stelkia is the nominated principal investigator of the BC Network Environment for Indigenous Health Research, an assistant professor in the faculty of health sciences at Simon Fraser University and co-director for the Centre for Collaborative Action on Indigenous Health Governance. She is Syilx/Tlingit from the Osoyoos Indian Band in the interior of British Columbia, Canada. Dr. Stelkia is an interdisciplinary Indigenous health researcher whose research primarily investigates the structural determinants of Indigenous peoples' health and wellbeing.

IMAGE CREDITS

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All biography photos shared courtesy of the individuals pictured.

With humility, respect and gratitude, we acknowledge that this event is held on the traditional, ancestral, unceded territory of the $\chi^w m \theta k^w \acute{e} y \acute{a} m$ (Musqueam) people, on the University of British Columbia - Vancouver campus and the city colonially known as Vancouver, which is also on the territories of the $S \acute{k} w \acute{x} w \acute{u} 7 m e s h$ (Squamish) and $s \acute{e} i l w \acute{e} t a 7 \acute{t}$ (Tseil-Waututh) Nations.

