



Hoti ts'eeda
NORTHWEST TERRITORIES
SPOR SUPPORT UNIT

Elèts'ehdèe Annual Gathering

May 22-24, 2018

FINAL REPORT



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ACRONYMS

- ACCESS: Attitudes towards Cancer in Indigenous Communities and Examining Uptake of Cancer Screening Services
- FOXY: Fostering Open eXpression among Youth
- GGC: Gwichya Gwich'in Council
- GIS: Global Information System
- HT: Hotii ts'eeda
- ICHR: Institute of Circumpolar Health Research
- IRC: Inuvialuit Regional Corporation
- NTHSSA: Northwest Territories Health and Social Services
- NWT: Northwest Territories
- NWTMA: Northwest Territories Medical Association
- SMASH: Strength, Masculinities, And Sexual Health
- SPOR SUPPORT Unit: Strategy for Patient-Orient Research (SPOR) Support for People and Patient-Oriented Research and Trials (SUPPORT)
- TRC: Truth and Reconciliation Commission of Canada

MAHSI

On behalf of the Governing Council of Hotì ts'eeda, I would like to thank you for participating in and contributing to our second annual gathering. Our Elèts'ehdèe is designed to embody the meaning of the word "Hotì ts'eeda": In the Tłıchq language, it represents a state of peace and wellbeing in mind, body and spirit. It is about collaborating with others and acting in a way that means when we part ways, we leave each other in a state of grace.

Hotì ts'eeda is a unique collaboration between governments and communities. Each province in Canada has a Unit like ours, but because the NWT doesn't have a university or teaching hospital, clinical trials or a large research community, we had to build our Unit based on what we do have. Our strengths lie in our communities, our relationships to the land and our people, and the Indigenous cultural knowledge held by our Elders. That's why our Unit focuses on Indigenous health and health research methods. The theme of this year's Elèts'ehdèe was Decolonizing NWT Health Research. During the conference, we invited you to envision what a decolonized health system could look like. We heard insightful comments and stories that reflected back to



John B. Zoe gives opening remarks at the Elèts'ehdèe.

us your vision for a health system designed to work with and for Indigenous people.

This report provides a record of the 2018 Elèts'ehdèe and an analysis of our discussions. We offer lessons learned to improve future meetings and a description of how priorities identified by you will inform Hotì ts'eeda's future work plans. We look forward to your feedback and to welcoming you to future meetings in the years ahead.

A handwritten signature in black ink, appearing to read "JBZ".

John B. Zoe, LLD (Hon.),
Chairperson, Hotì ts'eeda Governing Council



Participants enjoy the sun during a tipi session.

Executive Summary

The second annual Elèts'ehdèe was held May 22-24, 2018 at the Explorer Hotel in Yellowknife and the Aurora Village on Chief Drygeese Territory, the traditional territory of the Yellowknives Dene. The gathering brought together 130 people from across the Northwest Territories and Canada to discuss health and health research under the theme of “Decolonizing NWT Health Research”. Most importantly, the Elèts'ehdèe provides a space for renewing and creating relationships between stakeholders. It's a place for Hotiì ts'eeda to connect to our community of stakeholders to hear about what we are doing right, what we could be doing better, and your suggestions. This year's event gave staff and Governing Council members insight into ways we can work to better support communities in understanding and improving their own health.

This report gives a short overview of the goals of Hotiì ts'eeda, our structure, and who we are. It highlights Hotiì ts'eeda activities over the past year, and describes future directions for our organization. Plenary sessions held during the event are summarized and feedback on Hotiì ts'eeda priorities from participants is documented, followed by results of a youth engagement session focusing on how youth can be encouraged to get involved in health research and health professions. Finally, the report describes lessons learned that will shape our planning for an even better event next year.

Hotiì ts'eeda welcomes your feedback on the contents of this report.



The Yellowknives Dene Drummers lead a drum dance to close the 2018 Elèts'ehdèe gathering.



Participants listen to a research presentation at the dry fish station.



Tijchq Elder and cultural knowledge holder Mary Adele Rabesca gives Maria Sia a lesson in drying fish.



Petter Jacobsen and John Koadlak present the Tijchq Government's Boots on the Ground Caribou Monitoring Program.

What is Hotìì ts'eeda?

Hotìì ts'eeda (HT) supports and connects community members, organizations, and researchers involved in Northwest Territories health and health research. HT is funded by the Canadian Institutes of Health Research under the Strategy for Patient-Oriented Research (SPOR) as a SPOR SUPPORT Unit. HT is hosted by the Tłıchq Government and led by a Governing Council made up of representatives from the Tłıchq Government, the Inuvialuit Settlement Region, the Gwich'in Tribal Council, the Délıne Got'ıne Government, the GNWT Department of Health and Social Services, and the University of Alberta.

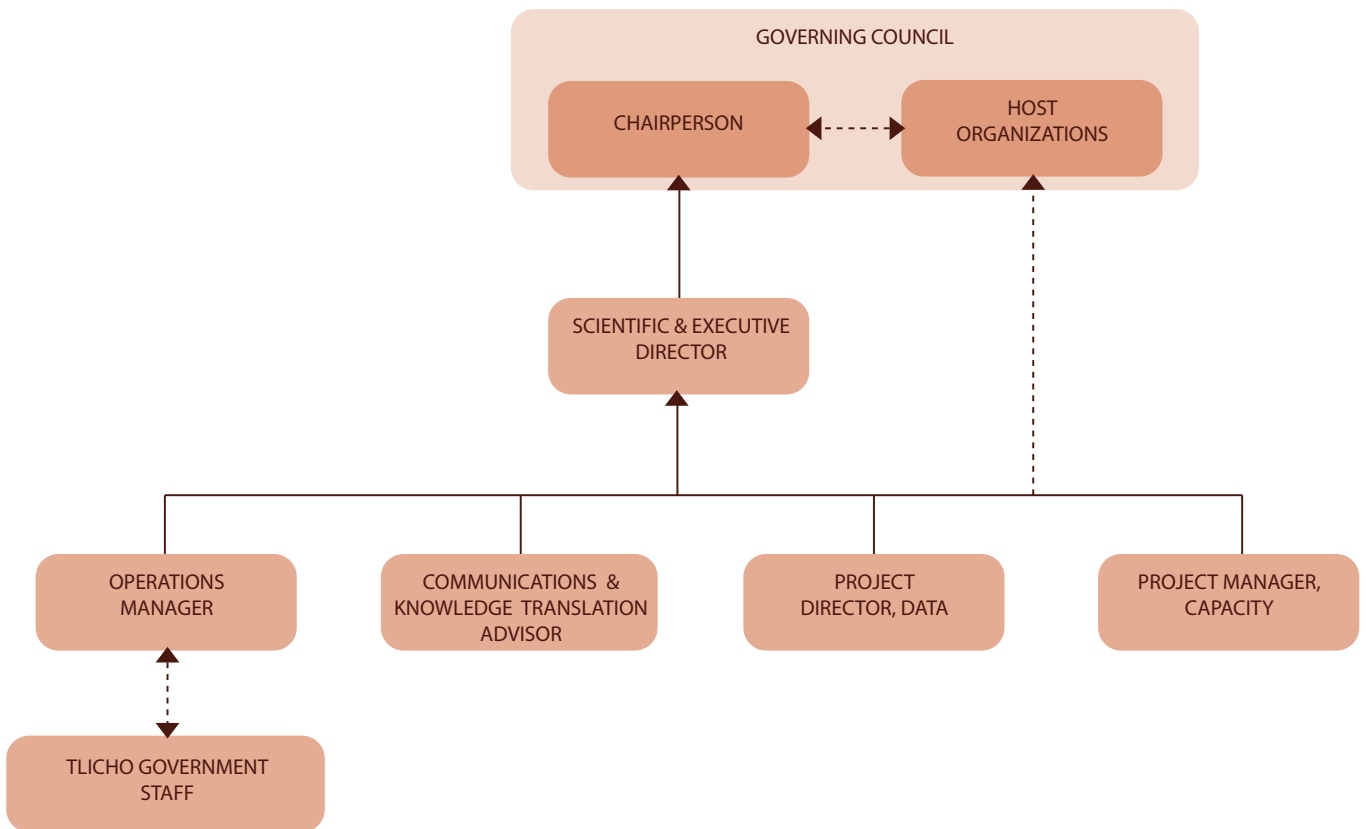
Our vision is to support health research and training that is rooted in Dene Naowo, Inuvialuit and Metis knowledge and responds to the needs of patients, communities and governments. Hotìì ts'eeda exists to revitalize and celebrate culture, improve capacity for individuals and families and support taking an evidence-based approach to policy. Hotìì ts'eeda supports activities promoting control and ownership of research by Indigenous peoples and communities. We aim to connect researchers and communities, build capacity and contribute to a health system that is culturally competent and inclusive of Indigenous methodologies and ways of knowing. We do this by acting as a connector: connecting researchers with communities, Indigenous organizations, and NWT health research priorities.

In the year since the last Ełèts'ehdèe, Hotìì ts'eeda has grown from a part time Scientific Director embedded with the Inuvialuit Regional Corporation, to include 2 full time staff members. These include a Communications Advisor embedded with the Tłıchq Government, and the Project Director, Health Data and Methods, embedded with the Inuvialuit Regional Corporation. During May we welcomed four summer students who are Tłıchq Citizens embedded in the Tłıchq Government, working from Behcho'ko and Yellowknife. In June, two additional summer students embedded with the Inuvialuit Regional Corporation and Délıne Got'ıne Government respectively, working in Inuvik and Délıne, and who are participants of their respective Indigenous governments' land claim agreements, joined our staff. During August, our full time staff complement will grow to include the Manager of Training and Capacity Development, based with the Gwich'in Tribal Council in Inuvik.

Organization Chart



ORGANIZATION CHART



*Chart does not reflect 25% of direct reporting to host organizations.

What Hotì ts'eeda Accomplished: 2017-2018

At the 2017 Elèts'ehdèe Annual Gathering, Hotì ts'eeda received advice and direction from our stakeholders. We identified nine recommendation categories. Below is an update on Hotì ts'eeda's accomplishments and ongoing work during the 2017/2018 work period, and highlights of future directions in each area.

Involvement of the Community in Health Research

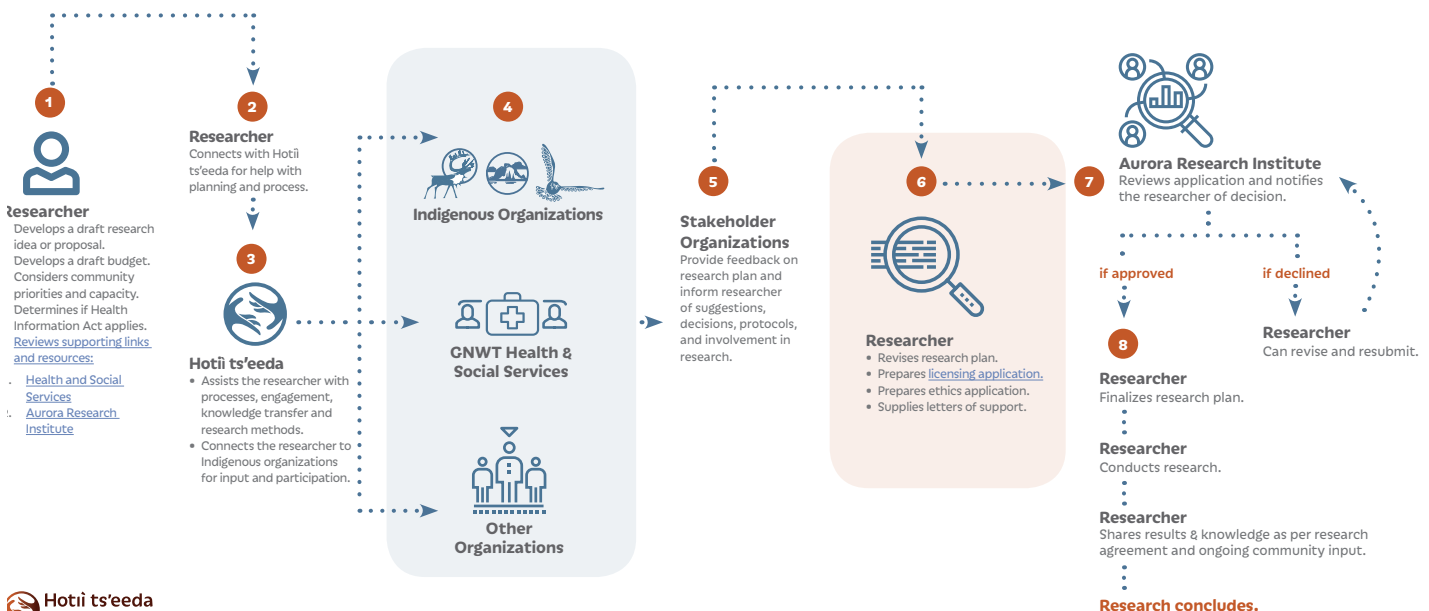
What we have accomplished

- Embedded employees at the Inuvialuit Regional Corporation, the Gwich'in Tribal Council, and the Tłı̄cho Government.
- Hired four summer students working out of Indigenous governments in Behchokq, Wekweti,

- and Yellowknife. Two more students are expected to be hired in Inuvik, with the Gwich'in Tribal Council and Inuvialuit Regional Corporation, and another with the Dèlìneq Go'ìneq Government in Dèlìneq.
- Launched the Community Researcher Development Program and Researcher Development Program to fund capacity and involvement of community members in research projects.
- Launched our website (nwtspor.ca) with a searchable research project database that is undergoing expansion and development.
- Researched and designed research project process maps for doing health research in the NWT generally (see below), and with the Tłı̄cho Government, Inuvialuit Regional Corporation and Gwich'in Tribal Council. These maps guide communities and researchers on the research process from idea to working with communities, to final approvals. We hope to work with more organizations in the NWT to document and share more maps.

HOW TO SET UP A HEALTH RESEARCH PROJECT IN THE NWT

Connect with the right partners, gather community input and obtain approval for your research in the Northwest Territories.



- Supported cultural competency training for NWT physicians in partnership with the NWT Medical Association, and partnered with the Canadian Evaluation Society to host a one day conference about Indigenous On-The-Land Program Evaluation.

What we are doing

- Supporting health research projects on food security and data indicators (Beaufort Delta region) and caribou (Tłıchq Region).



Louisa Nigiyok, Emily Kudlak, Mary Banksland, David Kuptana and Laverna Klengenber participate in a focus group for the Inuvialuit Food Security Initiative.

- Working with two NWT health research organizations to document best practices in Knowledge Translation, which NWT communities and health researchers will be able to access through our website.
- Developing a database of NWT Indigenous Research Methodologies.
- Providing funding to ensure projects are designed with communities and patients (in our case, Indigenous NWT residents) through consultation services and making connections between researchers and community members.
- Coordinating with Indigenous and public governments to become part of NWT research intake system.
- Working with two community-based governments to highlight their research needs on our website.
- Establishing a NWT Health Data Platform, which will include a searchable database of where NWT

health data information is held, how it can be accessed, and provide assistance to communities and researchers who wish to access available health data.

Future directions

- Form an Expert Panel of community representatives from across the NWT, including Elders and youth, to consult on relevant health research projects and related activities.
- Continue to work to improve the research intake system in the NWT.
- Continue to connect researchers to communities.
- Develop a database of community representatives.
- Develop and launch the NWT Health Leaders Program to build capacity and networks for Indigenous and NWT residents working in health-related fields.

Involvement of Elders and Youth

What we have accomplished

- Hired summer students who are integrated in Indigenous governments and provide a youth perspective on Hotı̄ ts'eeda activities.
- Launched Aurora College Research Studentship award to support and Aurora College student in conducting original research.
- Provided funding for two Aurora College nursing students to do a practicum in rural Norway, and apply their experience to nursing in remote NWT communities.
- Ensured that Elders and Indigenous university students attended the 2018 Elèts'ehdèe to share their knowledge, build their networks and become part of the SPOR initiative.

What we are doing

- Developing policies to allow for compensation of non-working participants on committees and working groups.



Hotiì ts'eeda summer students Roxanne Kotchilea and Genevieve Bekale greet participants at the Elèts'ehdèe registration desk.

- Dedicated one summer student to developing best practices on youth engagement and a Hotiì ts'eeda youth engagement strategy.

Future directions

- Ensure that Elders and youth are included in Expert Panel.
- Continue to work with communities and support research projects that include Elder and youth perspectives.

Building Relationships of Trust

What we have accomplished

- Hotiì ts'eeda's Project Director of Health Methods and Data accompanied researchers from the University of Ottawa to each of the communities in the Inuvialuit Settlement Region and facilitated focus groups for the development of an Inuvialuit Food Security Strategy.
- Developed a process map resource for researchers who wish to work in the NWT, which requires meaningful interaction with Indigenous governments and communities throughout the lifespan of a research project.
- Convened the second Elèts'ehdèe annual gathering.
- Launched two funding programs to increase capacity and involvement of community members

in research projects, to increase inclusion of community priorities in research

What we are doing

- Listening to our stakeholders and actively incorporating their feedback into our work and reporting back on progress.
- Supporting the inclusion of Elders and knowledge holders on a major national research proposal.
- Developing our Research and Consultation services platform to provide assistance with health research and program development.

Future directions

- Identify and implement activities that build trust with communities, and support communities in developing meaningful relationships with researchers, government and health care professionals.
- Connect researchers, policymakers and communities through our Expert Panel to develop trust between communities, researchers and NWT health system.

Indigenous Methodologies and Trauma-Informed Practice

What we have accomplished

- Supported and funded the Canadian Evaluation Society to have a one-day conference focused on evaluating Indigenous land-based programming.

What we are doing

- Dedicated one summer student to research and develop a database of Indigenous research methodologies, which will be available as a resource on our website.
- Supporting intergenerational trauma-related projects, including the Arctic Indigenous Wellness Foundation, in developing evaluation tools for their culture-based programs.
- Working with K'at'l'odeeche First Nation on their

trauma-informed programming development process.

Future directions

- Maintain trauma-informed practice and research and promotion of Indigenous methodologies as key areas of focus
- Continue to engage in and support ongoing evaluation projects related to on-the-land healing programs.

Cultural Competency for Researchers and Practitioners

What we have accomplished

- Supported and funded the Northwest Territories Medical Association to provide NWT physicians with a Continuing Medical Education credit in cultural competency training

What we are doing

- Dedicated one summer student to develop best practices for knowledge translation projects in the NWT in collaboration with FOXY and the Institute for Circumpolar Health Research.
- Offering support to ongoing work on cultural competency for health practitioners through SPOR's demonstration project program.

Future directions

- Develop more resources for researchers doing work in the NWT to increase their knowledge and competency.
- Plan to work with the Institute of Public Administration Canada in Yellowknife and Inuvik on cultural competency sessions for policy makers.

Achieve Sustainability

What we have accomplished

- Secured our first billable client for our Research

and Consultation services platform.

What we are planning

- Continuing to respond to potential clients under our Research and Consultation services platform.

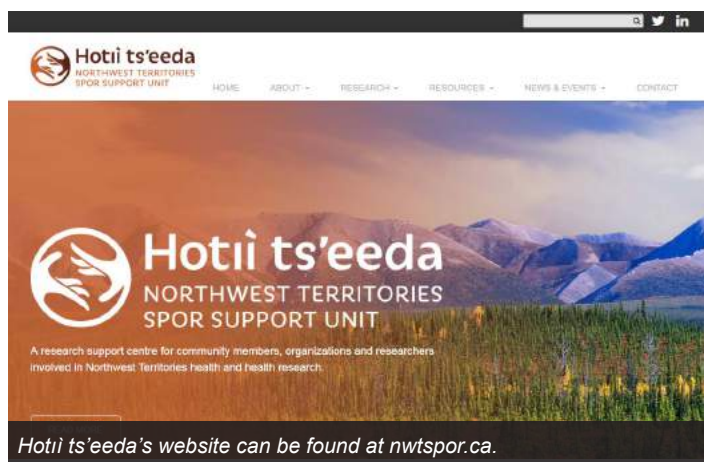
Future directions

- Continue to build our research and consultation platform, with the goal of becoming self-sustaining.
- Continue to develop our sustainability plan.

Open Communication

What we have accomplished

- Our online presence has been developed through our website, Twitter (@hotii_tseeda), Facebook and E-Newsletters.



What we are doing

- Developing a fall 2018 awareness and information campaign to reach out to communities and health practitioners.
- Our summer students will be presenting at the Idaa ts'ade Academic Summit in Behchokò to raise awareness about Hotii ts'eeda and listen to what young academics have to say.

Future directions

- Continue to strive to be transparent, responsive and open, both in online presence and person-to-

person interactions.

- Continue to improve our communications in response to feedback.

Making Sure Research Makes it Back to the Community

What we have accomplished

- Provided on-demand consultation to several researchers on best practices in engaging Northern communities.
- Launched funding programs to increase local community involvement in research projects, to improve how research makes it back to the people who can use it in the community.
- Hired a full time Communications and Knowledge Translation Advisor to ensure we can provide expertise in knowledge translation and exchange.

What we are doing

- Our Communications and Knowledge Translation Advisor is included on all projects to ensure appropriate and effective translation of knowledge.
- Dedicated one summer student to developing a resource describing best practices for knowledge translation in the NWT, in collaboration with the Institute for Circumpolar Health Research and FOXY.

Future directions

- Prioritize effective, efficient and culturally competent knowledge translation.
- Continue to work with researchers, policy makers and communities to innovate and improve knowledge sharing.

Research Funding in the NWT

What we have accomplished

- Responded to the GNWT Post-Secondary Education Framework to encourage development of a framework that will establish a NWT

university that can be a home to numerous small organizations (such as Hotìì ts'eeda) which could work together more effectively on their core programming.

- Advertised research funding opportunities on nwtspor.ca
- Launched our Strategic Priorities Program to provide funds for capacity development in research.

What we are doing

- We are working with the Aurora Research Institute to establish a memorandum of understanding that will result in Hotìì ts'eeda receiving additional support funding.

Future directions

- Plan to map existing funding in the NWT and Canada and develop recommendations for increasing research funding in the NWT.
- Will continue to explore traditional and alternative funding for research in the NWT.



Cultural knowledge holder Elder Jane Dragon teaches participants about working with Northern fur.



Cultural knowledge holder Elder Mary Adele Rabesca.



Elder Angus Beaulieu entertains participants during tipi sessions.

Overview of Plenary Sessions

Panel 1: NWT Doctors Reflect on Medical Practice and Research in an Era of Reconciliation

Tuesday, May 22, 2018 7:00 p.m.

- Sarah Cook (Family Doctor, Territorial Medical Director for the NTHSSA)
- Katherine Breen (Emergency Physician, President of NWT Medical Association)
- Matthew Quinn (Family Physician, Regional Public Health Officer Beaufort-Delta)
- David Pontin (Emergency Physician, Stanton Territorial Hospital, Chair of ICHR)

Sarah Cook has been in Yellowknife as a family doctor for ten years and has been able to travel to communities and hear stories about peoples' experiences with the health system. She spoke about relationships and cultural competency. For her, cultural safety and competency basically comes down to relationships. We can do a lot better in terms of supporting relationships—our statistics are not very good. Around 42% of people know who their regular physician is, as opposed to around 80% Canada-wide. Physicians fly in and out and may never come back. Physicians maybe have an online course, but don't have a real understanding of the issues in communities. If physicians know their patients in communities, they can provide more respectful care.

Katherine Breen has been in Yellowknife for four years, and prior was in Iqaluit for five years. Traveling to communities for a week at a time offered her the opportunity to get to know individuals and felt that this improved the care she was able to offer and allow her to focus on culture and how it influenced her patients' health. She worked on a TB research project in Iqaluit, and they incorporated local Inuit TB champions to be the face and the front line of that program, sharing

their experiences and speaking in Inuktitut. That enabled them to get the buy in and really influence screening for TB. Having more Indigenous players in the system is helpful.

Matthew Quinn has been based in Inuvik since last August, after being a locum in Inuvik for three years. He is also the community physician for Tuktoyaktuk. He has been a fly-in physician in the past, only visiting communities for 2-3 days at a time, trying to piece together what's going on with each of his patients. Now, once a month he travels to Tuk for a few days and does telehealth sessions once a week. Having the nurses in the community, who have been there for ten years, is very helpful. In Inuvik they did a day where doctors spent a day with local Elders learning about traditional healing.

David Pontin was at last year's Etèts'ehdèe and which impacted him positively. He has been working in Yellowknife since 2006, and has traveled frequently to Gameti and Behchokò. He believes that you have to live with the people you serve, and you have to do it for a long time. The cultural competency courses are a good start, but true cultural competence is built on over many years. You also have to be ok with being uncomfortable as a practitioner. You also need to reflect on what you do, and always try to improve. For example recently the NTHSSA realized the Behchokò nurses need on call support. So over the last six months a few physicians put themselves on call for the nurses in Behchokò and there have been very positive results. In terms of research, it's fundamentally important to build relationships between researchers and frontline practitioners. It's important that research transforms the frontline delivery of care that happens every day. We're not learning enough from each other or leveraging the incredible resources and expertise that exist in this small community.



Students Thomsen D'hont, Sophie Roher and Maya Lefkowich on the opening evening of the Elèts'ehdèe.

Discussion

Lesla Semmler asked if participants feel as southern doctors coming in to different regions they get enough time to get to know the community before being put out there. We say it takes time, but is the government providing that time? She asked if turnover in nursing and support staff affects their ability to get to know the community. Response was that no, we're not giving physicians enough time in the communities. We can look at that in terms of giving them more time. There has been a shortage of people, so they're sent in and brought back out as quickly as possible. But we need to give time and have that partnership where we're sending the same person and asking the community to invest the time and properly orient that person. How do we recruit and retain people to stay in the NWT? In terms of turnover, transient support staff can create difficulties for physicians. One thing the NWTMA is working on is to tailor training to communities and individuals working in communities.

Melinda Laboucan discussed the frustration from the community side of having to repeat their stories over and over again. She appreciates that the NWTMA is working to find research to support community-based programs for isolated communities. She hopes that we can all work to support these initiatives. One example that was discussed was the University of Calgary, which gives scholarships to kids from small northern and rural communities. They give them entry level scholarships to go to medical school without having to go through the standard medical school process and support them with mentorship. Then they can come here to complete some of their medical training and residency. This makes them familiar with those communities and reduces the fear of going into a very small community on your own as a practitioner. The more people trained in these situations, the easier it is to go out there and at the same time they build those relationships. It's a long-term investment. Grace Blake commented that it's important to utilize all the different mechanisms, like telehealth and other support systems. The GNWT system feels removed, it doesn't have enough local involvement or input.

It's really important that cultural competency create connections with residents. The response highlighted the potential of technology such as telehealth and other virtual care, and that we can explore ways to use this much more than we are. In the NWT we tend to move people around, but we don't need to do that as much as we do. We can use technologies to keep people closer to home.

Billy Archie commented that they've seen a lot of racism and discrimination in their health system and the hospital in Inuvik recently. One individual with racist attitudes can do a lot of damage. When we talk about trying to change things, what's the process to eliminate racist individuals and systemic discrimination? The response from the panel focused on naming these issues when they happen, speaking out about it is the first step. We need to not be afraid to be impolite or speak out. Sometimes it can lead to education, which needs to be done. But sometimes people just aren't a good fit for the NWT. It's much easier to do that as the clinical leaders of the health authority now to act on it—if people tell us it's happening.

Gita Sharma described an existing project that looks at patient experiences of health services. She's hoping to bring it to the NWT. The discussion focused around how the knowledge created by research often misses front line workers, who can influence the health experience through small changes that make a difference. Research needs to focus on getting information to front line providers.

Julia [last name inaudible] asked about cultural competency training and the four-hour course for health care practitioners. As a residential school survivor, it's important. She also noted that on the NWT doctors panel there was no mental health specialist. The response noted that emphasis on mental health and addictions is growing and hopefully next year they can share some of that information.

The TRC is well known among physicians, but there's more work to be done on that especially in terms of orientation and awareness. The NWTMA is working with Southcentral Foundation to look at their programming and at adopting some of their orientation and cultural competency programming to the NWT.

Norman Yakaleya commented that Indigenous medical knowledge and practices should be better acknowledged and we can create training to validate and recognize their medicine and knowledge side by side with the Western doctors. This would help integrate traditional food and medicine into the health system. We have the people, let's use them create policies to ensure there are Indigenous healers and knowledge there. Bob Simpson commented on a survey the IRC did on mental health, which demonstrated that people felt they needed to have the opportunity to talk to somebody in an environment of trust. Building a safe space for people, culturally and otherwise, is crucial. Closing responses were that focusing on qualitative research and community feedback is instrumental to driving health systems research, and that the NWTMA welcomes any information they can get about how to do better. Hearing stories helps inform how we can do better. We're looking at clinics like Wabano, where Indigenous healers and medical doctors work together. Our health provider population is very open to this right now. There are a lot of policy barriers, but we're working to advance that vision. Hopefully Hotii ts'eeda can be a catalyst for that as well.

Panel 2: Arctic Inspiration Prize Recipients – Celebrating Research and Program Excellence

Wednesday, May 23, 2018 10:00 a.m.

- Nancy MacNeill (FOXY/SMASH)
- David Codzi, Colville Lake (Dene Heroes of the Sahtu)
- Dakota Orlas (Dene Heroes of the Sahtu)
- Magnolia Unka-Wool (Arctic Indigenous Wellness Foundation)

Nancy MacNeill is a co-founder of FOXY and SMASH, programs that deliver sexual education to youth in the NWT and effectively address health gaps. The Arctic Inspiration prize has allowed the expansion of the sexual health program to the Yukon and Nunavut and expand their demographics to both girls and boys. The Arctic Inspiration Prize has allowed effective reach of target demographics.

David Codzi and Dakota Orlas worked on the Dene Heroes Publication in the Sahtu. The project fills in the

gaps about local history and local heroes. The book documents everyday Indigenous heroes who went above and beyond for somebody else and provides Dene youth in the Sahtu homegrown heroes to look up to.

Although Simeonie Nalukturuk wasn't present a description was read of the Unaaq Men's Association of Inukjuak. A series of suicides led the community of Inukjuak to investigate its causes. It has led to the creation of this project, which pairs young men with elders to pass on traditional teachings and values. The association has been successful at reaching youth and giving young men their bright futures back.

Magnolia Unka-Wool is the Vice Present of Arctic Indigenous Wellness Foundation. In northern Canada suicide is the leading cause of death in Indigenous youth. Males are disproportionately affected with suicide rates 3-11 times higher than non-Indigenous youth, are overrepresented in criminal justice system and have a higher rate of alcohol and drug use. Ninety percent of the homeless population in the



Nancy MacNeill (FoXY), David Codzi (Dene Heroes of the Sahtu), Magnolia Unka-Wool (Arctic Indigenous Wellness Foundation and Dakota Orlas (Dene Heroes of the Sahtu) at the Arctic Inspiration Prize panel.

NWT are Indigenous men. The Arctic Indigenous Foundation project is an urban land-based healing program targeting Indigenous men and youth who are at risk for incarceration and suicide. It uses therapeutic interventions combined with on-the-land programs and aims to improve the mental health of participants by instilling cultural identity, self-esteem and community belonging. The project was initially rejected by Arctic Inspiration Prize but with feedback from the group, it received the prize this year. The \$1M from the Arctic Inspiration Prize is allowing the beginning of programming and momentum to be built.

Discussion

The question and answer period starting off with a discussion of learnings the participants had drawn from their projects. Nancy MacNeill focused on the tendency to underestimate young people and how much better off we'd be if you listened to them more. The Dene Heroes team built on that, saying that they learned that youth want to help, but sometimes aren't offered avenues and so have untapped energy to contribute to their communities. Magnolia Unka-Wool emphasized the difficulty of getting funding and having to dedicate a lot of time and energy to applying for funding—she found it surprising, given that the NWT has a 50% Indigenous population and the call of actions from the TRC include healing centres.

Magnolia Unka-Wool was asked what the obstacles are preventing a fully integrated health system, and if that was even desirable. She responded that one of the biggest challenges with decolonizing and having Indigenous methods incorporated is getting past mainstream society and getting mainstream society and decision-makers to accept that Indigenous methods work too and are legitimate.

Audience member Grace Blake commented that the GNWT represents the communities rather than having a collaborative relationship with First Nations

and receives money on their behalf. She asked how Hotii ts'eeda will work with Aurora College and other Colleges to provide training and how will people from the south be oriented to northern Communities? David Codzi responded that in his community, they decided within the community they'd be responsible for themselves. They build their road and water plant. He emphasized that it's important to share these success stories with the rest of the communities, through projects like the Dene Heroes publication. The final question focused on language, and asked if Indigenous languages were part of their programs, and what their approach to language revitalization was? The responses focused on keeping programming in place, developing Indigenous healing centres and including language revitalization in programming, as well as keeping government out of the programming and collaborating between organizations.

Panel 3: Perspectives from Indigenous Wellness Program Practitioners: Why We Need Health Research and Why it Needs to be Responsive to the Needs of Indigenous Peoples *Wednesday, May 23, 2018 11:00 a.m.*

- Lesa Semmler (Inuvialuit Regional Corporation)
- Jennifer Drygeese (Yellowknives Dene First Nation)

Lesla Semmler has worked as nurse for 12 years in public health and long-term care and three years at Inuvik Regional hospital as a nurse manager. She now works in non-insured health benefits with the IRC. Beneficiaries struggle to get entitled services, and to know to what services they are entitled. Lesa tried to bring cultural activities and practices to the hospital when she worked there. She argued that to change policy for the better, we need Indigenous health care practitioners on the front line. Given that

the NWT has 11 different official languages and a lot of unique cultures we cannot take a 'cookie-cutter' approach. More local research and more collaboration with governments will lead to an improvement in outcomes.



Jennifer Drygeese and Lesa Semmler talk about their experiences as wellness practitioners.

Jennifer Drygeese started programming for children and youth in N'Dilo through creating a Wellness Department in 2012. All programs and services were formally evaluated via research focus groups with youth, elders and parents and community meetings. This led to the creation of four work plans: an admin work plan, which take care of proposals and reports, finances, advocacy, and staff management. A family wellness plan, which involves two staff working with elders, pre-natal and post-natal care, family support, early childhood programs, and healthy choices programs such as cooking and weight loss. A community wellness program includes culture camps and a recreation program which plans and delivers special events such as hand games and tournaments with youth. Finally, a Dene wellness program is responsible for on-the-land healing, counseling, and grief workshops. It delivers workshops to families directly and does treatment referrals. More research is needed to strengthen the existing programs. This research needs to work closely with communities as research often doesn't talk to the communities.

Discussion

Jennifer was asked to expand on the referral to treatment process. She explained that there are two people working in the Dene Wellness program. If someone needs help and wants to go to treatment the workers help them with counseling and assist them with the paper-work to get them help.

Lesla was asked how we can get Indigenous people into the health system. She responded that as a health professional, going back to your own community to work can create trust issues with patients, you're almost too close to the community because you grew up with them. Communities say they want more local nurses, but this can be an awkward experience too. Indigenous people need to apply to management jobs more. Often management job descriptions are difficult to understand and feel like a foreign language so Indigenous people don't apply but Indigenous people have the capacity. A participant asked how their organizations were working on recruiting and retaining Indigenous people to work in health care. Lesla responded that having Indigenous role models was personally something that inspired her. More partnerships with government to make sure mentorship and role modeling opportunities occur could help counteract the in-out nature of rotational nurses. Jennifer responded that they work on recruiting and head-hunting staff to work in their health programs.



Sahtu Elder Violet Doolittle.

Panel 4: Elders Perspectives on Health Research

Wednesday, May 23 2018 12:00 p.m.

- Florence Barnaby (Fort Good Hope)
- Grace Blake (President of GGC)
- Be'sha Blondin (Northern Integrated Cultures with the Environment)
- Violet Doolittle (Sahtu and Waterboard)
- Felix Lockhart (Stanton Hospital)
- Emily Saunders (Yellowknife Regional Wellness Council)

Florence Barnaby opened the session by talking about the GOBA group (meaning “light on the horizon”, part of the Attitudes towards Cancer in Indigenous Communities and Examining Uptake of Cancer Screening Services (ACCESS) project) for cancer patients in Fort Good Hope. The first sharing circle was in 2012 and there is a dedicated worker who does home visits, particularly with cancer patient who are having difficulty in the community. The aim of the program is that patients don't feel alone, which is a common feeling especially among Elders. The program allows them to help to talk about their problems with friends and families. There is a mix of people who are on their cancer journey including survivors and those facing cancer now. It is a place you can go and grieve and talk about what you are going through. There is also work done on cancer terminology which is helpful because there are no words for cancer terminology in the local language. It assists with explanations.

Be'sha Blondin stated that Indigenous people must go through a lot and it seems as though they are never allowed to take ownership of life. Indigenous people have always been told where to go and what to do. One of the most important things for research to do is to look at what community members need. Be'sha says community members need the following:

- Interventions for sexual abuse and incest.
- Help for people suffering impacts of suicide.
- Better programs for residential school victims.
- Better communication to all regions about nutrition.
- Cancer prevention programs and support for those with cancer.
- Programs that give families the tools to teach their children.
- Programming based on traditional family and people skills.
- Alcohol abuse programming.
- Community health and wellness programming.
- Physical health promotion.
- Encouragement of community members to be proud of their communities.
- Support to traditional education and training programs.

Felix Lockhart emphasized the need for discussions during the gathering to lead to action. He shared his story about working with a researcher working with his people, culture, and language, and not understanding what the research was for until later on in life. Now, everyone has the opportunity to have a say to researchers that want to come in and do work. Felix also talked about the importance of traditional foods in hospitals, especially for Elders—food is important for being healthy, and it communicates with people spiritually and emotionally, becoming part of their healing process. This gathering and things like it are important because it gives people the opportunity to share stories with doctors and other professionals that are here. The outcome will cut down racism, discrimination and violence, and lead to more awareness about the trauma from residential schools. He said he was inspired by Dakota Orlias (from the Arctic Inspiration Prize Panel) and it brought back memories from when he started speaking up and how the younger generation should be supported.

Violet Doolittle stated that one component missing



Elders Be'sha Blondin, Florence Barnaby, Felix Lockhart, Violette Doolittle and Emily Saunders share their perspectives at the Elders Panel.

in the medical field is the emotional part, such as understanding and addressing the negativity that people carry within themselves. She shared her story about the importance of relationships and valuing one another like the Elders. She said that medical professionals and health and wellness workers need to commit to be with the people as they are and spoke about her personal story of how residential school took things away from who she was and over time she took those things back. She reminded everyone to love themselves.

Emelie Saunders from the Yellowknife Regional Wellness Council elaborated on her work as an addictions counselor in the social work field for over 24 years. One thing that she enjoys about this gathering is everyone working together. She would like to see more information on diabetes, post-traumatic stress disorder (PTSD), Helicobacter Pylori Infection (H. Pylori), not just cancer, and more

research on legalization of marijuana: the mental health aspect of it, possible effects on communities and communicating these things with communities.

Grace Blake is the President of the Gwichya Gwich'in Council. She spoke about gaps in the education system, and how sometimes research with children takes place without parents' involvement in communities. She highlighted midwifery as an example of a gap—there is a lack of incorporating traditional knowledge and practices into modern midwifery, and this is only being offered to certain communities. Long term facilities and services for Elders should also be more community-based and reduce the need for Elders to leave their communities. She shared her personal story of growing up in a community where everyone was happy and joyful, and the impacts of residential schools.

Panel 5: Community-Based Health Research

Wednesday, May 23, 2018 7:00 p.m.

- Petter Jacobsen (Tłıchq Ekwo Nàowo: Cumulative Impact Study of the Bathurst Caribou Herd, Tłıchq Government)
- John Koadlak (Tłıchq Ekwo Nàowo: Cumulative Impact Study of the Bathurst Caribou Herd, Tłıchq Government)
- Sangita Sharma (Capital Health Research Chair in Indigenous Health, Centennial Professor, and Professor in Indigenous and Global Health Research in the Department of Medicine, Faculty of Medicine & Dentistry, University of Alberta)
- Melinda Laboucan (Community Cancer Co-ordinator, Fort Good Hope)
- Andrew Spring (Research Associate, Department of Geography and Environmental Studies, Wilfrid Laurier University)
- Melaine Simba (Environmental Coordinator, Ka'a'gee Tu First Nation)

Gita Sharma began working with Melinda Laboucan on Healthy Foods North, but Melinda brought up that cancer was an area of importance to community members. Their group began working on cancer in Fort Good Hope and other communities. They are now working to produce videos in local languages on screenings for various forms of cancer. This has been a good example of research data informing community work based on community priorities. Another project is based in Edmonton, including NWT residents who go to Larga House, and looks at patient experience. They've seen the need for a patient navigator who understands the NWT to explain their experience and facilitate their journey. They're also starting a senior's project in Inuvik to collect data on senior's health.

Melinda Laboucan from Fort Good Hope works with Gita Sharma on various projects. She shared a story

about working with a cancer patient in her community who shared that when he was diagnosed in Edmonton and another patient from the NWT supported him. She shared that she lost her mother to cancer, which drove her passion to begin working on cancer programs and cancer research. They have sharing circles, one-on-one home visits, traditional health week, on-the-land traditional medicine harvesting, fitness groups. She has found that attitude and community support have a significant effect on how patients survive.

Andrew Spring has been working with Melaine Simba in Kakisa when the First Nation was interested in looking at climate change and health. He conducts participatory action research, which is about more than just determining what the barriers are, rather it is about actively working to remove those barriers. Their work is about health access and traditional foods—they asked the community what they want to do about it. The community identified growing food, so they set up a garden. The community identified they wanted support taking care of the land, so they built a GIS program that tracks traditional and environmental knowledge which acts as a decision-making tool for the community. They identified recycling, so they have built up a recycling and compost project in the community. The community wanted to be on the land more, so they got on the land funding to talk about science and traditional knowledge on the land. They also worked with the community on capturing traditional place names and other knowledge. How they work has really evolved into a strong partnership and friendship with Melaine. Having that community champion has been crucial to the success of their work. However, when there is that community champion they tend to get asked to do everything, we need to protect their time. It's also hard to find the funding to support that person—Tri Council Funding likes to hire “Highly Qualified Personnel”, and they don't often count community members. We need to work to promote that and focus on sharing success

stories and how we can better support communities.

Melaine Simba grew up on the land and is happy to now be working on the land on environmental projects. They've built great relationships. She really enjoyed being brought down to Ontario and learning from all the different research projects. She commented that the structure of the Etèts'ehdèe conference was a powerful and touching way to connect communities to research. Communities have questions about their health and their environment, and important concerns due to development in the regions. Sometimes the work is overwhelming, but she is connected to the work because it's for the future of her community.

Petter Jacobsen works with the Boots on the Ground Caribou Monitoring Program that they run for the Tłıchq Government. The project stems from the decline of the Bathurst Caribou Herd, which was the main staple for the Tłıchq people. Tłıchq chiefs wanted to try to understand what's happening and try to find solutions. The project goes to Contwoyto Lake where caribou spend time in the summer and early fall. It's a small group of people. They learned that the more they followed the lead of local people like John, they realized they didn't need any technology. They act as a small hunting party and just watch the land. They build a very strong connection to the land. They also use the language of the Elders that tells us where caribou is. The success of the program has come from doing exactly what the Elders have done traditionally. Environmental monitoring becomes a personal journey for everyone participating in the program.

John Koadlak is from Contwoyto Lake. They are the only family left that lives there off the land year-round. When working on the land it must be stressed that the environment is very fragile. They've seen a lot of changes since the diamond mines started operating. First of all the animals have started slowly migrating

away. New animals are showing up that they've never seen before. Herds have split into different migration routes, which isn't properly understood by researchers. In the spring the land would be covered with caribou as far as the eye could see. He hopes that by recording and conducting research they can help maintain the environment. Last night he heard that our youth should be integrated into every organization. There aren't enough youth here. We should have more youth involved and integrated and included in these kinds of gatherings and conferences and meetings. He sees the first hand experiences between Elders and youths being lost through the modern world. First-hand land experiences are a must for young people.

Discussion

Elder Grace Blake raised her concerns about how the Inuit of Alaska don't believe they're threatened by the US Government saying they're going to drill in the calving grounds of the Porcupine caribou herd. They don't see it as as much of a threat as offshore drilling. But the Fort McPherson people depend on that herd. This is the second year there's no caribou near Fort McPherson, and that's caused a hardship to the people. There will be a gathering this fall to discuss that threat. Wildlife researchers agree that the caribou are in decline, and there are many reasons why. We're grateful to people living on the land all year who are there to see. Our people are audiovisual people—not born with pen and paper. We need to carry that on. The commenter shared a story about learning from her grandparents on the land and discussed the importance of children learning in this way. We need to keep their nature and traditional ways of learning intact. She commented that she really appreciated the working relationships evidenced by the panel.

Be'sha Blondin shared about when the first diamond mine came to the north and concerns were raised about the animals. Through observing on the land,

she has witnessed industry destroying animals. In a gathering of First Nations people across Canada, some Elders shared that the mines made the caribou separate – the majority went all the way towards Saskatchewan. They had to cross a huge river and thousands of caribou died. The mines changed the force of nature. That is something that will live with us forever. Research is needed to study more animals that are getting sick.

Panel 6: Emerging NWT Indigenous Scholars' Perspectives on Decolonizing Health Research

Thursday, May 24, 2018 1:00 p.m.

- Crystal Gail Fraser (University of Alberta)
- Karen Blondin Hall (Department of Health and Social Services)
- Thomsen D'hont (University of British Columbia)

Crystal Gail Fraser is Gwich'in from Inuvik. She is currently enrolled at University of Alberta and is in the process of finishing up her PhD in Canadian History. Her research is based on the history of residential

schools in the Inuvik region, which has strong links to health. Crystal discussed the way scholars can incorporate colonization as a lens when thinking about health and bodies in residential schools. These schools were built not only to colonize the mind but also the body. She emphasized that land is at the centre of decolonization—returning lands and treaties to the people to know that they are being honored is decolonization. Reconciling conflict is important. For example, Canada 150 was a very difficult time for most Indigenous people and could have been handled differently.

Crystal noticed that many people focused on governments when considering the TRC calls to action. So, she started to make a list of acts of reconciliation that everyday Canadians can do, and soon she had 40 points. She connected with a friend to create a list of 150 ways for people to enact reconciliation for the last 150 days in Canada's 150. These were published on activehistory.ca.

Karen Blondin-Hall is Sahtu Dene, born and raised in the Northwest Territories. She went to Dalhousie



Crystal Fraser (Gwich'in) PhD Candidate, University of Alberta

University, followed by a Master's degree at the University of Victoria. She was faced with many challenges being the only Indigenous student in her program—she was expected to know everything about Indigenous Knowledge and was faced with ignorant questions. She received support from an Indigenous professor who mentored her and introduced her to Indigenous health research and Indigenous scholars and events.

Her research has focused on cultural safety, which is looking at and ensuring that the health and social services are providing equitable care to our people. Her work has also focused on figuring out what in our system is creating the inequities that Indigenous people experience. To do this research you need to have access the health system. There are so few Indigenous people doing Indigenous health research Canada-wide, and even fewer in the north.

There are a lot of opportunities now for Indigenous students thinking of doing Indigenous health research. When Indigenous people do their own research in their community they already have that trust and relationship with the community and that is valuable.

Thomsen D'hont is Metis, and was born and raised in Yellowknife. Currently he is enrolled in his 2nd year in the Doctor of Medicine degree program at University of British Columbia. Through his medical program he did some research training courses, foundations in scholarship and received research training at Johns Hopkins University centre of the American Indian Health Research.

Thomsen reviewed what decolonize health research means to him—focusing on knowledge translation and community-led processes. Transferring knowledge, learning from elders and having the main methodology be based in knowledge translation and exchange is a solid and crucial practice. Worked on interviewing Metis Elders about traditional land use

on the shores of the East Arm of Great Slave Lake. Transfer of knowledge was solidified at the end of the project going out on to the land with Elders, that solidified the learnings. A report was written for future members of NWT Metis Alliance to learn about traditional use of East Arm, that report was held for members rather than published in an academic knowledge—thinking about protocols of where that knowledge belongs. Academics are always told that the end goal is to publish at all costs. That doesn't align with traditional protocols all the time. It's really important for Indigenous youth and scholars to see Indigenous doctors and academics doing Indigenous research in the field. Knowledge transfer and communication between doctors and patients can also be seen as research, there are important power dynamics there and it is important to empower people during that process—by respecting them and their cultures.



Thomsen D'hont (North Slave Metis), UBC Medical Student

Panel 7: Innovations Across Canada

Thursday, May 24, 2018 2:00 p.m.

- Michael Green (Ontario SPOR SUPPORT Unit)
- Tracey MacPherson (Discharge Coordinator at Yukon Hospitals)
- Caroline Tait (University of Saskatchewan)

Michael Green has a settler background English and Norwegian. His family grew up around Vancouver Island, British Columbia. He spoke about his connections to First Nations people, personally and professionally. His work with the Ontario SPOR SUPPORT Unit is focused on primary health care research and Indigenous health and cultural safety. He stated the reason his project is successful is because he works closely with Indigenous scholar Jennifer Walker, from Six Nations Ontario, and the Chiefs in Ontario. His project is focused on making a difference and building capacity and working in partnership with communities and Indigenous leadership. They have engaged patients in diabetes research and are working on creating a database for communities. Their project has one full time dedicated employee who works as an integrated project advisor, linking staff to communities. They also have an advisory panel of patients who guide their decisions.

Tracey MacPherson is a Metis social worker and a discharge specialist at the Yukon Hospital. The Yukon Hospital has had a First Nations Health unit since 1993, which requires three of the nine board of trustee members to be Yukon First Nations to ensure influence of First Nations into the health system. Currently, the First Nations Health unit has ten employees, nine of whom are First Nations. They ensure patient-centred care and see patients as partners. A key to success for First Nations Health is representations at all levels of the hospital—on the front-line, in middle management and at the director level. Their program offers patient advocacy, helps First Nations clients understand their medical

conditions and the hospital processes, as well as safe and appropriate discharging of patients from hospitals. Their program offers trauma- and colonization-informed Elder support, traditional food and translation services. They take on practicum students and provide mentorship into the program. A major challenge for their unit is measurement, how to tell if they are making a difference. Evaluation is a key point for the future.

Caroline Tait is Metis and grew up along the Saskatchewan River. She works on several topics in Indigenous Health. The first is First Nations, Metis and Inuit perspectives on harm reduction. The recovery model has put a lot of people on methadone in Saskatchewan, but there is criticism that this may not be the right model for Indigenous populations and has been compared to alcohol as a method of social control. The second is land-based therapies, developing more research to encourage the government to fund these initiatives. One solution would to hold a conference with locally-identified experts on land-based therapies and then create a report which can be taken to government. The third area is culturally safe care and trauma-informed care, which research shows is important in prison and childcare settings as well as healthcare settings. Knowledge translation and evaluation are two big challenges in Caroline's work.



Participants listen to a plenary session in the Aurora Village main hall.

Panel 8: GNWT's Role in Health Research

Thursday, May 24, 2018 3:30 p.m.

- Kami Kandola (Deputy Chief Public Health Officer)
- Nathalie Nadeau (Director of Child Family & Community Wellness, NTHSSA)
- Pertice Moffitt (Aurora Research Institute)
- Luke Spooner (Research Coordinator, Department of Health and Social Services)
- Janet Leggett (Chief Health Privacy Officer, Department of Health and Social Services)

Kami Kandola has been working in the NWT for 15 years. The questions she is concerned with are: How do researchers work in effective partnerships with the NTHSSA? And how does that research improve policy? One example is that there are higher rates of colorectal cancer among Dene and Inuit men in the early 2000s. A study was done, but there wasn't public awareness about colorectal cancer screening in spite of a 2011 recommendation that screenings be recommended to anyone between 50 and 74. Culturally-sensitive research was done on people's perception of cancer and screening. The research validated that uptake of colorectal cancer screening was low and that information was not reaching community members about the importance of screening. They also found that the original test was not appropriate or comfortable for community members. So, they came up with a new test that community member was more comfortable with. This is an example of a positive approach to community research that has real health impacts.

Natalie Nadeau has a large portfolio, oversees mental health and addictions. Often there isn't a lot of evidence-based research in the NWT for family and child wellness. Typically, the research used is based on southern programming and practices. Her division also works to improve community research by helping communities to set their research agenda. They have

recently partnered with a Master's student to research how child and family services can work in a more preventive way rather than reactive, with collaboration from Elders. Her aim is that recent NWT-focused research can be used to shape future GNWT policy.

Pertice Moffitt worked as a nurse in the NWT for 40 years and is now working with the Aurora Research Institute. She has done a lot of work on intimate partner violence and breastfeeding. She suggested it's important to question how we define health research, and how data will be captured and used. At the Aurora Research Institute, 212 licenses were granted in 2016, and the same number was granted in 2017. Eight percent of that was considered health research (22% social science, 5% contaminants, 6% biology, 7% traditional knowledge). It's important to determine how these categories are defined and ensure that proper methods are used. People in communities feel they have been researched too much, and that too little change has happened from research. People want proper methods and for results to benefit communities.

Luke Spooner is the research coordinator at the GNWT. His focus is on how research requests are dealt with by the GNWT Health and Social Services and best practices in how to work with our division. He works with researcher to tailor their projects, so they can ensure everyone benefits. Sometimes he is contacted by researchers who are interested in conducting health research in the NWT but don't have a defined project. In those cases, he recommends they look at the GNWT Research Agenda which has five main research priorities: improving the health status of the population through prevention and education, improving access to primary care services, mental health and addictions, child and family services and addressing disparities of aboriginal health. He also refers them to Hotì ts'eeda because they have the expertise and the capacity, capabilities to help create strong proposals both in



Sahtu cultural knowledge holder Lucy Yakelaya, Jessica Dutton of Aurora College, and the Tłıchǫ Government's John B. Zoe.

terms of methods as well as communicating their research results to the communities and players in the health system. Part of his work is looking at developing partnerships with researchers, and connecting researchers to interesting topics, fostering partnerships to get students studying in the north.

Janet Leggett is the Chief Health Privacy Officer of the GNWT Department of Health and Social Services. People ask what privacy has to do with research, but there is a lot of concern about balancing the benefits of health research and knowledge to people with the right of the individual to agree to their information being used. Her role is to advise the development of policy and a privacy framework to help balance individual rights and privacy with the benefits that come with research. Science Act and other legislation has different rules. Confusion can lead to researchers coming up with a license and wanting to go in a community but not having their research reviewed correctly. Everyone is very attracted to data right now, especially in the north. In this rush we may not have the balance right. She hopes to work with Hotii ts'eeda to conduct process mapping of all the various procedures, guiDélı̄n̄ę and regulations and streamlining. She is in the process of recommending amendments to the Health Information Act and Scientist Act to ensure that all research is reviewed

locally. She is also working to ensure that there is more Indigenous representation as research is being evaluated and getting documents translated into the official languages.

Discussion

Elder Billy Archie asked the panel how to challenge some services in the community, for example some people are brought in but never get involved with the community and people don't know what they're there for. How can we challenge complacent health care workers? The responses focused on the recent changes to the NTHSSA, which respondents hope will encourage more collaboration with patients and families and a more clear structure with opportunities for feedback and input from the community. They are trying to be more effective in meeting needs and standardizing the accountability process so there are clearer expectations and people can expect the same level of service across the territory. People can always enter a complaint or speak to their Regional Wellness Council. It is important to know the Regional Wellness Council representative from your community.

Elder Grace Blake asked where health research permit applications go (e.g. to a local Council or board like the land and water applications). Communities need to set out guidelines for how researchers need to contact and be in touch with the community, timelines and policies in terms of hiring locally and things like that. She also expressed personal discomfort with the term mental health, because of the history of people being diagnosed as mentally unstable and sent to institutions down south. Maybe a softer word could be used that focuses more on wellness. Respondents answered that yes, the licensing requirements need to be more consistent and local research ethics boards need to be developed. Local research ethics boards reviewers would ensure guiDélı̄n̄ę are followed in terms of working with Indigenous communities, respecting

traditions, incorporating community feedback, etc. Aurora Research Institute does much of this but are not always used. There is discussion around having a research ethics committee set up for clinical research. Pertice commented that when someone applies for an ARI research license, they do alert people in the regions that a researcher is applying in that region. Perhaps they should look at who is on that list and if that is a good way of getting community involvement and input.

Heidi Yardley asked if there were Indigenous persons informing decisions around child and family community wellness and integration of culture into these programs, or if there were any initiatives to get local people into some of these positions instead of hiring from down south. Respondents said that the Regional Wellness Councils, which are new, will hopefully help establish the mechanisms to inform decision making in these areas, as well as forming teams of Elders, youth, community members that get involved in different areas such as addictions. The GNWT Indigenous Health and Wellness division is also involved in a lot of projects and programming. One of the things the Regional Wellness Councils hope to do is identify people within the communities with interest in certain fields (e.g. counselling) to try to train them and build them up into the positions.

Ethel Jean Gruben, chair of the Beaufort Delta Regional Wellness Council, sent a message of taking ownership and responsibility in the NWT to improve our health care system. She wants to raise awareness that discrimination, racism and bullying are real in the NWT health system but that awareness is the first step to improving it. We need to deal with what we know exists within our systems if we ever want to achieve cultural safety and best practices. We need to work together to take a stand against these issues in our health system and work together to stop them.

Elder Violet Doolittle commented on nepotism and

changes in advisory councils not being made public to everyone, even members of existing advisory boards. There are very limited spaces in the regional centres and people are having a really hard time getting into them because they don't qualify. We need much more transparency around who is making these decisions and what those decisions mean for the communities and regions. Local people know things like who is suicidal in communities, RCMP and other officials from down south don't know. People won't go to southern counselors or people who don't integrate into the community. She told a story about a residential school counselor in Norman Wells who most members of the community did not know about. There are a lot of capable people in the community that could be trained and hired. We can change these policies. Respondents agreed with Violet's comments and stated the importance of working with community members and Elders. They hope that the Regional Wellness Councils can be voice of the communities, they have a lot of influence in decision making. They planned for a separate conversation about Violet's specific issues. As far as building community capacity, they are in the process of hiring a traditional counsellor coordinator in the Sahtu to pilot a model where people have more access to different types of programming, youth-focused, on the land, etc. Mental health initiatives need to be more integrated into all health and wellness programming and work together to support wellness in all areas.

Hotì ts'eeda Priorities for 2018-19

Hotì Ts'eeda Progress Report & Priorities Session

Thursday, May 24, 2018 9:30 a.m.

Jullian Maclean, Project Director: CIHR is the main funder for all NWT SPOR unit. Every SPOR Unit has a data platform to assist researchers how to identify where health data can be found, how it can be accessed and helps with analytical assistance. Focus of our platform is on NWT and Indigenous health data, requires partnerships and collaborations with other holders of health research. A demonstration project is a trial run in identifying the types of data indigenous governments need in order to plan its programs and services, to figure out who holds data and what data can be accessed, and to figure out what are the important needs to meet indigenous governments.

Accomplishment outcomes of this data:

1. Improve decision making for health interventions
2. It will increase evidence-based priority setting for programs
3. It will improve planning, execution, and effectiveness in health research
4. More effective intergovernmental corporation.

Rachel MacNeill, Communications & Knowledge Translation Advisor: Knowledge translation (KT) Platform goals are to be responsive and flexible to the community. Wants to let everyone know what K.T is up to through the new website which was launched in February, In terms of health and health research. Project database is accessible on the website as well, slowly building on different projects. Purpose of the projects is to provide a show piece for researchers. Building communication through the nwtspor.ca website, newsletters and social media presence.

Knowledge translation is about ensuring that

research is accessible rather than sitting on a shelf. It is important for us to understand what could be done better in terms of communications. Knowledge translation is about capacity building, it is also about using and sharing information in ways that make sense for communities.

Stephanie Irlbacher-Fox, Scientific Director: Provided an overview of the next activity which is having participants to advise us on the Hotì ts'eeda priorities for next year. We have to report back to our funders and stakeholders. One of the primary goals of the Elèts'ehdèe is to gather advice from stakeholders on our activities and strategic focus. A handout was given out in conference bags that outlined accomplishments, current activities and future directions.



Stephanie Irlbacher-Fox, Hotì ts'eeda Scientific Director

Participants were asked to break into small discussion groups and record their comments. Participants also had the option to fill out the handout on their own. The following questions were asked:

Building trust between residents and the NWT health system:

- What are some examples of how to build trust, or

examples where trust has been built?

- How can we help build trust between communities, researchers and the NWT health system?

Data and statistics:

- What kinds of statistics and information/data do Indigenous governments need to better serve members?
- Do we know what we need?
- How can we better understand what the needs are? How can we identify what data is required and how it would be managed?

Health research capacity:

- What are other examples of existing programs we can support or develop?
- How do we build health research capacity in ways that meet your needs?
- What else do we need to know?

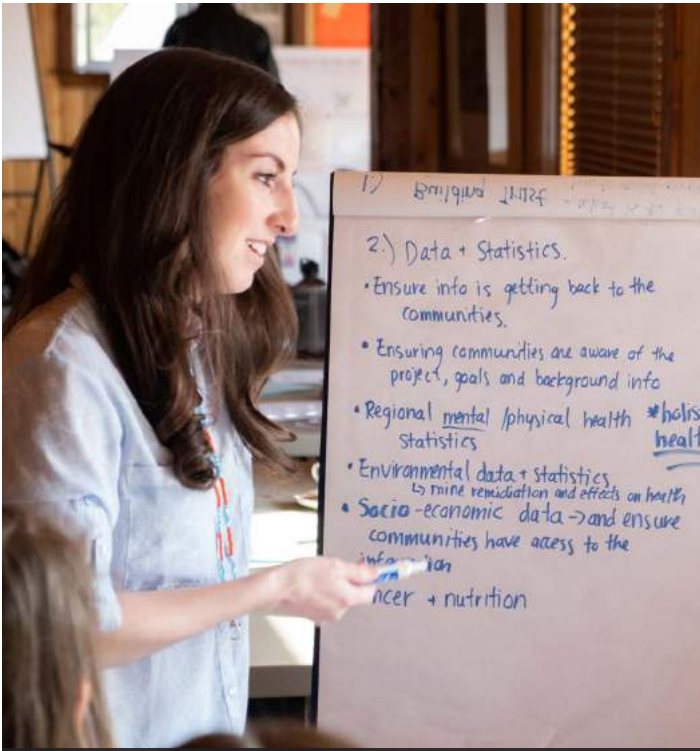
Community involvement in research:

- How should we involve community members if a national research proposal wants, for example, an Indigenous Elder and youth with an interest in a particular project (e.g. mental health, diabetes, food security)?
- Who should we be consulting?
- Should there be a designated contact within each Indigenous government who can help identify people? Other ideas?
- We provide support for participation and knowledge translation. How else should we support involvement?

After the breakout sessions, participants left the main lodge to participate in another round of tipi sessions. After lunch, Rachel MacNeill and Stephanie Irbacher-Fox reported a preliminary analysis of the priorities session notes to the group. The next section provides those results and a closer analysis of the comments and feedback.



Melinda Laboucan (Fort Good Hope) takes notes during the priorities session.



Kelsey Robertson takes notes for her group during the priorities session.

Hotii ts'eeda Priorities: Small Group Results and Analysis

Most groups addressed priorities for the broader NWT health system, rather than specific priorities for Hotii ts'eeda's work. However, this is still valuable information that will function to guide our work as we strive to contribute to improvements in the NWT health landscape. Below, we summarize the feedback we received about these key areas and provide key takeaways for Hotii ts'eeda's future work under each theme.

Building Trust between Residents and the NWT Health System

- Trust can begin to be established by researchers and health/health research teams by recognizing and respecting that there is a lack of trust among residents and the health system. Communication and understanding play an important role. First and foremost, researchers must be respectful and open-hearted. Researchers must be open to

spending time in the communities and having in-depth conversations.

- Privacy and confidentiality in the health care system are major concerns for community members and may contribute to a lack of trust.
- Implementing the Truth and Reconciliation Commission's recommendations is an important step in building trust.
- Traditional medicine, sacred sites and on-the-land cultural healing could make a significant contribution to community healing and wellness. Elders must be involved.
- Health practitioners and researchers need to have empathy, openness and transparency, and prioritize patient comfort and autonomy.
- Our spaces need to change: medical and research centres should meet spiritual and cultural needs, including traditional foods and space for traditional healing practices, such as end-of-life traditional gatherings. This would contribute to a sense of



Gina Dolphus and Norman Yakelaya.

trust and partnership in the NWT health system.

- Racism in the health care system needs to be addressed structurally.

Key takeaways for Hotii ts'eeda

- Hotii ts'eeda will support the development of a medical protocol and terminology/language workshop to help residents understand chronic illnesses and related health issues such as medication management and drug interactions.
- Hotii ts'eeda will continue to offer support to the GNWT Department of Health and Social Services, the Northwest Territories Medical Association and other organizations that are working on cultural competency resources for NWT health practitioners.
- Hotii ts'eeda will ensure that an emphasis on trust, empathy, respect and openness is built in to our Research and Consultation Services and all resources we offer to researchers.

Data and statistics

- Communities need to be made aware of health research projects going on in their region. This includes understand the background information and aims of the project, as well as who is involved.
- Communities should have the opportunity to identify community priorities, and create a community wellness plan to inform what data is needed. Elders must be included.
- There is a need for a central organizing plan or framework to keep track of research projects and available statistics and data. Transparency is needed with regard to who is responsible for what data and how it is being used. Jurisdictions should collaborate to integrate data systems.
- Participants expressed interest in having more data and analysis regarding social determinants of health, mental health, chronic illness and co-morbidities, as well as related environmental and socio-economic data.



Participants talk about priorities for the Northwest Territories health and health research systems.

- Stakeholders are interested in looking at comparative data at a local and regional level, as well as data over time.
- Research teams need to prioritize knowledge translation to ensure residents can use results to improve health and wellbeing.
- Community health workers should work together to support programming and monitor health data over time.

Key takeaways for Hotì ts'eeda

- Hotì ts'eeda will continue to work with the GNWT, Indigenous governments and other stakeholders to advocate for a data framework for the NWT.
- Hotì ts'eeda will include the following priorities in the research priorities shared through our Research and Consultation Services: social determinants of health, mental health, chronic illness, co-morbidities, environmental data, socio-economic indicators, comparative data across community, region and time.
- Hotì ts'eeda staff will be available to communities who wish to discuss data priorities and connect with researchers who can support their community wellness.
- Hotì ts'eeda will continue to offer support for developing community priorities.
- Hotì ts'eeda will ensure that data sharing and transparency is built into our Knowledge Translation and Research and Consultation Services platform, with emphasis put on the First Nations principles of OCAP.

Health research capacity

- Researchers need to recognize and learn about the historical context of colonization and the barriers that Indigenous communities face. They also must be aware of the history of helicopter research and results not being returned to communities.
- Researchers must take time to build relationships of trust and understand why community members



Sonia Wesche, Debbie Delancey, Robert Charlie, Marnie Anderson, Billy Archie and Gerry Kisoun.

might be reticent to participating in research.

- Communities should be provided with project information prior to arrival and ensuring have input in and approval of research permit applications.
- Capacity should be built from the community's perspective, worldview, and language.
- Foster interest in research with youth and engage them in the research process.
- It is important to use a strength-based approach and be dynamic and flexible throughout the research process. This will enable the positive relationships to research projects that will lead to capacity being built.
- Sharing results with northern frontline workers should be mandatory to enable them to make the best, most informed health care decisions.

Key takeaways for Hotì ts'eeda

- Hotì ts'eeda will continue to prioritize the inclusion of youth through our summer student program, the Aurora College Studentship, our two capacity funding programs, and our Health Leaders program.
- Hotì ts'eeda will take steps to ensure more inclusion of youth at next year's Etèts'ehdèe.
- Hotì ts'eeda's summer students will engage in awareness-building among youth in their regions.
- Hotì ts'eeda will build strengths-based approaches and Indigenous methodologies

into our online and consultation resources for researchers.

- Hotiì ts'eeda will communicate take actions to promote policy makers and frontline workers being informed about research projects and research results.

Community involvement in research

- The teachings of Elders must be involved in the health research process. It is important that sacred traditional Indigenous knowledge be passed down to the next generations and research is one process that can incorporate and share this knowledge.
- When research is done in a community, researchers enter into a social contract with community members. Design and decision-making for community-based research projects should be done collaboratively and reflect community needs. Communication should be clear and done in a way that can be understood by all community members.
- Each community should create a space for interaction to build relationships and partnerships.

- There is a need for a community champion/ advocate on each research team to ensure follow-through is responsive to the needs of the individual and community.
- Community committees could help establish ownership in the research process.

Key takeaways for Hotiì ts'eeda

- Hotiì ts'eeda will continue to advocate for meaningful community and Elder inclusion through our Capacity and Training, and Research and Consultation Services platforms and online resources.
- Hotiì ts'eeda will take action to promote community involvement in research project teams as part of our work with Research Methods, Capacity and Training, and through online resources.
- Hotiì ts'eeda will build a roster of regional and community health contacts within each Indigenous government who can identify individuals, Elders and knowledge holders to include in research projects.



Participants gather together during a break to share stories.

Youth Engagement Session: Results

Facilitators:

- Roxanne Kotchilea (Behchokq)
- Joni Tsatchia (Wekweeti)
- Genevieve Bekale (Behchokq)

Youth participants:

- Dakota Orlas (Colville Lake)
- Janelle Nitsiza (Whati)
- Tyler Smith Tsetta (Dettah)

On the afternoon of Thursday, May 24, Hotiì ts'eeda's summer students held a separate youth discussion for self-identified youth Elèts'ehdèe participants. Participants began by discussion around general cultural revitalization, and then turned the focus to more specific topics around health research. Below is a summary of their discussion and some key takeaways for Hotiì ts'eeda.



Joni Tsatchia and Roxanne Kotchilea (Tl̓chq̓ summer students with Hotiì ts'eeda) host the youth engagement session.

Have any of you been part of any youth program research or have been asked to be involved?

The students identified programs they had participated in and know about. The students expressed concern that there was not enough advertisement of the programs—they typically had heard of the programs by word of mouth or

independent research. Participants had been involved/asked to be involved in the following programs:

- Tall Ships
- Students On Ice
- Activate Leadership
- Ambassador Program
- A First Nation Youth Council
- Northern Youth Abroad
- Canada World Youth Abroad
- Indigenous internship program
- Winterlude Festival
- Taiga Summer Camp

How do you continue to increase your cultural language/identity/traditions/language?

The participants discussed ways to strengthen their communities' culture, language, identity, and traditions. It was acknowledged that the initial place to promote and teach about culture is within the child/adult family system. However, alternative methods such as apps are opening doors for the younger generation through technology and social media. This plays an important role in independent learning about Indigenous language vocabulary and pronunciation through a dictionary, and games. However, participants stated that there are some challenges with the Tl̓chq̓ language app.

At a community level, participants felt cultural revitalization could be provided through workshops and programming that linked to health and wellness, language and traditional activities such as trapping or hand games. For instance, language workshops that integrate cultural activities where youth can learn words while doing hands-on traditional activities. Participants discussed that communities should provide programs that give community members opportunities to take youth out on the land engaging in traditional activities to promote health and wellness.

Do you have any suggestions on ways to promote increased cultural immersion amongst youth today?

To promote increased cultural immersion amongst youth today it was suggested that communities provide more formal and informal cultural education. Community recreation facilities with cultural rooms, Elders on site and cultural programming options in a safe and welcoming space could provide a space for cultural revitalization and also provide space for community discussing and accessing community members. Participants also felt that incorporating Indigenous languages into school curricula would strongly support cultural revitalization. Youth involvement in community life and activities through councils and advisory boards was noted as a way to increase the youth voice in community decision making and initiatives.

What does “decolonize health care and health research” mean to you?

Participants want more Indigenous people involved in health programs decision-making process. They want community members to have the opportunity to tell their own stories and have their opinions included in program development.

It was also stated that healthcare professionals should be provided with workshops to learn about cultural competency and the history of communities in order to learn about local people and their history. Equally important, participants emphasized the need for traditional food/food from the land within the health care system for elders who are in long-term care. Many elders depend on traditional food and without it in the hospital they usually end up getting weak because they are not used to processed foods.

How can we engage and encourage Indigenous youth to be part of the health care and health research processes?

The participants discussed ways to engage and influence Indigenous youth to be part of the health care and research processes through a variety of methods. For instance, they felt youth would respond to researchers hosting an open house session that provides healthy snacks and information about getting involved in an ongoing research projects or sharing results from research.

Participants recommended use of social media, online surveys and prize give-aways to encourage youth participation. Research projects that enter communities should have a community program to ensure the unique individual needs of each community are met.

Lastly, youth health care advisories and representatives should be integrated into health promotion research and programming.

What tools are needed in your community to build trust between residents and the health care system?

The participants stated that it was important that health centres and community agencies take policies around confidentiality seriously. Some of the participants expressed that when patients go to the health centre, community members know every detail and purpose of why a patient might be there. Gossip and lack of confidentiality was expressed as a major issue that can lead to a lack of trust in the NWT health system.

It is also important that nurses and doctors learn cultural competency as well to be better able to understand social determinants of health when working with Indigenous people.



Denezë Nahkehk'o holds the microphone for cultural knowledge holder Elder Rassi Nashalik as she lights the qulliq.



Cultural knowledge holder Elder Mary Adele Rabesca reaches for some drying fish during the tipi sessions.



The qulliq.



Lessons Learned

After the Elèts'ehdèe, Hotì ts'eeda staff and summer students debriefed to discuss lessons learned and ways to improve future Elèts'ehdèe events. Using information from that debrief, feedback from participants and facilitators, and information from the evaluation forms, we've distilled some lessons learned that we will apply to future Elèts'ehdèe events. They are provided below under the categories of Content and Scheduling.

We try to improve the experience each year, and there are limitations that must be respected. Evaluations and feedback tell us that the atmosphere of an on-the land meeting and having a smaller meeting where it is easier to meet and talk with people should be maintained. There is so much to share, scheduling and timing of sessions are an ongoing challenge.

If you feel we've missed something from this list, please feel free to reach out to us to share your suggestions for improving future events.

Elèts'ehdèe Content

- Invite participants to include youth delegates or take other measures to ensure youth involvement. Set a specific target for number of youth participants and meet it.
- Invite naturopaths and other recognized/regulated health practitioners next year; include mental health practitioners/psychiatrists, particularly with a focus on Indigenous-specific issues.
- Invite Indigenous healers/counsellors/ specialists recognized in their nations as healers.
- Consider the knowledge economy aspect of health research next year.
- Consider improving inclusion of different demographic groups through reporting back, for example, have youth, Elders, researchers, practitioners give report backs.

- Incorporate more capacity building (e.g. add on a cultural competency training day or take other actions) for researchers to do research in a good way.
- Include content on how to get research projects in your community (both working with Hotì ts'eeda and researchers).
- Set clear learning objectives.
- Incorporate more visuals.
- Better integrate presentations with the concurrent cultural activities
- Include time to ask SPOR staff questions.
- Make sure there is inclusion of mental health in health care panels.
- Include information on Indigenous history to provide context.
- Make sure there are support people available for difficult conversations, or resources available, or structure sessions so that facilitators can manage difficult conversations.
- Include no more than four people per panel, apart from the research project pairs.

Scheduling

- Transition time and longer breaks need to be built into the agenda to ensure the schedule stays on track and people have time to adequately rest and refuel between sessions.
- There should be fewer indoor plenaries, and these should not be in long blocks on the schedule. Plenaries should be given more time on the agenda to ensure that there is ample time for discussion.
- Ensure last panel ends on a positive note.
- Consider extending the conference an extra day rather than including evening sessions.
- Find a way to incorporate introductions in a more cohesive way at the beginning of the event.



Participants close the 2018 Etêts'ehdée with a drum dance from the Yellowknives Dene Drummers.



A group of participants enjoys the sun while learning about health research during a tipi session.

Contact Us

For questions, comments or to talk about how Hotiì ts'eeda can support health and health research in your community, please contact:

Rachel MacNeill

Communications and Knowledge Translation Advisor

Hotiì ts'eeda: NWT SPOR SUPPORT Unit

T: 1-867-766-4003 x1011

E: communications@nwtspor.ca



Jim Corkal learns how difficult moose hide tanning can be from cultural knowledge holder Melaw Nahkehk'o.

Mahsi Cho

Mahsi cho to all who participated in the 2018 Etèts'eh-dèe. A special mahsi goes out to our panelists, tipi presenters and cultural knowledge holders:

Elders

- Billy Archie
- Rosa Mantla
- Pat Martel
- Grace Blake

Elder host

- Irene Roth

Cultural Knowledge Holders

- Sarah Rogers
- Emelda King
- Angus Beaulieu
- George Mandeville
- Mary Adele Rabesca
- Melaw Nahkehk'o
- Judy Lafferty
- Lucy Yakeleya
- Alfred Taniton
- Morris Neyelle
- Jane Dragon
- Joy Dragon

Tipi Presenters

- Mary Ollier
- Sonia Wesche
- Jullian MacLean
- Andrew Spring
- Melaine Simba
- Caroline Tait
- Mahalia Yakeleya Newmark
- Janis Geary
- Marnie Anderson
- Sangita Sharma
- Pertice Moffitt
- Violet Camsell-Blondin
- Maya Lefkowich
- Kristen Tanche
- Leslie Dawson

Panelists

- Sarah Cook
- Katherine Breen
- Matthew Quinn
- David Pontin
- Kami Kandola
- Nathalie Nadeau
- Pertice Moffitt
- Luke Spooner
- Janet Leggett
- Nancy MacNeill
- David Codzi
- Dakota Orlias
- Magnolia Unka-Wool
Florence Barnaby
- Grace Blake
- Besha Blondin
- Violet Doolittle
- Felix Lockhart
- Emily Saunders
- Petter Jacobsen
- John Koadlak
- Sangita Sharma
- Melinda Laboucan
- Andrew Spring
- Melaine Simba
- Crystal Gail Fraser
- Karen Blondin Hall
- Thomsen D'hont
- Michael Green
- Tracey MacPherson
- Caroline Tait

Facilitators and Co-chairs

- Kyla Kakfwi-Scott
- Dëneze Nahkehk'o
- Cristina Popa
- Jessica Simpson
- Sophie Roher
- Rachel Leblanc
- Roxanne Kotchilea

Event planner

- Darlene Mandeville

Hotìì ts'eeda is a Strategy for Patient-Oriented Research (SPOR) SUPPORT Unit funded by the Canadian Institutes of Health Research.



Hotìì ts'eeda is hosted by the Tłı̨chǫ Government.





Hotii ts'eeda Elèts'ehdèe Agenda
May 22 – 24, 2018, Aurora Village, Yellowknife NT

Hotii ts'eeda acknowledges that the Elèts'ehdèe is being held on the Chief Drygeese traditional territory of the Yellowknives Dene.

TUESDAY, MAY 22

- 6:00 p.m. **Welcome to the Hotii ts'eeda Elèts'ehdèe**
Dr. John B Zoe, Tłı̨chǫ Government and Chair of Hotii ts'eeda Governing Council
Joanne Barnaby and Deneze Nahkehk'ó, Elèts'ehdèe Co-Chairs
Elder Jane Dragon, Prayer Offering
Dinner
Introduction of Hotii ts'eeda Elèts'ehdèe Participants
Review of the Goals of the Elèts'ehdèe
- 7:00 p.m. **Plenary Panel One: NWT Doctors Reflect on Medical Practice and Research in an Era of Reconciliation**
NWT medical practitioners share challenges and solutions for meeting the health needs of Indigenous residents; the importance of health research for improving health delivery; personal and professional responses and experiences working to improve health services and accessibility for Indigenous populations and communities; and, areas requiring further effort.

Dr. Katherine Breen, President, NWT Medical Association
Dr. Sarah Cook, Territorial Medical Director, NT Health and Social Services Authority
Dr. David Pontin, Emergency Physician, Stanton Territorial Hospital
Dr. Matthew Quinn, Physician, NT Health and Social Services Authority

WEDNESDAY, MAY 23

- 8:30 a.m. **Buses to Aurora Village depart from Explorer Hotel**
- 8:45 a.m. **Hotii ts'eeda Elèts'ehdèe Registration** (Aurora Village main hall)
- 9:00 a.m. **Opening Ceremony**
Yellowknives Dene First Nation Drummers, Prayer
Elder Alfred Taniton (Deline), Fire Feeding Ceremony
Review of Agenda, Locations of Presentations and Cultural Activities

- 10:00 a.m. **Plenary Panel Two: Arctic Inspiration Prize Recipients – Celebrating Research and Program Excellence**
 Arctic Inspiration Prize recipients will provide descriptions of their projects and how the projects promote wellness, and support Indigenous values and decolonization. This is an opportunity to celebrate the recipients' efforts, to share inspiration, and to understand how health research takes many forms.
- David Codzi, Dela Got'ine Dene Heroes Publication*
Nancy MacNeill, FOXY/SMASH
Simeonie Nalukturuk, Unaaq Men's Association of Inukjuak
Dakota Orlias, Dela Got'ine Dene Heroes Publication
Magnolia Unka-Wool, Arctic Indigenous Wellness Foundation
- 11:00 a.m. **Health Break**
- 11:15 a.m. **Plenary Panel Three: Perspectives from Indigenous Wellness Program Practitioners—Why we need health research, and need it to be responsive to the needs of Indigenous peoples.**
 Practitioners will talk about their roles in their communities and how good relevant health research can help them in their work: designing and delivering programs; assessing needs; and advocating for program change and development with funders.
- Les Semmler, Inuvialuit Health Systems Navigator, Inuvialuit Regional Corporation*
Jennifer Drygeese, Wellness Director, Yellowknives Dene First Nation
- 11:45 a.m. **Plenary Panel Four: Elder's Perspective on Health Research**
 Indigenous Elders share their wisdom and perspectives on health research: their reflections on involvement they have had with health research projects in the past or present; and, their thoughts on incorporating Indigenous knowledge into research.
- Florence Barnaby, Outstanding Elder Award Recipient, Fort Good Hope*
Grace Blake, President, Gwichya Gwich'in Council
Be'sha Blondin, Northern Integrated Cultures with the Environment (Northern ICE)
Violet Doolittle, Sahtu Land and Water Board
Felix Lockhart, Stanton Territorial Hospital
Emelie Saunders, Yellowknife Regional Wellness Council
- 12:30 p.m. **Lunch**
- Plenary Panel Five: Community-Based Health Research in the Northwest Territories**
 Panelists will highlight projects currently being undertaken in the NT communities, particularly drawing out examples of how working with communities has promoted a decolonizing or partnership approach.
- Petter Jacobsen, Tłı̄chǫ Ekwo Nàowo: Cumulative Impact Study of the Bathurst Caribou Herd, Tłı̄chǫ Government*
Dr. Sangita Sharma, Capital Health Research Chair in Indigenous Health, Centennial Professor, and Professor in Indigenous and Global Health Research in the Department of Medicine, Faculty of Medicine & Dentistry, University of Alberta
Melinda Laboucan, Community Cancer Co-ordinator, Fort Good Hope
Andrew Spring, Research Associate, Geography and Environmental Studies, Wilfrid Laurier
Melaine Simba, Environmental Coordinator, Ka'a'gee Tu First Nation

- 1:30 p.m. **Overview: What Hotì ts'eeda has accomplished since last year, based on direction from the 2017 Èlèts'ehdèe** — *Dr. Stephanie Irlbacher-Fox, Scientific Director, Hotì ts'eeda*
- 1:45 p.m. **Tipi Presentations and Cultural Knowledge Activities**
- 5:00 p.m. **Buses return to Explorer Hotel**
- 6:00 p.m. **Dinner** (Explorer Hotel)
Elder Be'sha Blondin, Prayer Offering
Dr. Kue Young, Professor and Dean, School of Public Health, University of Alberta
Be'sha Blondin, Northern Integrated Cultures with the Environment (Northern ICE)
Dr. Kuan Li, Project Lead, Strategy for Patient-Oriented Research, Canadian Institutes of Health Research

THURSDAY, MAY 24

- 8:30 a.m. **Buses to Aurora Village depart from Explorer Hotel**
- 9:00 a.m. **Welcome**
Rassi Nashalik — Lighting of the Quilliq
Report on Progress of Hotì ts'eeda and Programming in Development
Jullian MacLean, Project Director, Health Methods and Data, Hotì ts'eeda
Rachel MacNeill, Communications and Knowledge Translation Advisor, Hotì ts'eeda
Summary of Day One
- 9:45 a.m. **Plenary Panel Six: Emerging NWT Indigenous Scholars' Perspectives on Decolonizing Health Research**
 Emerging scholars share an Indigenous and Northern perspective on ways the research enterprise could be improved and adapted to the Northern context, and how research can be used to improve NT health care.

Karen Blondin Hall, Senior Advisor, Aboriginal Health, Department of Health and Social Services
Thomsen D'Hont, University of British Columbia
Crystal Gail Fraser, PhD Candidate and Contract Instructor, Department of History & Classics, University of Alberta
- 10:45 a.m. **Health Break**
- 11:00 a.m. **Plenary Panel Seven: Innovations Across Canada**
 Panelists will share about initiatives that have been successful across Canada in supporting Indigenous and rural health, decolonization and effective community-based health research.

Marnie Anderson, Research Coordinator, Aboriginal Children's Health and Well-being Measure, Indigenous Peoples' Health Research Centre
Dr. Michael Green, Lead of INSPIRE-PHC (OSSU Research Centre), NPI and Ontario SPOR SUPPORT Unit
Tracy MacPherson, Discharge Planner / Community Liaison, First Nations Health Programs, Yukon Hospital Corporation
Caroline Tait, Professor, University of Saskatchewan, First People First Person Research Network

- 12:00 p.m. **Lunch**
Plenary Panel Eight: GNWT’s Role in Health Research (Aurora Village main hall)
This panel discussion will have representatives from various arms of the GNWT discussing their division’s role in health research, from making contact with researchers, to accessing data, to application of research findings.
- Dr. Kami Kandola, Deputy Chief Public Health Officer, Department of Health and Social Services*
Jannet Ann Leggett, Chief Health Privacy Officer, Department of Health and Social Services
Pertice Moffitt, Manager, Health Research Programs, North Slave Research Centre, Aurora Research Institute
Nathalie Nadeau, Director, Child, Family and Community Wellness, Northwest Territories Health and Social Services Authority
Luke Spooner, Research Coordinator, Department of Health and Social Services
- 12:00 p.m. **(Concurrent Session) Open Discussion: Youth in Health Research (Tipi six)**
Youth attendees are invited to join Hotii ts’eeda youth staff in an open discussion on youth involvement in NT health research and developing recommendations for engaging youth in health programs and research projects.
- 1:00 p.m. **Plenary: Setting Hotii ts’eeda’s Priorities for the Next Year**
Reflection on what Hotii ts’eeda has accomplished in its first year, and where it should focus during the 2018-2019 year.
- 1:30 p.m. **Tipi Presentations and Cultural Knowledge Activities**
- 3:45 p.m. **Closing Remarks**
Dr. John B Zoe, Tłı̄chǫ Government and Chair of Hotii ts’eeda Governing Council
Dr. Stephanie Irlbacher-Fox, Scientific Director, Hotii ts’eeda
- 4:00 p.m. **Closing Prayer and Drum Dance**
Yellowknives Dene First Nation Drummers
- 5:00 p.m. **Buses return to Explorer Hotel**

APPENDIX 2: Ełets'ehdèe Evaluation Form Comments

The following answers are taken from completed evaluation forms received after the Ełets'ehdèe. Comments are transcribed verbatim.

- 1. What did you think of the approach that embeds the research project presentations with cultural activities?**
 - A. 38 Individuals found this enjoyable and interesting
 - B. 3 Individuals found this too distracting
 - C. 13 Individuals found that it was a good way to have discussion
 - D. 9 Individuals found this approach was easy to ask questions
 - E. 16 Individuals liked this approach

- 2. What did you think of the plenary presentation in the main lodge?**
 - Off topic
 - Crowded, space too small
 - Long chunks of time setting, need breakout sessions (sitting) possibly in teepees
 - Elders panel should have been given more time not split up
 - This integration is innovative & honouring all types of knowledge but important to inform all partners of how this flows or what to expect to ensure everyone (presenters & cultural knowledge holders) have ample time to be heard
 - It was thought provoking, engaging
 - Very helpful to allow questions and comments
 - Good groupings by theme

- 3. Are you satisfied with what you learned about health research taking place in the NWT?**
 - Not much new information
 - Overwhelming
 - Very diverse perspectives – well rounded
 - Very Informative
 - More Health staff with decolonization focused on mental and emotional health and healing from trauma
 - To the degree that action for changes follow
 - It is a turn in our future and history in the making for medical professionals and researchers to finally work with the Indigenous peoples to better the care and quality of our peoples health and wellbeing
 - There is room for improvements; however, we appreciate the interest and work being done
 - Need more sharing on how to do research in a good way - teaching

4. Which speaker(s) did you learn the most from?

- Staff from Hotù ts'eeda sharing updates
- Panel on NWT Health Doctors
- Elders on Health
- Comments from participants during plenary session

5. What did you enjoy or appreciate the most?

- Time for conversations
- Elders, Youth, Community members
- Having a comfortable space to bring vital people together to share and learn from each other
- Plenary panels
- Connecting and having discussions with other participants
- Hearing that we are finally being listen to, taken seriously, and making improvements based on recommendations
- Cultural activities, small group discussions, words from elders

6. What should we do better next time?

- Learning objectives and keep people on topic
- Having visuals that's more engaging
- Communicate with facilitators about how many sessions, timing and provide suggestions on how to combine presentation and cultural activity
- Make time to ask SPOR staff questions
- No evening presentations. Too much information in one day
- Have Youth involve and partner them with an Elder for the conference
- Slow down, give more space, extend 3 days if needed to do this.
- It is important to have audience to comment.
- Do a presentation on how to get researchers to come to your community
- Participants receive brief information on presentations either emailed or on website
- Make sure Elders can rest during/after an intensive session
- Have a huge tent on field for plenary presentation including the main lodge
- Invite Inuvialuit/Inuit youth to assist with conference to speak about their journey success and barriers

7. How would you rate the meeting on a scale from 1 (poor) to 10 (excellent)?

- 7 (2 people)
- 8 (9 people)
- 9 (6 people)
- 10 (8 people)

8. Please provide any additional comments or feedback:

- There seems to be some persistent lack of differentiation between program implementation and research. Maybe more background on what the terminology means would be helpful. Or possibly the SPOR is trying to help communities by funneling research money to programs, it's not clear.
- Serve some sort of protein for breakfast and during breaks, important for diabetic people
- Have a Psychologist in panel
- A panel member with knowledge about aboriginal history – we have to know where we come from and what happened to us as people on contact (healers past so we can move forward)
- Great way to connect communities with communities
- Provide water in tipi
- Make sure there are support people available for difficult conversations or resources available

Hotì ts'eeda Overview

What is a SPOR SUPPORT Unit?

The Canadian Institutes of Health Research (CIHR) have spearheaded the Strategy for Patient-Oriented Research (SPOR). SPOR is a coalition of federal, provincial and territorial partners committed to:

- engaging patients as partners in research;
- ensuring that health research is relevant to patients' and policy-makers' priorities, and,
- ensuring research results are used to improve healthcare systems and practices.

CIHR promotes the philosophy of SPOR through SPOR SUPPORT (Support for People and Patient-Oriented Research and Trials) Units in every province and territory. SUPPORT Units do not provide research funding. Instead, they facilitate and catalyze research-based improvements to the health care system in response to locally identified needs. SUPPORT Units bring together key stakeholders and provide a structure for stakeholders to identify and respond to local research needs.

Hotì ts'eeda

The NWT SPOR SUPPORT Unit is Hotì ts'eeda. It is administered by the Tlicho Government. Its staff will be embedded with Indigenous governments in the NWT. The Unit has \$8M in funding from CIHR over 5 years; another \$16,798,780 M is being provided in-kind and in cash from Hotì ts'eeda stakeholders.

Stakeholder	Contribution Detail	Five Year Contribution Total
Aurora Research Institute	Staff, equipment and facilities \$21,500.00/Year	\$107,500.00
Dehcho First Nations	Staff time, databases \$77,748.87/Year	\$4,388,744.35
Deline Got'ine Government	Staff time \$6,000.00/Year TK Database Value: \$100,000.00	\$130,000
GNWT Department of Health and Social Services	Staff time, facilities, materials, \$1,838,507.20	\$9,192,536.00
FOXY	Staff time and resources \$200,000.00/Year	\$1,000,000.00
GTC Department of Cultural Heritage	Staff time, policies, databases, platforms \$509,500/Year	\$2,547,500.00

Gwich'in Tribal Council	Staff time, training materials \$20,000.00/Year	\$100,000.00
Gwich'ya Gwich'in Council	Staff time \$4,500.00/Year	\$22,500.00
Indigenous and Global Health Research Group (University of Alberta)	Staff time, training materials, facilities \$226,000/Year	\$1,130,000.00
Inuvialuit Regional Corporation	Staff time, facilities, knowledge holders, databases \$277,400/Year	\$1,387,000.00
Tetlit Gwich'in Council	Staff time, facilities \$15,000/Year	\$75,000.00
Tides Canada	Staff time \$5,000.00/Year	\$25,000.00
Tlicho Government/ Dedats'eetsaa	Staff time and expertise, facilities, databases \$138,600	\$693,000.00

Unit Activities and Priorities

CIHR requires that each SUPPORT Unit undertake activities in the following areas: Research Methods; Consultation and Research Services; Databases; Training and Capacity; Knowledge Translation; and Clinical Trials. Patient Engagement is required in all of these areas. Hotii ts'eeda is unique in that it focuses on Indigenous health and Indigenous health research. Its Governing Council includes a majority of Indigenous Governments, along with the GNWT Department of Health and Social Services, and the University of Alberta Indigenous and Global Health Group. The Governing Council has both permanent members who are making considerable contributions to the Unit, and rotating members to ensure all stakeholders have an opportunity to participate in the Governing Council.

How Are Stakeholders Involved?

The Unit will need ongoing input from stakeholders in various ways. Stakeholder organizations and their representatives will be encouraged to join Hotii ts'eeda's Patient and Expert Advisory

Panel; they may have representatives on the Governing Council; stakeholders are invited to attend the yearly information sharing, priority-setting and accountability gathering (the Elets'ehdee); Unit staff are on hand to provide advice, connect researchers and communities, and receive requests for training funding and support for research projects; and Unit staff will seek advice from stakeholders and invite representatives to sit on Advisory Teams who will guide Hotì ts'eeda's staff in different aspects of their work.

Hotì ts'eeda Vision: Support health research and training that is rooted in Dene Naowo, Inuvialuit and Metis knowledge, research that is relevant and responds to needs of patients, communities, and governments, to build capacity