

HOTIÌ TS'EEDA EŁÈTS'EHDÈÈ



Elder Florence Barnaby, Dr. Jim Corkal, and Marie Adele Rabesca.

MAY 30 – 31, 2017
FINAL REPORT



Dr. James Makokis leads a small group discussion; youth tanning moose hide with Melaw Nahkehk'o.



Participants listening to a plenary presentation; dancing to the Tłı̄chǫ Drum songs on Day Two.

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MAHSI



Thank you

On behalf of the Governing Council of Hotì ts'eeda, I would like to thank you for participating in our first annual gathering, our Elèts'ehdèe.

The purpose of this first meeting was to seek your advice on priorities for Hotì ts'eeda in the year ahead, and to provide the opportunity for stakeholder organization representatives, community members, and researchers to build and renew relationships. We wanted to do this in a way that emphasized our commitment to Indigenous Knowledge being the foundation for our activities.

This report provides analysis of our discussions, and through photos and text, provides a meeting record.

We welcome your feedback, and look forward to being in touch and welcoming everyone back to future meetings in the years ahead.

John B. Zoe, LLD (Hon.)

Chairperson

Hotì ts'eeda Governing Council

EXECUTIVE SUMMARY

The welcoming remarks from four of the Governing Council representatives touched on the word “Hotì ts'eeda” and its meaning in Tlicho language: it is about peace and wellbeing in mind, body and spirit, about moving beyond diplomacy to true collaboration so that when we part ways we leave each other in a state of grace. Hotì ts'eeda exists to revitalize and celebrate culture, improve capacity for individuals and families and support taking an evidence-based approach to policy. It is about moving control and ownership of research back to Indigenous peoples and communities.

The first Èlèts'ehdèe provided time for partners and researchers to meet or see each other again, learn about Hotì ts'eeda and suggest priorities for its first year as it sets up. This report gives a short overview of the structure of Hotì ts'eeda, its place within a new national network and as a unique collaboration between governments and organizations in the Northwest Territories.

The Èlèts'ehdèe included a number of plenary panels, with stories and presentations that shared experiences and wisdom, that highlighted priorities, showcased existing work and framed the importance of this new collaborative organization. Small group sessions were held throughout the two-days to identify priority areas for Hotì ts'eeda's first year. Short analysis of each is provided below. Certain broad questions were raised and these are identified in this report as they will help guide Hotì ts'eeda.

A resounding priority throughout the sessions was the importance of continuing to strengthen meaningful collaboration and revitalize traditional knowledge and medicine. Pragmatic ways Hotì ts'eeda can support this is included providing training to researchers on appropriate methodologies and protocols, providing support to Northern students and researchers to continue their training and careers and continuing to support strong relationships as the foundation for good work.

WHAT IS HOTIÌ TS'EEDA?

Each participant was provided with a short overview of Hotiì ts'eeda in their participant package, which is appended to this report.

Right now, Hotiì ts'eeda is a unit with 1.5 staff positions and a Governing Council. Three more staff will be hired in the coming months. They will be part of and managed by Indigenous Governments and partner organizations, hopefully located outside of Yellowknife.

Hotiì ts'eeda's purpose is to provide support to health research being done in the NWT: matching communities and researchers, assisting with making sure best practices are available and accessible to researchers and communities, and helping to ensure that research results start to shape the health system: for example, the way health programs and services are designed and delivered. It will assist Northern students and community members to access training in health research and health professions. It will promote including Northerners in shaping health research. It will help to ensure that the health system is influenced by research results. Stakeholders were clear that they do not like the term "patients" – we are all patients at some point and all have a stake in shaping health research and how results inform improvements in our health system.

Hotiì ts'eeda is new. It is part of a national network of Units that provide support to ensuring health research is done in a way that included patients, and that research results are used to improve the health system. Each province in Canada has a Unit that does this work. However, the NWT Unit focuses on Indigenous health and health research methods. It is very different in that Hotiì ts'eeda does not have access to large universities and teaching hospitals, clinician researchers, databases and clinical trials experts. Instead, our strengths in the NWT rest with our communities, and in the Indigenous cultural knowledge of our Elders. Our health challenges are unique –

as Dr. James Makokis and Crystal Fraser reminded us during their presentations at the, colonization, its policies such as residential schools, and its outcomes such as settler colonialism, have all resulted in health impacts for Indigenous peoples, who are worse off compared to non-Indigenous people in the NWT. Poor health outcomes are related to social determinants of health: poverty, lack of adequate housing, poor educational attainment, institutional racism, and a variety of other factors. Such factors directly affect peoples' diets, and restrict access to the land, the healthy foods and positive cultural activities that the land provides.

Another strength that became clear at the Ełèts'ehdèe is that Indigenous governments and researchers are willing to work together for good health, and are willing to participate in Hotì ts'eeda.

Over the next few months, once staff are hired, Hotì ts'eeda will undertake specific activities that focus on increasing the quality and impact of health research in the NWT. These will include developing information data bases about best research practices, research needs, and research results; holding a yearly Ełèts'ehdèe to provide a way to share health research results among communities and researchers; acting as a "dating service" for communities and researchers: understanding what research communities want, what research that academics are interested in, and helping to match interests and assist with finding funding; promoting cultural competency among health professionals; contacting stakeholders about advising on projects and activities being undertaken; and, identifying and funding demonstration projects and health research and skills training for Northerners.

Hotì ts'eeda has been funded for a five year period. After that time, our funder, the Canadian Institutes for Health Research, is hoping Hotì ts'eeda that will become self-sustaining, through funding from other partners and revenues from consulting services.

PLENARY SESSIONS – OVERVIEW

Archie Norbert, Tsiigehtchic, began the Elders Perspectives on Health panel, sharing stories and highlighting the importance of making people aware of problems with housing and water contamination. Billy Archie, Aklavik, spoke of traditional ways to cure ailments, the impacts of residential schools, even for those who never attended it, and that “healthy, wealthy attachment to land”. Florence Barnaby, Fort Good Hope, critiqued the current approach in health care for always responding to a crisis - we need to look “up the river” and focus on prevention and an approach to health that is mental, emotional and spiritual. Culture is the missing piece for the youth and we need to promote and preserve it. Joanne Barnaby, Hay River, shared a powerful story of a recent encounter with a wolf and the spiritual support and guidance connected with that encounter.

The keynote panel on acknowledging colonization, settler colonialism and associated health impacts began with a reflection on the word “Indigenous.” It means you have been in one place for 10 generations or more, which is the time it takes for bodies to become in tune with the environment so that all you need the land provides for you: “All grandma needs is caribou meat.”

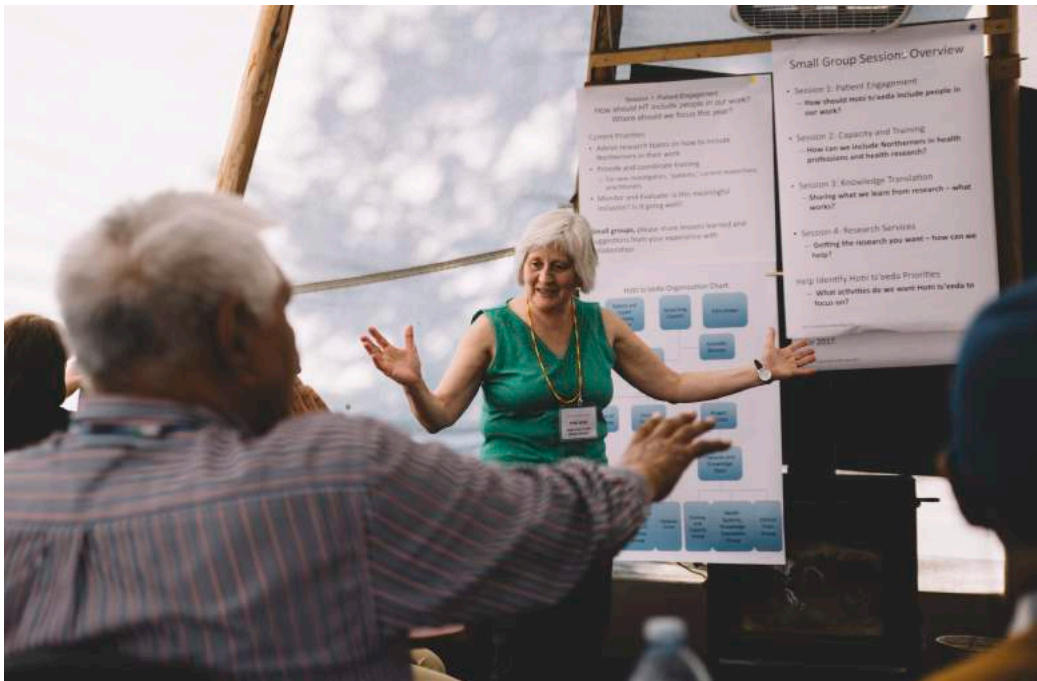
James Makokis, MD, (Saddle Lake Cree, Alberta), spoke of the distinction between Indigenous health and the social sicknesses from colonization: “Everything we need to heal is ceremony, thought, language.” The hospitals and pharmaceuticals we need to deal with the social sicknesses. He told a story of the buffalo and the moose, and spoke and shared photos of dances the original medicines: culture and identity need to be put back in the centre. Crystal Fraser, PhD Candidate, University of Alberta (Gwich’in), spoke of her story becoming a PhD candidate and her research on residential schools and the colonization of the body. She spoke of the power of relationships

and family to undo colonization and ways to practice “micro-interruptions” everyday. Stephanie Irlbacher-Fox, PhD, Hotì ts'eeda Scientific Director, spoke of settler colonialism and the theory of social suffering which sees suffering as an expression of oppressive policies. Settlers blame Indigenous people for their suffering, but when a government chooses policies that traumatize people, suffering is the logical response. Settler colonialism is where the settlers haven't left and it involves a whole system weighted in favour of settlers: this is settler privilege. Settlers have a responsibility to unlearn and understand how we got here and she shared suggestions for that work and stories from the ongoing journey of decolonizing and “unlearning.”

The research panel presentations at the gala dinner showcased other examples of health research in the NWT. Dr. Janis Geary (University of Alberta) and Elder Billy Archie described the *h.pylori CANHelp* project that began in Aklavik. Dr. Nicole Redvers, ND (Gaia Naturopathic Clinic) introduced the Arctic Indigenous Wellness Foundation and the work they are doing to revitalize traditional knowledge in medicine. Dr. Audrey Giles (University of Ottawa) and Ms. Meghan Etter (Inuvialuit Regional Corporation) spoke of the client-centred on-the-land programming the IRC provides and ways they are using research to look at appropriate, trauma-informed evaluation techniques that capture the story and experience of these programs. Dr. Alice Legat spoke about time on-the-land, its distinction from “going camping” and how in the face of climate change, stories – linked to the land – provide hope and understanding of changes through time and examples of leaders finding solutions.

The final plenary panel was from Wellness Practitioners in Communities. Paulina Roche, Director of Programs, Dèlìne Got'ìne Government, shared stories that highlight the love for and service to the people that is at the heart of community wellness work. Community wellness work goes way beyond 9-5PM. She shared an inspiring story of the community rallying to support homelessness. Evelyn Storr, Director of Community Development, Inuvialuit Regional

Corporation, shared how personal experience of grief and care-giving provides perspective for her programs. She spoke of the operational approach, to updating the wellness plans, to accessing funding and renegotiating the reporting requirements to be less burdensome. Dollie Simon, Wellness Program Manager, Deninu Kue First Nation, inspired with her photos and stories of the programming and their Mission Island cabins and the healing power of being on the land, away from distractions.



Ethel Blake leads a small group discussion in a tipi.

SMALL GROUP RESULTS: ANALYSIS

Questions Asked

A variety of questions were asked during the small group discussions. While some had definite answers, others will prompt discussion and consideration as Hotì ts'eeda is built and begins offering services to stakeholders and researchers. Below are some questions asked during the small groups:

- *How do we ensure Elders input? Is there an Elders Council? How do we ensure Youth input?*
- *Unless we're careful, everything happens in Yellowknife. How do we ensure there is support in the communities?*
- *To be a healer is a gift – how does that work with training?*
- *What is the next step after the funding runs out?*
- *Are patients going to be involved in deciding what research is conducted in their community?*
- *Who is the "patient" in "patient-oriented" research?*



Thomsen D'hont, Candice Lys and FOXY youth facilitators during a small group session.

Suggestions About Research Required

Throughout the small groups, suggestions were made about where health research should focus. This was an unintended benefit of having participants gather together and will assist in informing Hotì ts'eeda's thinking going forward with respect to identifying health research priorities for academics and communities to consider. Suggestions included research in the following areas:

- *Mold in housing and health effects, and environmental health;*
- *Trauma and its links to health, homelessness and drug use;*
- *Cancer;*
- *Research on cultural values, land based healing and medicine;*
- *Use and monitoring of health related prevention campaigns;*
- *On the land treatment and follow up;*
- *Cultural competency training for researchers; and,*
- *Developing Indigenous methods of evaluating on the land or Indigenous healing and care.*

Overarching Themes and Issues

There were overarching themes that ran through virtually all groups. Participants told us that incorporating Indigenous knowledge into research through the involvement of Elders was essential. Closely related to this was the message that building relationships was at the foundation of good research – and that relationships are built on trust and respect. This requires effort with respect to communications, involving Elders, knowledge holders and youth, as central best practices in doing research that is high quality and effective.

While best practices exist, communities are unique. What works in one community may not work in another, and researchers and Hotì ts'eeda need to be aware that how to build relationships differs depending where you are. Flexibility in working with communities is necessary.

More information about Hotì ts'eeda is needed as the organization develops so that stakeholders can better work with and advise Hotì ts'eeda.

Participants told us that:

"Patient" is sickness not wellness. Focus on "community." We need more meaningful language.

For communities to work effectively with researchers, and build relationships that extend beyond the research itself to include

knowledge translation, resources must be dedicated to enabling communities to develop capacity. Both researchers and Hotì ts'eeda need to play a role in ensuring that funding is available to community committees, individuals working with projects are properly recognized and compensated, and communities have access to resources to do research.

Participants told us that the NWT health system is changing and information needs to be provided on that. It is an opportunity to work on issues related to health professional training, training community people, and using practices that work such as home visits and other methods for promoting health and building trust in health research.



John B. Zoe and Joanne Barnaby during plenary session.

How Should Hotì ts'eeda include people in our work?: Patient Engagement

Small groups were asked to respond to the following priorities, whether they agreed with them or not, and to provide examples of what works:

- *Advise research teams on how to include Northerners in their work*
- *Provide and coordinate training for new investigators, "patients," current researchers, practitioners*
- *Monitor and Evaluate: is this meaningful inclusion? Is it going well?*

Themes emerging from small group discussions turned on the notion that effective research results from relationships rooted in trust and respect. Implicit in the discussions was acknowledgement that the ways research is done is often not rooted in relationship. Researchers often fail to see relationships as the primary research method, and in some cases are only funded to maintain a relationship, while research is being done. Knowledge translation (communicating research results to people and promoting the use of results in improving health care delivery, disease prevention, and treatment) does not receive the attention it should, and is sometimes done as something outside of the relationship with communities instead of in partnership.

Small groups had a variety of suggestions about how to build and maintain relationships, and emphasized that "patients" included everyone. Perspectives reflected that in the Northern context, given that historically research was often viewed as a tool of colonization, inclusion based on trust building is both essential and challenging.

Below are highlights about best practices that Participants shared:

- *Researchers need background and training on Northern culture and traditional knowledge.*
- **Researchers should talk with community partners about how communication is going to happen in advance. Share information, using translation. Report back on results.**
- Include Indigenous cultural (traditional) knowledge. (Follow guidelines/Dene laws, this is a powerful medicine, learn from animals).

- Provide resources to ensure capacity of communities to participate in research.
- Ensure youth involvement, including in decision making and developing research questions.
- Include an evaluation component to ensure what we are doing is working and to learn how it can be improved.
- Include front line staff and health care providers in research.
- **Don't reinvent the wheel – Indigenous Governments and local communities may already have research and relationship protocols. Work with what is in place.**
- Trust is essential. The role of trust should be researched. In pre-contact days, trust was the basis for survival. Relationships must be built before research begins.
- Integrate into already existing programs (e.g. Youth workshops – FOXY, SMASH), piggyback on community gatherings.
- Focus on indigenous research methods in high school, (for example the Tlicho Community Action Research Team (CART) method uses Elders).
- Ensure proper compensation for research assistants.



Participants enjoying the beautiful weather during research/cultural sessions.

Capacity and Training

Small groups were asked to respond to the following priorities and confirm or suggest priorities over the coming year for Hotì ts'eeda activities related to capacity and training:

- *Cultural Capability: working together*
- *Indigenous and Northern Health Research and Methodologies*
- *Knowledge Translation: using what we learn*
- *Scholarships, embedded training, research assistantships*

Participants emphasized that to promote capacity in health research and to encourage participation of Northerners in health professions, the education system has to be involved. For example, better school attendance is an issue that must be addressed; existing programs such as the Tlicho CART are examples of the type of career path available; and math and science education and health professions is

needed. “Co-management” approaches to research, with researchers and community co-leads, could help promote participation and relationship building.

Within the health system, there should be a greater emphasis on developing Indigenous Northern talent and focusing on retention of Northerners. Health care providers should be encouraged to take part in research and are in an excellent position to build relationships with communities and be involved with building relationships with universities. Career and health fairs would assist in informing students and community members of the possibilities for training, participation and health/research careers. Encouraging summer job participation and summer job training for students would also be an excellent way to develop career paths for students.

Training in Indigenous and decolonizing methodologies for researchers and health professionals, led by Northern Indigenous academics, is also an important element of capacity and training, and would assist researchers to draw on best practices for working with communities. This also relates to the need for trauma-informed practice training for health professionals. Similarly, community members receiving training must be provided with capacity development in a supportive way – it would be pointless to deliver training that may overwhelm or alienate possible health researchers from communities.

Participants take in presentations during plenary sessions.





Co-Facilitators Dëneze Nakehk'o and Joanne Barnaby enjoying Métis fiddle music and guitar by Angus Beaulieu and George Mandeville.

Knowledge Translation

Control of resources and the need to dedicate resources to knowledge translation was a theme arising from the discussions on this topic.

Accessibility: providing information to communities in ways that will engage with different age groups and interests is important and requires innovation and giving ourselves the permission to take risks, evaluate what works, and be responsive in our approach to communicating.

Small group participants were asked to provide feedback on the following issues and priorities, and make further suggestions:

- *Communication is vital*
- *Indigenous Research Policies and Protocols exist at national, territorial, regional levels.*

- *However, there is a lack of sharing of research outcomes and dissemination of reports.*
- *High travel costs are a challenge*
- *Elèts'ehdèe is Knowledge Translation*
 - *Information sharing and relationship-building*
- *What are best practices?*
 - *Gather in person; follow up face-to-face; social media; video; stories; ensure health care delivery learns from research.*

Participants told us that effective knowledge translation occurs within the context of relationships. Understanding the audience and engaging in ways that make sense, and ways that can evolve to meet needs is essential. Knowledge Translation planning must begin at the outset of projects, and must take into account the unique community context and audiences.

Participants also emphasized that Knowledge Translation must occur in ways that take advantage of institutions, relationships, protocols, events, and structures that are already in place. Participants believe utilizing what is already in place will strengthen relationships and improve knowledge sharing and translation.

Terminology development and training was also raised by participants: this work needs to be done. As research and research questions are developed, ensuring that we have the proper terms in the languages is essential for communication, and also for ensuring Indigenous knowledge and culture is reflected. Elders providing guidance to research projects are the experts in this, and that expertise should be drawn upon. This is also an issue for Elders negotiating the health system itself. Developing terminology and building relationships will likely assist in improving the experience of Elders in the health system itself and contribute to cultural competency among researchers and health professionals.

Plain language is essential for effective knowledge translation. Hotì ts'eeda should assist in developing plain language and communication best practices. Graphics and graphs should be used as well – ways that communicate information directly, and visually, and that will spark additional discussion, conversation and relationship development. Existing media channels should also be used to communicate: Facebook, Instagram, snapchat and use of “teenager-speak” to connect directly with youth should be considered. Television and radio are other ways to connect with adults and Elders, for example through Indigenous-language radio shows. Again, communities must be involved in designing and testing what works with respect to getting information out.

Hotì ts'eeda has a role to play as an advocate: with funders, universities, and researchers. Providing travel funding for community members and youth to attend workshops and conferences where results are presented is an essential part of relationship, trust, and capacity building.

The strong message coming out of this session, regarding knowledge translation:

“Nothing about us, without us.”

Research Services

Small groups were asked to respond to the following questions about the type of research support that Hotì ts'eeda can provide:

- *Call anytime with any question! – Everyone is welcome.*
- *Current “Menu”: Help with research proposal writing, ethics, research design/collaboration*
 - *Research assistantship training, mentorship, scholarships*
 - *Support with evaluation, data analysis, KT, networking*

Hotì ts'eeda has just started operating and is in the process of staffing up. Participants need to know more about the Unit and its role and

how they can work with Hotì ts'eeda. Elders and leaders need to be informed – and informed in ways that are effective and understandable. Hotì ts'eeda can also play a role in navigating systems and networks that exist: for example contacting possible supervisors for students, creative ways of working within established organizations, policies and rules to assist communities to access resources.

Participants indicated a strong desire for research funding, researchers – as in fully-funded academic university positions – should be located in the Northwest Territories. Assisting in any way possible to recruit and retain Indigenous people for such roles was a goal emphasized in the discussions. Indigenous students should be provided with supports to assist them in accessing health professions; medical students need opportunities to experience rotations in Indigenous communities.

Participants noted issues such as high travel costs and other funding barriers to Northerners wishing to work in health professions.

They also emphasized a role for Hotì ts'eeda in recognizing a system of Indigenous knowledge holders and promoting their expertise and knowledge in research.

Similarly, communities and researchers may need assistance in negotiating the current processes for applying for funding, applying for licensing, ethics approvals, and developing research projects. Hotì ts'eeda should provide assistance with that. Hotì ts'eeda can also assist in communicating what research needs exist, and assist communities in having their priorities researched.

Some specific suggestions from participants included:

- *Fellowship stipend for Northern mentorship*
- *Travel support for students*
- *Access to networks (supervisors, signing authorities)*
- *Support for Northern professorships (cross-postings, salary support)*

- *Training in research – northern relevant, youth focused*
- *Support funding Northern based research assistants (data analysis, writing-up academic manuscripts)*
- *Address challenges with honorariums/expert fees*
- *Share info about and results of research already done by communities (places, plants, etc.)*
- *Support consistency between communities*
- *Develop guidelines for research, i.e. How to work with Elders.*
 - *Not rules, but how to work locally to identify what is needed*
- *Communities should lead timing of research, i.e. plants and animals at the right time. Local knowledge improves research quality.*

Below: Elder Judy Lafferty teaching Dene beading techniques.





Elder Florence Barnaby shares her wisdom during the plenary panel: Elders Perspectives on Health. Below: Debbie DeLancey, GNWT Deputy Minister of Health and Social Services.



HOTIÌ TS'EEDA EVALUATION FORM CONSOLIDATED COMMENTS

Summary

All participants were invited to fill out the evaluation form, which was distributed on the last day of the Ełèts'ehdèe. A total of 41 evaluation forms were received. A summary of responses and suggested remedies for the next meeting are provided below; transcribed evaluation form responses are included after this summary.

General Findings and Suggestions

Presentations and Cultural Activities

In general, participants found that embedding project presentations with cultural activities was an interesting and enjoyable approach that resulted in a setting for good discussions. Participants noted some exceptions; as a result, the following are suggestions that should be taken into account for the next meeting if this approach is taken again:

- *Ensure that cultural knowledge holders and presenters are aware of their roles and are prepared to undertake them;*
- *Presenters, if they wish to have introductions, should involve a facilitator who can effectively manage time constraints;*
- *Have facilitators "float" between venues to ensure that the presentation/cultural sessions are unfolding in ways that allow for both presentations and cultural activities to take place;*
- *Check with knowledge holders and presenters when groups form to provide for translation where possible.*

Plenary Presentations

In general, participants appreciated the plenary sessions; however, ensuring everyone is comfortable is necessary so that participants can fully focus on the session. This includes keeping sessions to no longer than an hour.

Presentation Content and Information Sharing

Participants appreciated the presentation content and responded well to speakers. One participant suggested a “mapping exercise” to have a visual representation of the research projects [and cultural activities?] to give a sense of the broad range of research being undertaken, and perhaps orient participants to the categories of health research being undertaken. This suggestion should be adopted at future meetings. Due to time constraints and some miscommunication, some presentations did not occur. At the next meeting, more effective planning and time management will likely prevent this from occurring again.

Speakers

Participants appreciated the speakers; in particular, speakers responded well to the keynote panel speaker Dr. James Makokis, who was brought to provide insight into the relationship between decolonization and Indigenous health. Having an Elders panel and a practitioners panel was also appreciated by participants.



Dr. Nicole Redvers, Dr. Janis Geary, Dr. Audrey Giles and Meghan Etter presenting their research at the Gala Dinner Panel.

Building Relationships

A key purpose of the meeting was for participants to build relationships in a context that privileged Indigenous knowledge and culture. All participants who responded indicated that aspects of this shared learning and networking-focused environment was extremely appealing. In order to engage in productive knowledge exchange, to gain confidence about doing health research in communities and use research results effectively, trust and relationships between individuals must be built. Trust must also be built between Indigenous communities and researchers, on terms set by the communities and in accordance with community protocols. This meeting format attempted to contextualize research in Indigenous culture and knowledge, as a basis for developing and renewing relationships as an essential element of creating understanding.

The Food and Location

A majority of participants rated both the food and location as very good to excellent. Aurora Village was closed for the season, but with a mere two weeks notice, the Aurora Village owner and staff agreed to re-open exclusively for our event. The Aurora Village provided a stunning location which allowed for very comfortable and culturally accommodating tipi, firepit and outdoor sites for the meeting activities. Unfortunately, the beautiful weather meant that the main lodge became very warm at times. As a lodge catering to winter tourism, it does not have air conditioning and fans. If this venue is used again, it is suggested that fans or air conditioning be available, or that the lodge is used in the early part of the morning and not in the afternoon when the day is hotter.



Elders being served at the Gala Dinner.

Other Comments

From the first session on the first day, the meeting did not run to schedule. Between having to bus in participants and unanticipated delays in the time activities would take and other factors, it was not easy to keep to the planned schedule. To address this issue, organizers might consider devoting consecutive sessions to tipi-based activities to ensure that time required for transitions between sessions is minimized; that plenary speakers have specific time limits on their presentations; and that more time is allocated to breaks which can be shortened to better absorb shifts in the schedule.

More clarity was needed around the purpose of Hotì ts'eeda. Given that the Unit had one staff person working part time up until two weeks before the meeting, and that most of that role was devoted to planning how the Unit would be set up, communications materials and materials explaining the Unit were minimal. The next meeting should have clear, plain language material on the role and purpose of the Unit and how researchers and communities can become involved. While information on those elements was provided at

the meeting, the comments show that participants did not pick up on that information or sought more detail about information provided.

Finally, translation services should be available for Elders. At future meetings, individuals or organizations bringing Elders or others requiring translation should advise organizers of translation needs. Translation was arranged ahead of time for those who responded to organizer inquiries about needs and for those who requested it.



Bob Simpson participates in a small group session in the main lodge.



Dr. James Makokis and Elder Morris Neylle in conversation during a break.



Elders George Mandeville and Angus Beaulieu share stories and music.



Elder Rassi Nashalik, opening our second day with the lighting of the *Qulliq*.

Hotì ts'eeda Èlèts'ehdèe

May 30-31, 2017

Aurora Village, Cassidy Point, Ingraham Trail

AGENDA

Co-Chairs: Co-Chairs Joanne Barnaby and Dëneze Nakehk'o

DAY ONE, TUESDAY, MAY 30

| | |
|---------------------|--|
| 9:00 AM | FIRE FEEDING WELCOME CEREMONY Elder Alfred Taniton Yellowknives Dene Drummers |
| 9:15 AM – 9:45 AM | WELCOME FROM GOVERNING COUNCIL REPRESENTATIVES Eddie Erasmus, Grand Chief, Tlicho Government Evelyn Storr, Director of Community Development, Inuvialuit Regional Corporation Debbie DeLancey, Deputy Minister, GNWT Department of Health and Social Services Osei Bosompem, Executive Director, Hotì ts'eeda |
| 9:45 AM – 10:00 AM | ÈLÈTS'EHDÈE PURPOSE AND ACTIVITIES OVERVIEW – PLENARY Co-Chairs |
| 10:00 AM – 10:30 AM | NETWORKING HEALTH BREAK Tipis outside. |
| 10:30 – 11:15 AM | ELDERS PERSPECTIVES ON HEALTH Archie Norbert, Tsiigehtchic Billy Archie, Aklavik Florence Barnaby, Fort Good Hope Joanne Barnaby, Hay River |
| 11:15-12:30 PM | KEYNOTE PANEL: ACKNOWLEDGING COLONIZATION AND SETTLER COLONIALISM AND ASSOCIATED HEALTH IMPACTS - PLENARY James Makokis, MD, (Saddle Lake Cree, Alberta) |

| | |
|--------------------|---|
| | Crystal Fraser, PhD Candidate, University of Alberta (Gwich'in) |
| | Stephanie Irlbacher-Fox, PhD, Hotì ts'eeda Scientific Director |
| 12:30 PM – 2:00 PM | LUNCH AND TIPI RESEARCH PRESENTATIONS/CULTURAL EXPERIENCES |
| | <i>Tipis outside</i> |
| 2:00-2:30 PM | HT UNIT OVERVIEW AND GOVERNANCE – PLENARY |
| | John B. Zoe, PhD, and Jim Martin, Tìjchq Government |
| | Debbie DeLancey, GNWT Department of Health and Social Services |
| | Evelyn Storr, Inuvialuit Regional Corporation |
| 2:30 - 2:45 PM | PLENARY INSTRUCTIONS FOR SMALL GROUPS |
| 2:45 – 3:30 PM | RAPID SCOPING SESSION: How should Hotì ts'eeda include people in our work? |
| | Breakout groups inside or tipis outside |
| 3:30 PM – 4:30 PM | HEALTH RESEARCH WORLD CAFÉ, CULTURAL EXPERIENCES |
| | Poster area indoors and tipis outside |
| 4:30- 4:45 PM | ANALYSIS OF BREAKOUT SESSIONS - PLENARY |
| | HT Staff Presentation |
| 4:45 PM | BUSES LEAVE FOR CHATEAU NOVA HOTEL |
| 6:00 PM – 8:30 PM | HEALTH RESEARCH HIGHLIGHTS - GALA DINNER |
| | Location: DND Mess Hall, 4816 49 Street |

RESEARCH HIGHLIGHTS PANEL SPEAKERS

Dr. Janis Geary (University of Alberta), "The *CANHelp* Working Group: Lessons from a decade of community-driven research"

Dr. Nicole Redvers, ND (Gaia Integrative Clinic) "The Arctic Indigenous Wellness Foundation"

Dr. Audrey Giles (University of Ottawa) and Ms. Meghan Etter (Inuvialuit Regional Corporation), "Project Jewel: Using Inuvialuit ways of Knowing to Understand How In-the-Land Programming Can Foster Wellness"

Dr. Alice Legat (Gagos Associates) and Violet Fabian (K'átłodeeche First Nation) "Finding Solutions to the Health Impacts: K'átłodeeche First Nation Health and Climate Change Project"

DAY TWO, WEDNESDAY, MAY 31

| | |
|---------------------|--|
| 8:30 AM – 9:00 AM | BUSES DEPART CHATEAU NOVA HOTEL TO AURORA VILLAGE |
| 9:00 AM | DAY TWO WELCOME –LIGHTING OF QULLIQ Elder Rassi Nashalik (Inuit) |
| 9:45-9:55 | DAY ONE SUMMARY, ANNOUNCEMENTS AND HOUSEKEEPING Co-chairs, HT Staff |
| 9:55 AM – 10:45 AM | WELLNESS PROGRAMS IN COMMUNITIES: PRACTITIONERS PERSPECTIVES PLENARY Paulina Roche, Director of Programs, Délı̄në Got’ı̄në Government Evelyn Storr, Director of Community Development, Inuvialuit Regional Corporation Dollie Simon, Wellness Program Manager, Deninu Kue First Nation |
| 10:45 – 11:30 AM | CULTURAL EXPERIENCES Tipis outside |
| 11:30 – 11:40 AM | PLENARY BREAKOUT GROUP INSTRUCTIONS |
| 11:40 AM – 12:15 PM | RAPID SCOPING SESSION: How can we bring Northerners into health professions and health research? Breakout groups in tipis |
| 12:15 – 1:45 PM | LUNCH AND CULTURAL EXPERIENCES Tipis outside |
| 1:45 PM – 2:30 PM | RAPID SCOPING SESSION: Sharing what we learn from research. Breakout in tipis |
| 2:30 – 3:00 PM | RAPID SCOPING SESSION: Getting the research you want – how can we help? Breakout groups in tipis |
| 3:00 – 3:15 PM | PLENARY RESEARCH HIGHLIGHT Sangita Sharma, PhD, University of Alberta, Indigenous and Global Health Research Group: Overview of NWT Projects |
| 3:15 – 4:15 PM | DRUM DANCE Tı̄jchq Drummers |

4:45 PM

CLOSING PRAYER

Yellowknives Dene Drummers

BUSES DEPART TO HOTEL

TIPIS AND LAND LIFE OUTSIDE

The format reflects the philosophy of Hotì ts'eeda, where most discussions will take place in a cultural immersion environment. During tipi or land-based cultural activities, researchers will have 5-10 minutes to talk about their projects. The remainder of the time will involve Elders demonstrating or guiding participants through a cultural activity. In the course of that activity, discussion is expected to ensue around the connections between the activity and the research being highlighted.

Tipis are where participants can take part in cultural activities, small group discussions, traditional foods, and quiet reflection.

| | |
|------------------------|---|
| Firepits | Gather round in the fresh air and sunshine to enjoy the beauty of the land, one-on-one conversation and some quiet time. |
| Traditional Foods Tipi | Come and try Arctic char, Great Bear Lake trout, Muktuk from the Mackenzie Delta. |
| Inuvialuit Whaling | Elder Sarah Rogers of Inuvik shares life on the sea in the Western Arctic. |
| Métis Fiddling | Elder Angus Beaulieu of Fort Resolution and Elder George Mandeville of Yellowknife will lift your spirits with Métis music and stories. |
| Dene Drum Making | Join Morris Neyelle and Elder Alfred Taniton of Deline to gain an understanding of Dene drum making. |
| Sewing and Beading | Award winning Sahtu artists Judy Lafferty and Lucy Ann Yakeleya share knowledge of sewing on hand-tanned hides, an occupation that Dene women have passed down through generations. |
| Moose Hide Tanning | Melaw Nakehk'ò, Dehcho Dene, has been recognized in the NWT for her efforts researching and revitalizing Dene moose hide tanning traditions. |
| Moose Hair Tufting | Elder Georgina Fabian shares the art perfected by the Dene and Métis women in the community of Fort Providence. |

Safe Journey Home

Elders and Cultural Knowledge Holders, and Research

Elders and Cultural Knowledge Holders

| Name | Topic |
|--------------------------|---|
| Melaw Nakehk'o | Moose Hide Tanning - Dehcho |
| Angus Beaulieu | Métis Fiddle - Métis |
| Georgina Fabian | Moose Hair Tufting - Dehcho |
| Judy Lafferty | Dene Sewing and Beading, Hide Tanning - Sahtu |
| George Mandeville | Métis Musician – North Slave |
| Morris Neyelle | Drum Making - Sahtu |
| Mary Adele Rabesca | Making Dry Fish - Tłjchq |
| Sarah Rogers | Inuvialuit Whaling - Inuvialuit |
| Alfred Taniton | Drum Making - Sahtu |
| Lucy Ann Yakeleya | Dene Sewing and Beading - Sahtu |
| Rassi Nashalik | The Qulliq in Inuit Culture - Inuit |
| Dehcho First Nations TBC | TBC |

Research Presenters

| Name | Topic |
|--|---|
| James Makokis, MD | Gender and Health Nutrition Cultural and Traditional Knowledge |
| Crystal Fraser, MA, PhD Candidate Dehcho First Nations Researcher TBC | Colonization Impacts TBC |
| Meeka Otway, Indigenous and Global Health Research Group, University of Alberta | Working with the Communities to develop educational materials about Cancer Screening |
| Kate Kerber, Indigenous and Global Health Research Group, University of Alberta | Indigenous Perspectives of Maternal Health and Health Care Services: a systematic review |
| Holly Rippin, Indigenous and Global Health Research Group, University of Alberta | Reducing Prevalence and Risk Factors for Overweight and Obesity in Indigenous Children in Northwest Territories (NT): Community-based Interventions |
| Jennifer McKeen, Indigenous and Global Health Research Group, University of Alberta | Community Perspectives of the cancer ACCESS project |
| Se Lim Jang, Indigenous and Global Health Research Group, University of Alberta | CAPRICORN: Culturally Appropriate Practical Solutions Relevant to Indigenous Seniors and Caregivers Of Remote Northern Communities |
| France Benoit and Mary Rose Sundberg | Movie: Guardians of Eternity - YKDFN |
| Audrey Giles, PhD, and Meghan Etter | Project Jewel: Using Inuvialuit ways of Knowing to Understand How In-the-Land Programming Can Foster Wellness |
| Sam Jr. Mantla and Co-Presenter | Tłjchq Sexual Health Survey |
| Candice Lys, PhD Candidate | “What can lower HIV risk in the North is accepting you are |

| | |
|--|---|
| | LGBT: Exploring social drivers of HIV with Indigenous and Northern LGBT youth in the Northwest Territories" |
| Kayley Mackay and Derek Lindman | FOXY and SMASH: An Overview |
| Morris Neyelle | Dél̄ı̄n̄ę Self Government Through Culture |
| Pertice Moffitt, PhD, and Rosa Mantla | T̄ı̄ch̄q̄ Breastfeeding Project |
| Pertice Moffitt, PhD | Knowledge Translation |
| Karen Blondin Hall, MA Candidate | Cultural Competency Training for Health Professionals |
| Nicole Redvers, ND | Arctic Indigenous Wellness Foundation |
| Allice Legat, PhD | TBC |
| Janis Geary, PhD and Amy Colquhoun, PhD, University of Alberta Department of Medicine | "The CAN <i>Help</i> Working Group: Lessons from a decade of community-driven research" |
| Thomsen D'hont (MD Student) | Recruitment and Retention of Indigenous Physicians in the NWT |
| John B. Zoe, LLD (Hon.) | Trails of Our Ancestors |
| Evelyn Storr | Inuvialuit Wellness Programs |
| Paulina Roche | Dél̄ı̄n̄ę Got'ı̄n̄ę Wellness Programs |

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APPENDIX 1: Hotii t'seeda Briefing Note

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. [Hotii ts'eeda](#) The NWT SPOR SUPPORT Unit is Hotii 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 Hotii 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 \$4388,744.35 |
| Deline Got'ine Government | Staff time \$6,000.00/Year \$130,000.00 TK |

| | |
|--|---|
| | Database Value: \$100,000.00 |
| GNWT Department of Health | 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 \$2,547,500.00 \$509,500/Year |
| Gwich'in Tribal Council | Staff time, training materials \$20,000.00/Year \$100,000.00 |
| | Staff time \$4,500.00/Year \$22,500.00 |
| Indigenous and Global Health Research Group (University of Alberta) | Staff time, training materials, facilities \$1,130,000.00 \$226,000/Year |
| Inuvialuit Regional Corporation | Staff time, facilities, knowledge holders, \$1,387,000.00 databases \$277,400/Year |
| 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
\$693,000.00 \$138,600

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. Hotì 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 Hotì 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 Èlèts'ehdè); 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, creating a culturally competent health system, and improved health.