

National Inuit Health Information Conference: Inuit defined health information needs and directions.

Proceedings from the National Inuit Health
Information Conference,

June 2001, Inuvik, NWT.

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In June 2001, over 40 delegates from across Canada gathered in Inuvik, NWT to learn, discuss, review and advise the Inuit Tapiriit Kanatami (ITK) Health Department on directions required with regard to Health Information and Health Information Initiatives for Inuit.

Purpose of the Conference

Conference delegates provided direction to Inuit Tapiriit Kanatami regarding the development of an Inuit Health Information Initiative. The conference also provided an opportunity to increase interest in health information at the regional and community levels.

The objectives of the conference were:

- To address the relative absence of Health Information about Inuit.
- To identify key issues for Inuit on the challenges involved in addressing the relative absence of Inuit health information.
- To outline resources needed to take action on issues identified during the conference.
- To make recommendations on directions, activities, resources and key issues related to Health Information.
- To make recommendations on Inuit participation in ongoing activities.

Background

The Inuit Health Policy Forum

In February 2000 Inuit Tapiriit Kanatami (then ITC – Inuit Tapirisat of Canada), held an Inuit Health Policy Forum to provide the Inuit Tapiriit Kanatami Health Department with clear direction and vision regarding Inuit health and Inuit Health policy. Delegates from this Forum agreed the most important aspect of health information for Inuit was the need for Inuit-specific research and health statistics.

“Good planning depends on good data. It is difficult to build policy without information on Inuit needs and the illnesses affecting Inuit.”

- Inuit Health Policy Forum Transcript 1999

The Forum delegates also recommended the following priority research areas when developing Inuit Health Policy.

- *Inuit-specific research and health statistics must be collected.*
- *Data from Inuit-specific research and tailored health statistics should be used in policy development.*
- *More research is required to define the underlying causes of Inuit health problems. For example, what effects do poverty; high unemployment and overcrowded living conditions have on Inuit health in the long term?*
- *Research previous coroner's reports to determine what Inuit have died of in the past. Greenland for example, analyzes data over time in attempts to predict future health problems and plans accordingly.¹*

What is Health Information?

Two critical understandings of health information were revealed during this conference.

1. The need for information about health by clients and consumers of health care.
2. [Collecting and maintaining health data improves the ability to manage and ultimately impact health status in a positive manner.](#)

Both of these points are of equal importance. The Canadian Health Infoway² discusses the need to empower the public through provision of relevant health information and the need for health professionals to base their decisions, programs and practices on evidence collected during regular health care system operations.

The premise of a population health approach is to engage in strategies that will effect change on predetermined indicators of the overall health of a population. This is often called evidence-based planning and may be used as a good measure of whether particular interventions are effective or not.

What is the Inuit Health Information Initiative?

Background

In 1999, the Federal Budget included a commitment to “building the health lane of the information highway”. A First Nations component was included in that commitment resulting in the development of the First Nations and Inuit Health Information System (FNIHIS). The FNIHIS is a computer software product to assist the health delivery system in performing case management functions and allowing reports to be generated electronically. The FNIHIS project includes funding the development of an enhanced software product, the deployment and

¹ Inuit Tapirisat of Canada (2000), Inuit Health Policy Forum Document, pp.

² Author (1999), Canadian Health Infoway Presentation.

installation of computer hardware and a network technology, education on the use of the software and the ongoing maintenance of the system.

Inuit Context

The FNIHIS is only available to Inuit regions that do not have a health information system. FNIHIS is therefore only available in Labrador, because Nunavik, Nunavut and the Northwest Territories all have health information systems within their provincial or territorial jurisdictions.

However, there is still a need to develop a coordinated approach in reporting Inuit health status. At the 1999 Inuit Health Policy Forum, the first recommendation was:

“The recognition of Inuit as one people, with a common language and culture and with a need to work together and share information, experience and expertise across provincial-territorial boundaries.”

-Summary Report, Inuit Health Policy Forum 1999

This recommendation provides the emphasis for the Inuit Health Information Initiative (IHII). The IHII goal is to increase Inuit ability to report nationally on population health status. Reports are currently based on regional and national (census) data, and do not focus specifically on the Inuit populations in Canada.

When Inuit data is not separate from First Nations or provincial/territorial data, the unique needs of the relatively small Inuit population disappear into larger population contexts. Health inequities are evident in Inuit communities but not so evident to Canadians nor evident in the data.

The IHII is a set of activities related to the management, analysis and reporting of health information such that Inuit Health Status can be reported nationally, regionally and locally.

The IHII objective is to address the relative absence of health information about Inuit. The IHII recognizes the need for an Inuit-specific vision, appropriate partnerships in order to ultimately report on Inuit Health Status at the national, regional and community levels.

The IHII recognizes that data sharing, access to health information and the ability to analyze information will become a reality only when strong partnerships are built between the Inuit Associations and the health care delivery systems at the regional level. Each Inuit region needs the organizational capacity to collect and analyze information as well as the skills to identify common indicators allowing for the comparison of Inuit population health from the community level to that of regional information, and ultimately to the Canadian population health indicators.

What is the process?

The June 2001 NIHI Conference was the beginning of the IHII process, gaining guidance from Inuit across Canada. Inuit youth, Elders, women and men were also asked to share their thoughts on unique health issues affecting their groups. Related stakeholders from government and other non-governmental organizations were invited to share in the process and to contribute to its development.

The ITK Health Department will ensure Inuit communities become fully informed of health status, community actions that facilitate change and the building of capacity at the community level.

Structure of the Conference

A series of plenary sessions, discussions and working group sessions produced a number of common themes that were categorized. Recommendations were then outlined for action.

The Presentations

The Inuit Health Information Initiative

What makes data meaningful?

“Cervical cancer is high among Inuit women, but research has only been done in parts of the Baffin region. Leukemia and blood cancers make up 21% of Inuit cancer, and there is no understanding of why it is so high in Inuit. We need information on all factors relating to Inuit health. This includes studies on our access to country foods and the condition of that food. Inuit have the right and the expertise to be involved in the research and management of their own health.

- Annie Quirke

Annie Quirke, of the Nunavut Social Development Council (now known as the Nunavut Tungavik Incorporated - NTI), described the value of information to Inuit. She provided examples of successful uses of data and the existing gaps in the current information available to Inuit. Quirke emphasized that Inuit across Canada firmly believe they should have input in what information, data or research is conducted on Inuit, the questions asked, and how the answers are interpreted and reported.

Ms. Quirke described how the data leads to knowledge, which helps decision makers determine where funding and resources will be directed. Information is often used to determine how healthy people in are in their communities comparable to other Canadians. This is important for Inuit who are dealing with a higher cost of living than most other Canadians, and experiencing changes unlike anything Inuit have ever encountered before. To keep our communities well, we need data comparable to other Canadians, which can work to generate policy and program directions.

Ms. Quirke raised numerous questions for delegates to consider. What questions are most important to ask in an Inuit context? How can the health planning process be more responsive to Inuit health priorities? There are unique situations and needs in the North that require Inuit participation to ensure the information collected is true and meaningful.

Until now, the elements of Inuit culture that Inuit use to determine health have not been considered.

Inuit have the right to access health services equal to other Canadians. This includes the right to define and develop methods that respond to their cultural and community needs, as well as the right to holistic treatment and preventative services. Information collection and management can help to facilitate responses to ensure these rights are met.

The ability to collect data is only useful when there is capacity to interpret the information. The information must then initiate strategic actions. This will require skill development in Inuit communities and related government departments. Periodic Survey holdings, census and the last Aboriginal Peoples Survey information is currently available and used by Indian and Northern Affairs, Statistics Canada, and the provincial and territorial governments. Inuit can negotiate access to such holdings and then ensure appropriate feedback is included in the reports generated by these information sources.

How can health planning be more responsive to the health priorities Inuit have identified?

1. Collect the data
2. Use the data analysis to determine appropriate direction.
3. Take the proposed directions to decision makers who in turn can ensure resource allocations are directed to Inuit priorities.

Inuit program planners can directly use the information to help their own regions and communities. Collecting necessary information after a program has been implemented teaches us what does and does not work.

Data is meaningful when it makes sense to the people who provided it. When the data makes sense to them, we know it is true, because it matches their reality. Data would have more meaning if Inuit designed, collected and interpreted their own research. Information is only valuable when we know about it. An ongoing commitment to inform communities about current knowledge must be part of a complete approach.

Elder's perspective

“Living with someone who has Alzheimer’s disease is like dealing with an adult-sized toddler... I had to get rid of the guns, the house knives and everything that could be harmful if it fell into his hands. I have to make sure the stove elements are off, and that everything harmful is safely out of reach. I’m asking you for help today.”

- Mary Adams.

Using her personal experiences dealing with a family member struck by Alzheimer’s disease, Labrador Elder Mary Adams described the desperate need Elders have for access to prolonged health care in the smaller Inuit communities.

Ms. Adams summarized the changes in the kinds of diseases Elders encounter as they age. When she was growing up, Ms. Adams said she knew of elderly people who lost their capacity to care for themselves, who regressed back to children, but there was no term for this condition. There was no information about what caused it or how to care for someone who had it. She only learned about the devastating effects of Alzheimer’s Disease when her husband was diagnosed some years ago.

Caring for her husband was complicated by the lack of support and resources she and her family encountered. Ms. Adams said she has never seen any information about Alzheimer’s disease in Inuktitut. Although many families in the South have access to chronic care facilities,

such facilities are sadly lacking in most Inuit communities. Ms. Adams talked about the frustrations and the personal anguish of trying to care for her husband as his condition worsened. The lack of resources, training and facilities meant her family was alone in their struggle to care for her husband.

As her husband's disease progressed, Ms. Adams and her family were forced to accept the only solution available. Mr. Adams was sent to a chronic care facility in the south where he was cared for in a foreign culture. Ms. Adams and her family suffered guilt over not being able to care for their loved one in his familiar surroundings.

Youth perspective

"Ilarasuk means so much respect for a person's knowledge it borders on fear. There is never any question of that person's advice or treatment. It is something my parent's generation grew up with; believing that of the Qallunaat physicians and teachers who came North. To move beyond this will require better education in the next generations. If we can manage this, our children will be better equipped to tackle both worlds effectively."

-Tunu Napartuk

Tunu Napartuk, former President of the National Inuit Youth Council and originally from Puvirnituq, Nunavik, expressed his excitement about the IHII project and Conference.

Mr. Napartuk stressed the importance of youth involvement. Today's Inuit youth have had drastically different upbringings than their parents and as a result, many of them are not benefiting from their elders' Inuit traditional knowledge and experience. Mr. Napartuk expressed the urgency of documenting elders' knowledge of Inuit elders now for the benefit of the next generations of Inuit youth. He said a lifetime of knowledge is lost each time an elder dies, unless that knowledge is preserved in some format during their life.

. Napartuk said another priority is to provide more support for his parents' generation who were the first to be caught between the Qallunaat and Inuit cultures. He used the term *ilarasuk* to describe the conflict his parents had trying to bridge the two cultures. *Ilarasuk* is to accept someone's judgment without question

Preventative measures and treatment was also highlighted by Napartuk, who said that investing in preventative health care today will save later. Acknowledging traditional Inuit healing practices and making them more accessible is one way of installing cost-effective prevention treatment such as counseling that might save lives later on. Napartuk stressed the need to support frontline workers to reduce the burnout rate and loss of good staff. Mr. Napartuk talked about community health providers who are exhausted, moving from one crisis to another and the consequences this has on the community.

Napartuk finally suggested the demographics of the Inuit population today indicate solutions must be immediately identified. "If most Inuit housing conditions are inadequate today," he asked, "what will happen in 10-20 years, when the population has doubled? We need to organize ourselves and look not just at today, but at what the conditions could be in thirty years."

Women's perspective

“There are many things we want to do and these concerns are shared across the regions. We want an end to substance and alcohol abuse, an end to domestic violence. The damage of physical abuse suffered as a child is a lifelong legacy. Children’s lives are damaged before they’ve even begun. Hearing our Elders here has touched us. My generation grew up not taking traditional knowledge and healing practices very seriously, but we are going to revive this knowledge for our children.”

- Reepa Evic-Carlton

Donna Kisoun and Reepa Evic-Carlton representing Pauktuutit, Inuit Women’s Organization started with the statement that when identifying priorities and setting health research priorities, it is important to consult with all sectors of society – elders, women, youth, persons with disabilities and others. It is necessary to gather information in various manners, seeking out those who may not be comfortable speaking in public meetings. This is particularly important considering there is little Inuit specific health data available in general, and even less specifically about Inuit women.

Women play an integral and essential role in Inuit families and communities , traditional harvesting and the traditional economy. It is therefore important that Inuit women be involved in identifying health priorities from the beginning.

Health Issues for Women

- Breast Health
- Reproductive Health
 - Sexually transmitted infections
 - Birth control and family planning
 - Abuse and assault
- Life Changes – Menopause
- Child birth – away from families’
- Parenting, Values and Raising Children
- Balance of work and family
- Care giving for aging parents – significant lack of services for elders
- Mental Health and Depression
- Primary role for health and well-being
- Children’s Health
- Addictions
- Fetal Alcohol Syndrome/Fetal Alcohol Effects

There are also many sensitive issues that need to be addressed, that many women are not comfortable openly discussing. These include substance abuse, suicide, Fetal Alcohol Syndrome, family violence and abuse of women, children and elders.

The number of children with FAS in Inuit communities is too high. One child with FAS is one too many. However, to address this entirely preventable condition, it is necessary to know how many children are currently affected and the needs of their communities while treating them.

Studies show children with FAS have greater difficulty in school and their community. There are lifelong consequences of their condition, which sometimes lead to destructive behaviour, to themselves, to others, and can result in conflict with the law. More information about

FAS/FAE will help establish effective programs to support affected children at the community level.

The Pauktuutit representatives also said that in addition to the need for Inuit-specific health information, care should be given to how it is accumulated and used. Once gathered, this information will play a crucial role in identifying health priorities and accessing resources.

Aboriginal People's Survey II – Survey of Living Conditions in the Arctic

“This survey will provide us with a snapshot of our lives today. It is important for anyone surveyed to participate, because the data helps as a planning tool for policy development. The Inuit-specific statistics will help us build sound comparisons of Inuit living conditions in the Arctic and other Aboriginal groups, instead of all being combined in one category.”

- Pitseolak Pfeifer, Director of ITK Socio-Economic Development Department

The Aboriginal Peoples Survey II (APS) and the Survey of Living Conditions in the Arctic (SliCA) was described by Pitseolak Pfeifer as an example of projects underway to ensure Inuit are included in the development and implementation of statistical surveys at the national level. Inuit will be involved in the information analysis and will ensure the final reports are meaningful and interpreted from an Inuit perspective.

The APS II survey includes sections on health, education, social activities, language, childcare and household information. The Inuit-specific component, The Survey of Living Conditions in the Arctic (SliCA), is an international survey, comparing living conditions of Inuit in Canada with that of Inuit in the rest of the circumpolar world.

Pfeifer described the compromise, agreement and partnership required to include even a few Inuit-specific questions in the APS II survey. He also stressed the importance of participation in the survey. Assurances were given on the regulations ensuring the privacy and confidentiality of the people surveyed is respected.

The project generated employment opportunities in many Inuit communities. Training opportunities such as survey and partnership development, information management and other transferable skills were also provided at the community level.

Mr. Pfeifer closed his presentation with three thoughts for delegates to consider.

1. Should Inuit own the data or own access to that data?
2. Development of skills in data analysis is necessary.
3. Partnership the foundation of success in this project is a best practice.

Aboriginal Health Infostructure

“The vision for the Aboriginal Health Infostructure is that it will include all Aboriginal groups. The Infostructure combines health information and communication technology, including text, audio, computer, telephone and satellite. It will be far more robust and reliable than the paper records most health systems have on their patients today.”

- Alexa Brewer; Health Canada, First Nations and Inuit Health Branch.

Ms. Alexa Brewer from the First Nations and Inuit Health Branch (FINHB) of Health Canada presented the overview for an Aboriginal Health Infostructure (AHI) in Canada. The vision of the AHI includes the development of an Inuit specific component to meet the multiple needs of Inuit communities.

Infostructure is a relatively new term in English. It is basically a framework that combines people, organizations and technologies working towards a common interest and with a common goal – to improve health through better information. Having appropriate information accessible to the right people at the right time is crucial to attain this goal. The AHI includes a number of elements and activities aimed at health delivery improvement:

- Health Information for the public,
- Health Information management, Surveillance and Research,
- The Electronic Health Record,
- Telehealth and
- Telecare.

There is movement across Canada to establish a health infostructure to incorporate the many layers of health information, including personal health, health promotion, public information requirements, research, health planning and management.

Ms. Brewer highlighted four of seven recommendations made for the Aboriginal Health Infostructure similar to the issues emerging from the Conference's working group sessions:

1. Capacity Development and Training,
2. Support of surveys that will meet the needs of individual aboriginal groups,
3. Connectivity – getting the technology to the community and
4. Information for Health Providers specific to the needs of northern health care providers.

The Electronic Health Record (EHR) is an activity within the AHI. The EHR is a project with a vision to reduce fragmentation of health information and improve access to information vital to individual care. Telehealth is another component of the AHI, with tremendous potential in northern communities. Ms. Brewer outlined Telehealth projects being piloted across Canada and some of the lessons learned on the delivery of Telehealth becoming an efficient and effective patient care service. Until now, Inuit participation in AHI has been mostly through Inuit Tapiriit Kanatami. A blueprint is in the development stages to reflect the unique needs of Inuit communities to satisfy their specific priorities and information requirements.

Health Renewal

Health Renewal is a project of the First Nations and Inuit Health Branch (FNIHB) examining the current health care system for Inuit. Health Canada has three objectives for the health renewal project:

1. To improve (with a managed budget) the health outcomes for Inuit,
2. To improve access to a quality of health services,
3. To increase Inuit control of health programs.

The Health Renewal Project is also reviewing human resources, home care, health promotion, prescription drug costs and health technology infrastructure.

Eight elements of this process will result in an Inuit-specific strategy and a Joint Inuit Strategy, that will focus primarily on issues Inuit and First Nations have in common.

Eight Elements of Health Renewal

1. Primary Care
2. Health Human Resources
3. Health Promotion And Wellness
4. Information Technology And Info Structure
5. Non-Insured Health Benefits
6. Accountability
7. Health Outcomes
8. Health Policy And Relationships

The Discussions

Conference delegates were given two questions to discuss in small working groups. The facilitators identified common threads based on each group's presentation following their discussions.

Some of the common threads from each working group are as follows.

Communication

- Information needs to be shared with all who need it.
- Better systems are required to collect data.
- Communicating information about diseases needs to be improved.
- Cultural training and orientation for healthcare professionals new to the North and Inuit culture must be provided.
- Inuit could organize their own communication system.
- Improve communication between the regions.
- Develop better information flow between the regions and the federal government.

Capacity

- Many communities/regions currently lack the resources/capacity to work with available data.

- Treatment centers must better complement Inuit concepts of healthcare.
- Priority concerns need to be addressed.
- Further empower regional Inuit associations and organizations to manage health planning and programming.
- Increase local capacity for to participate in program development at the community level.

Specific Health Priorities

- Language is always a major barrier to effective healthcare and data maintenance.
- Diversity of Inuktitut dialects makes communication difficult within each region and community.
- Information and reports from the governments should be translated, not only Inuktitut syllabics, but all Inuktitut dialects, including Inuvialuktun, Inuinnaqtun and Labradorian.
- Information and government reports should also be written in plain, easily understood language.

Regular training should be made available to all Inuit interpreter/translators in the field to update and standardize clinical, medical and technical terminology.

Research

“Inuit are the authors of many theses, but they are not often acknowledged.”
- Working Group Discussion

- New processes are required to establish better trust between southern-based researchers and Inuit.
- Inuit who assist southern-based researchers must at least be recognized, if not share joint credit for their contributions. These research projects often become an academic thesis and while the student in question receives a degree or financial benefits, the Inuit who assist are rarely credited for their help.
- More research must be done on the causes of health problems.
- Identify gaps in research.
- Research should be relevant and respond to needs as identified by the communities.
- Inuit should run their own tobacco cessation programs.

Scientists and academics rarely share their conclusions with the Inuit communities they studied. Some of these results are therefore not always accurate. Drafts of research findings should be sent back to the communities/Inuit in question for feedback to ensure what is being said/published is correct.

The Recommendations

Based on the common themes heard from the discussion groups, the following recommendations were made:

Data

“Health isn’t just about health, it’s linked to a number of factors. Everything plays a role in our health status, early childhood education and development, economics, poverty, poor housing conditions, nutrition. Some Inuit depend on store-bought food often, but many don’t know how to cook from scratch so they rely on frozen food. Do they know the nutritional value of what they’re eating? We should be looking at how lifestyles affect our overall health.”

-Working Group Discussion

1. Identify and establish a set of wellness indicators relevant to the needs of Inuit.
2. Test these indicators in selected Inuit communities.
3. Develop an approach to encourage community involvement and awareness of health data.

Research

“Researchers often ask my mother for information. They pay her \$60 for her work, and often the researcher ends up with a university degree. It doesn’t seem fair, since it was my mother’s work in the first place.”

- Working Group Discussion

The Conference delegates asked that Inuit Tapiriit Kanatami advocate regional research protocols that ensure:

1. That Inuit contribution to research projects is publicly acknowledged.
2. That relevant communities review all research results for accuracy before publication or it is released to the general public.
3. That researchers obtain proper licensing and permission before beginning research projects in Inuit communities.
4. That ITK protect the rights of Inuit and Inuit communities regarding research projects.
5. That Pauktuutit and ITK will continue to work together to ensure that the needs of all people are considered.

Health Care Systems

“Inuit need the self-confidence to seek treatment and make themselves clearly understood. They often assume their doctor’s diagnosis and prescribed treatment is correct even if they know they haven’t communicated their symptoms properly. A lot of the time, especially the Elders will just accept the treatment without arguing, even though they know it might not be the right one.”

-Working Group Discussion

1. Cultural awareness workshops should be mandatory orientation for healthcare workers providing service for Inuit both north and south.
2. Ensure Inuit are informed of their individual rights within the healthcare system.
3. Ensure ongoing training for existing personnel in the communities regarding medical procedures and treatments.
4. Inuit patients should be provided with better explanations of prescribed treatments and procedures.
5. Encourage new healthcare professionals to recognize participation in community life is part of a positive and holistic approach to healthcare.
6. Describe and develop a holistic approach to healthcare that reflects Inuit Traditional Knowledge.

Partnerships

1. Review previous work, summarize and the develop models for partnership, showing measurements for effective relationships that are meaningful to Inuit.
2. Establish a Health Technical Working Group to develop the program.
3. Establish a community committee (interagency) as an advisory committee to the program.

Communication

“It’s important to have a good communication system in place so we can share information between regions.”

-Working Group Discussion

1. Ensure communication is conducted in the appropriate Inuktitut dialects.
2. Communicate information and studies at community forums and focus groups, not just through written texts.

3. Working group should look into costs/benefits of Information Technology options and partners.

Specific Health Priorities

“Incorporating Inuit traditional knowledge into health treatment and healing programs is both economic, effective and accessible. There are Elders in every community who could teach us how Inuit healed themselves before the Southern physicians came with their Aspirins and bandages.”

- Working Group Discussion

1. Create an Inuit-Specific Health Agenda by:
 - a. Distributing the report of the Inuit Health Policy Forum, 2000.
 - b. Identifying priorities from current documents.
 - c. Developing an Inuit-specific implementation plan for the national Health Agenda.
2. Exploring the feasibility of establishing a National Inuit Cancer Registry in the form of a pilot project to explore partnership, repository, and capacity needs.
3. Developing a national Inuit policy on Health Partnership and consultation. Clarify the roles and responsibilities of existing and emerging Inuit and Aboriginal health organizations (NAHO, CIHR-IAPH).
4. Assess the need for a national Inuit health survey.

Capacity

1. Establish an Inuit Health Technical Working Group, with representation from the six Inuit regions, Pauktuutit, Elders and youth, and related stakeholders.
2. Seek long-term commitment from Health Canada and other Federal departments to support the related Inuit organizations’ capacity in information management.
3. Seek commitment from Health Canada to ensure transparency where government plans are concerned.
4. Seek commitment from Health Canada for long-term sustainability of the IHII project.
5. Explore the feasibility of establishing an Inuit-owned and controlled data repository, including ongoing resource requirements.
6. Ensure direct involvement in relevant federal, territorial and provincial government processes.
7. Incorporate gender analysis from inception and throughout.

Language

“Let’s say I have a problem with my liver and I’m from Nunavik, sent down south for treatment. The interpreter assigned to me might be from another region where the word for liver means something completely different. So the interpreter thinks my word for liver is something else, and she communicates this to the doctor, and I end up getting treated for something that has nothing to do with my liver, and meanwhile my liver condition remains untreated.”

- Working Group Discussion

1. ITK should explore funding from appropriate sources to coordinate translation of health documents to ensure Inuktitut dialects are respected.
2. ITK should advocate for enhanced interpreter/translator workshops to standardize medical/health terminology. Elders should be included in these workshops to ensure proper Inuktitut words and terms are used and understood.
- 3.
4. ITK should lobby for the creation and updating of Inuktitut health/medical terminology glossaries specific to each dialect and make it available in each community.
5. Communicate health related material with plain language, written or verbal.

One Year Later ...

Current Status of the Inuit Health Information Initiative

ITK was able to secure funding for Health Liaison Officers (HLOs) in six Inuit regions during the 2002-2003 fiscal year and therefore the Inuit Health Technical Working Group has met twice during the past year. This funding is a result of a collaboration between the Health Renewal Project and the Inuit Health Information Initiative.

The HLOs are working with ITK to establish the vision, purpose and direction of an Inuit Health Status Report. The Inuit Health Technical Working Group is in the process of reviewing documents to help determine the indicators to be used to describe Inuit health status. We are currently developing a plan that would allow us validate health status indicators at the community level, where communities would also be able to use this work to contribute to the well-being of their own community.

The Papers we have developed include:

1. The Environment as a Determinant of Health
2. Population Health Indicators for Inuit Communities – Scoping Paper
3. Mental Health, Community Health and Justice
4. Client Satisfaction Surveys
5. ADI/HCC Data Requirements
6. Capacity Building Phase 1: Building Community Readiness
7. Connectivity in Inuit Communities: an Environmental Scan
8. An Inuit Specific Partnership Strategy and Framework
9. The Inuit Health Information Initiative and Data Model
10. Language and Health
11. National Inuit Identification Cards (Inuktitut)

Next Steps

The Inuit Health Technical Working Group (IHTWG – name is subject to change) is reviewing the abovementioned papers in order to develop an action plan. We are also working on defining the vision, purpose, audience, processes and partnerships required to develop a National Inuit Health Status Report. We anticipate going to communities over the next year to gain feedback into the process and the report.

For copies of any of the above papers (English only unless indicated – translation is in progress), to provide input into the Inuit Health Information Initiative or for any other concerns please contact the Inuit Tapiriit Kanatami Health Department at 1-866-262-8181.

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Kerrie Duncan, ITK
Catherine Dallas, ITK
Eugene Tomasky, ITK
Roy Wilson, ITK
Sydney Sackett, ITK
Pitseolak Pfeifer, ITK

Pauktuutit

Tracy O'Hearn, Pauktuutit
Reepa Evic-Carton, Pauktuutit
Donna Kisoun, Pauktuutit and Inuvialuit

National Inuit Youth Council

Tunu Napartuk, NIYC

Non-Governmental Organizations

Michael Martin, NAHO
Sitanor Shoush, CIHR-IAPH
Annie Quirke, NSDC

Governmental Organizations

Federal

Roda Grey, FNIHB
Alexa Brewer, FNIHB
Adam Probert, FNIHB
Laura Commanda, FNIHB
Therese Boudrioux, Northern Secretariat

Territorial

Vicki Lafferty, GNWT
Bill Fennell, GN

Glossary of Acronyms and Abbreviations

AFN	Assembly of First Nations
APS	Aboriginal Peoples Survey
CHR	Community health representative
EEG	Electroencephalogram
GNWT	Government of the Northwest Territories
GP	General practitioner
HLC	Health Labrador Corporation
HTF	Health Transfer Fund
IRC	Inuvialuit Regional Corporation
IRHSSB	Inuvik Regional Health and Social Services Board
ITK/ITC	Inuit Tapiriit Kanatami (previously Inuit Tapirisat of Canada)
JBNQA	<i>James Bay and Northern Quebec Agreement</i>
JTF	Joint Task Force (on Future Management Options for the Non-Insured Health Benefits program)
LIA	Labrador Inuit Association
LIHC	Labrador Inuit Health Commission
MSB	Medical Services Branch (Health Canada)
NIHB	Non-Insured Health Benefits
NLCA	<i>Nunavut Land Claim Agreement</i>
NRBHSS	Nunavik Regional Board of Health and Social Services
NSDC	Nunavut Social Development Council
NTI	Nunavut Tunngavik Inc.
HR	Health Renewal
ACHI	Advisory Committee on Health Infostructure
ADM	Assistant Deputy Minister
AFN	Assembly of First Nations
AHI	Aboriginal Health Infostructure
CHI	Canadian Health Infostructure
CHN	Canadian Health Network
COO	Chiefs of Ontario
DG	Director General
FNIHB	First Nations and Inuit Health Branch
FNIHIS	First Nations and Inuit Health Information System
FNIHP	First Nations and Inuit Health Programs
HC	Health Canada
HIS	Health Information System
HPPB	Health Promotion and Protection Branch
HQ	Headquarters
IACB	Information, Access and Connectivity Branch
ISMD	Infostructure Systems Management Division
ITK/ITC	Inuit Tapiriit Kanatami (previously Inuit Tapirisat of Canada)

NAHO	National Aboriginal Health Organization ³
NHSI	National Health Surveillance Infostructure
OCAP	Ownership, control, access, and possession
OHIH	Office of Health and the Information Highway
QA	Quality Assurance
RHS	Regional Health Survey
SliCA	Survey of Living Conditions in the Circumpolar Arctic

ADSL	Asynchronous digital subscriber line
B2B	Business-to-business
B2C	Business-to-customer
BBA	Basic broadband access
bps	Bits per second
CAP	Community Access Program
CO	Central office
CRTC	Canadian Radio-television and Telecommunications Commission
CSD	Census sub-divisions
DSL	Digital subscriber line
Gbps	Gigabits per second
GOL	Government On-Line
HDI	United Nations human development index
HDSL	High bit-rate digital subscriber line
ICT	Information and communication technology
IHAC	Information Highway Advisory Council
ISDN	Integrated services digital network
ISP	Internet service provider
IT	Information technology
ITU	International Telecommunications Union
Kbps	Kilobits per second
Mbps	Megabits per second
NTSC	National Television System Committee
MIZ	Metropolitan influenced zone
OECD	Organization for Economic Co-operation and Development
PoP	Point of presence
QOL	Quality of life
SME	Small and medium-sized enterprises
TAP	Telecommunications Access Partnership program (Ontario)
VDSL	Very high bit-rate digital subscriber line
XDSL	A generic term for the suite of DSL services, where the “x” can be replaced with any of a number of letters, including “A,” “H,” “M,” “RA,” “S,” and “V.”

³ prior to March 2001, usually referred to as the Aboriginal Health Institute