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The *Canadian Coast Guard Ship (CCGS) Amundsen* was used during the Inuit Health Survey. The ship is pictured here outside Taloyoak.
All photographs courtesy of Inuit Health Survey staff and students.



Nurse and member of the research team Anna Bergen gets a ride from Mark Kutsiutikku of Kugaaruk.



The Nunavut Inuit Health Survey: Understanding its influence and legacy

EXECUTIVE SUMMARY

Nunavut Tunngavik Inc.'s (NTI) 2011/12 and 2012/13 *Annual Report on the State of Inuit Culture and Society* focuses on two related topics: the Nunavut portion of the 2007/08 Inuit Health Survey (IHS) and the role of research in Inuit communities. The IHS continues to provide a wealth of information about the diverse factors impacting Inuit physical and mental health, and these findings have the potential to inform the development of effective public health policy.

Yet an issue that's arisen with the IHS is that its results have generally been disseminated to an academic audience in isolated fragments rather than showing how the results fit into a larger picture of Inuit health. For example, information that came out of the IHS about food security confirms that too many Inuit households are in need of food, yet the survey does not tie food security back to issues like education, employment, and poverty or explore how these issues are connected to government policies that can be improved through innovation and cooperation. In order to show these connections, NTI uses the first half of this

report to place IHS findings into the needed historical, social, and political contexts necessary to make its findings more relevant to citizens and policy-makers.

Related to the issue of research dissemination is the important role research can play in helping to bring about positive change in our communities. Research has a tainted legacy in Nunavut, characterized by uneven power relationships between Inuit and researchers. Unfortunately, aspects of this legacy can be seen in the way the IHS was carried out. NTI looks at the IHS as a case study in the second half of this report, describing what NTI feels was successful as well as shortcomings that future research and researchers can learn from. NTI then lays out the role Inuit expect to play in research that affects our communities and highlights relevant policies and guidelines for ethical research that support this position. This step is necessary in order to ensure that Inuit have an authoritative role in research that takes place in our communities and to cultivate the cooperative relationships with researchers and research institutions needed to do so.



Community research assistants Darlene Hokanak and Kenny Taptuna of Kugluktuk take a moment to enjoy the sun.

INTRODUCTION

The Nunavut portion of the IHS was carried out in 25 communities in 2007/08, and collected information about an array of physical health determinants that include housing, education, environmental contaminants, food security, family medical history, nutrition, and diet from 1,923 participants. The mental health and community wellness segment of the survey collected information from 1,710 people. Similar surveys were also carried out in the Inuvialuit Settlement Region and Nunatsiavut. Traveling aboard the Canadian Coast Guard Ship (CCGS) *Amundsen*, a team of researchers gathered health data throughout the territory that provide baseline information about the health status of Inuit. NTI, the Government of Nunavut (GN), and the Nunavut Association of Municipalities (NAM) formed the Nunavut Steering Committee that worked with researchers from McGill University and the University of Toronto to develop and guide the International Polar Year-funded project from its inception to completion.

IHS findings have been helpful for some advocates and policy-makers, providing a clearer picture of the physical and mental health challenges facing many Inuit. IHS findings were published in a summary report in 2010, with a separate community and personal wellness summary report published in 2012. At the time of writing this annual report, 13 papers describing different aspects of IHS findings have also been published in various academic journals. The information contained in these papers is of tremendous importance, yet their practical use can be limited to the academic audience they were written for. Related to this issue is the topical nature of IHS publications, which tend to examine survey outcomes in isolation from the broader social, cultural, political, and historical contexts in which Inuit health challenges exist.

In order to help Nunavummiut and policy-makers understand and use the IHS findings more effectively, NTI sought to present IHS findings in the bigger picture in which they exist. Related to this goal of improving the usefulness of the IHS, NTI also describes the expectation for the future conduct of research in our communities, both as a means of ensuring that researchers and research institutions uphold their ethical responsibilities to Inuit and communities and in order to facilitate the use of research by advocates and policy-makers.

In order to provide background for discussion of these and related issues, Part 1 of this report focuses on the evolution of the IHS, briefly describing how and why the survey was developed, who was involved in its development, and challenges associated with this process from the perspective of IHS researchers. This section then provides a description of key IHS findings and interprets what these findings tell us about the state of Inuit culture and society. This interpretation shows how many of Nunavut's health challenges are interrelated and speaks to the importance of cross-sector cooperation between NTI, Regional Inuit Associations (RIAs), the GN, and the Government of Canada to overcoming them.

Consistent with past reports, NTI highlights the science of early childhood development to show how the health status of adults is influenced by experiences in the earliest years of life. By doing so, NTI demonstrates that many of the challenges that the IHS and this report highlight are rooted in childhood experiences and the environments in which those experiences take place, and thus require child-focused solutions. NTI emphasizes that public health policies focusing on prevention in the early years is a sensible and economical approach to improving Nunavut Inuit health status.

Part 2 of this report establishes the role Nunavut Inuit expect to play in future research carried out in our communities. The role of research and researchers in Inuit and other Indigenous communities has commonly been exploitative, with researchers tending to benefit more from research than Indigenous participants. This is unacceptable today, and growing numbers of Indigenous communities are developing policies and guidelines for the ethical conduct of research carried out in communities. These policies and guidelines are further supported by national standards around ethical research practices in Aboriginal communities, practices that help to further legitimize our expectations.



Part 1:

INUIT HEALTH SURVEY HIGHLIGHTS AND CONTEXT FOR MOVING FORWARD

The 2007/08 IHS shows persisting gaps between the health status of Nunavut Inuit and Canadians as a whole, with physical and mental health outcomes for Inuit much poorer overall. Inuit are more likely than other Canadians to be daily smokers, live in food insecure households, and be overweight or obese. Inuit are also more likely than the rest of the Canadian population to have experienced physical and/or sexual abuse during childhood, suffer from depression, and to have seriously considered or attempted suicide at some time.

These gaps are partially symptoms of government policies that contribute to inequity, such as a severe shortage of housing across the territory, poor infrastructure that contributes to Nunavut’s high cost of living, and a scarcity of health care providers relative to the size of the population. These factors contribute to severe inequity for Inuit in many areas of life and make it challenging for people to live well.

Before moving forward with a discussion of the political and historical context from which many of these gaps have emerged, NTI describes a vision for Inuit health and wellness in Nunavut.

NTI’s vision for Inuit health and wellness in Nunavut

NTI envisions a society in which the social and cultural needs of Inuit are met, with the aim of ensuring that children grow up in safe environments conducive to positive, lifelong outcomes.

NTI, the GN, and the Government of Canada must work together to ensure that international human rights to adequate housing, food security, and Inuit self-determination over education are met through full implementation of international human rights instruments. NTI sees Nunavut Land Claims Agreement Article 32 as foundational to strengthening relationships between these entities.

NTI envisions a society in which researchers, advocates, and policy-makers work together in a spirit of collaboration, sharing expertise and resources in order to focus on strengthening the capacities of children and adults now while preventing social and economic challenges before they arise.

NTI sees Inuit health and wellness as a balance between the social, cultural, and spiritual aspects of peoples’ lives. The Inuit

values of family and community cohesion, knowledge of language and culture, a positive self-perception, and self-reliance are important to achieving this balance.

International human rights and Inuit

As a member state of the United Nations (UN), Canada is obliged to uphold international standards for the fair treatment of its citizens, yet has failed to ensure that basic rights to adequate housing, education, food security, and social services are met for many Nunavut Inuit. The social and economic challenges described in this report are symptoms of this failure and reflect that a timeworn double standard exists when it comes to Canada’s treatment of Inuit and other Aboriginal Peoples compared with its non-Aboriginal population.

This double standard is coming under increased international scrutiny. The UN Special Rapporteur on the Right to Food, Olivier De Schutter, heavily criticized the Government of Canada’s treatment of Aboriginal Peoples at the conclusion of an eight-day fact-finding mission to Canada in May 2012. The UN Special Rapporteur on the Right to Food is an independent expert appointed by the UN Human Rights Council and is responsible for promoting the full realization of the right to food for all people. De Schutter “was disconcerted by the deep and severe food insecurity faced by Aboriginal Peoples across Canada living both on- and off-reserve in remote and urban areas,” stemming from “a long history of political and economic marginalization [that] has left many indigenous peoples with considerably lower levels of access to adequate food relative to the general population.”¹

Figure 1 shows international human rights instruments, date of ratification by Canada, and articles that are relevant to the IHS findings described in the paragraphs that follow. NTI sees the inclusion of this information as necessary in order to keep international human rights in the forefront of our thinking about policy areas that are in need of improvement, and to show how responsibility for the basic welfare of Canadian citizens lies with the highest levels of government. Although NTI lacks space in this report to discuss the IHS findings with respect to the full range of international human rights that Canadian citizens are entitled to, the instruments cited in Figure 1 provide a helpful overview.

Figure 1. International human rights instruments

Human rights instrument	Date of ratification by Canada	Rights recognized
UN Declaration on the Rights of Indigenous Peoples ²	Nov. 12, 2010	Article 14: Indigenous control of educational systems and institutions; right to provide education in Indigenous languages, in a manner appropriate to Indigenous cultural methods of teaching and learning. Article 23: Indigenous participation in the development and administration of social programs.
UN Universal Declaration of Human Rights ³	Dec. 10, 1948	Article 25: Human rights to food, clothing, housing and medical care and necessary social services.
UN Convention on the Rights of the Child ⁴	Nov. 20, 1989	Article 19: Children's right to protection by State Parties from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.
UN International Covenant on Economic, Social and Cultural Rights ⁵	May 19, 1976	Article 11: Human right to adequate standard of living for family and self, including adequate food, clothing and housing, and to the continuous improvement of living conditions.

Placing Nunavut Inuit health status in context

All too often, media and research fails to place health outcomes into the historical, political, and economic contexts in which they exist. Doing so can leave communities vulnerable to victim blaming without the necessary actions being taken to eliminate the structural inequities in place that often make it difficult for people to achieve health and wellness.

In the following sections, NTI highlights aspects of Inuit adult mental and physical health status. It is necessary to preface these descriptions by placing findings into the appropriate context in which they exist because many of today's social challenges stem from past and present social policies.⁶

Nunavut Inuit have experienced rapid social, economic, and cultural changes in the last century stemming from the colonization

of the Arctic by the Government of Canada. Many of these changes were forceful and traumatic and led to the emergence of social challenges that continue today. Even though many families are generations removed from the direct impacts of events like community relocations and residential schooling, people commonly attribute the onset of social challenges, such as elevated suicide rates, to this period of rapid social transition.⁷

Whereas the Government of Canada prior to World War II largely ignored Inuit, the 1950–1970 period marked the beginning of a high level of government activity in the Canadian Arctic and the beginning of rapid cultural and social change for Inuit.⁸ Within two decades, most Inuit transitioned from living in small, seasonal camps to permanent, year-round settlements where services such as nursing stations, schools, Hudson's Bay stores, airports, and missionaries were located. An increase in alcohol and drug abuse, accidents, family violence, and other social problems are associated with this transition.⁹



Social, cultural, and economic changes set in motion by the earliest Qallunaat (non-Inuit) whalers, trappers, and missionaries in the Arctic prior to 1950 were accelerated by Government of Canada policies that aimed to relocate Inuit into permanent settlements. Government authorities wished to do so in order to more closely monitor and deliver services to Inuit.

By 1950, the Government of Canada had established a more permanent role in the Arctic and, between 1956 and 1957, commenced Cold War construction of Distant Early Warning (DEW) radar stations across the Arctic in order to defend against the possibility of a Russian attack. These stations brought southern workers north while creating employment opportunities for some Inuit.

Some Inuit families moved into settlements voluntarily where medical services, schools, and material goods were available, but government authorities coerced many others into moving by threatening to withhold the family allowances that many depended on, or by promising ideal living conditions in settlements with readily available food and housing.¹⁰ Far from ideal, the living conditions in settlements were what sociologist Frank J. Tester has called “a public health disaster in the making.”¹¹ Inuit often suffered in crowded and inadequate housing in settlements, with many families forced to build shacks of tin, wood, cardboard, and skins to deal with persistent housing shortages.

Crowded and unsanitary living conditions contributed to the spread of tuberculosis (TB) and other infectious diseases in the then Northwest Territories (NT) at a time when TB rates were dropping in the rest of Canada. Between 1938 and 1959, the death rate for TB of the respiratory system for Canada (excluding the then NT) dropped from 45.4 per 100,000 in 1938, to 9.9 in 1953, and for TB other than respiratory, death rates declined from 9.6 per 100,000 to 2.4. In contrast, Inuit in the NT died by TB of the respiratory system at a rate that rose from 153.6 per 100,000 in 1938, to 298.1 in 1953, with death from TB in other forms declining from 57.6 per 100,000 to 56.8 during the same span of time.¹²

By the early 1960s, nearly 50 per cent of Inuit spent time in southern sanatoria for TB treatment.¹³ Many people experienced severe culture shock, racism, linguistic isolation, and estrangement from their families during their time in the south, leaving some people traumatized.

Parallel to these experiences, Inuit also experienced a loss of mobility during this time, when the Royal Canadian Mounted Police (RCMP) and other authorities shot hundreds of sled dogs whose care in settlements was considered unsatisfactory under ordinances that were foreign to Inuit.¹⁴ Sled dogs were vital to transportation and hunting and were an important status sym-

bol for hunters. Their loss contributed to the breakdown of gender roles in settlements, hastening Inuit dependence on social assistance payments and expensive, nutritionally inferior store-bought foods. Sled dogs symbolized autonomy and self-reliance for hunters and their families, and their loss was a traumatic blow to the self-esteem and self-worth of many hunters.

Many of the health disparities that Nunavut Inuit face today can be traced to this period of rapid social and cultural change, which has continued with few opportunities for healing or reflection. Policy issues such as poverty, crowded housing, and high store-bought food prices continue to contribute to the poor health status of Nunavut Inuit today. This period of change is characterized by the disempowerment of Inuit and the breakdown of traditional gender and community roles in a way that has thrown an entire society out of balance. However, Inuit are in the process of restoring balance to our society through greater awareness of these challenges and a deeper understanding of the policy changes needed to help overcome them.

Inuit Health Survey background and process

This section provides background information on the manner in which the IHS was carried out. It includes details about how the idea for the survey emerged and highlights challenges that researchers involved with the survey experienced while carrying it through to completion.

The IHS was in large part modelled on the 2004 Nunavik Inuit Health Survey, including the means of administering the survey and aspects of survey content.¹⁵

That survey involved a partnership between the Ministère de la Santé et des Services sociaux, Nunavik Regional Board of Health and Social Services, Quebec’s public health institute (Institut national de santé publique du Québec), and the Public Health Research Unit of the Laval University Hospital Centre. The five-week survey was carried out on board the CCGS *Amundsen* by a team of nurses, researchers, interviewers, and interpreters travelling to each of Nunavik’s 14 communities.

Similarly, the Nunavut portion of the IHS involved partnerships between southern universities and researchers, and northern organizations. As an International Polar Year-funded project, the IHS was well financed and enjoyed a larger scope than the Nunavik study. International Polar Year was a massive, international scientific research initiative that focused on the Arctic and Antarctic from 2007 to 2009, pouring millions of dollars into 200 research projects carried out by thousands of scientists from over 60 nations examining physical, biological, and social re-

search topics. The Government of Canada invested \$150 million over six years to support Canada's participation in the initiative, which included 45 science and research projects.¹⁶

The IHS's lead academic partners were Grace Egeland of the Centre for Indigenous Peoples' Nutrition and Environment at McGill University and Kue Young of the University of Toronto. These academic partners approached key Nunavut stakeholders about carrying out the IHS and invited stakeholders to participate in crafting its content once consent was obtained.

The Nunavut Steering Committee that consented to the survey and provided input consisted of NTI, the GN, and NAM representing community officials across Nunavut.

NAM was the link between the steering committee and Nunavut communities and helped coordinate community logistics, providing randomized house numbers used to coordinate the door-to-door aspect of the survey in each community. NTI and the GN participated in the development of survey focus areas and survey questions, and brought an Inuit perspective to the overall design.¹⁷

The IHS aimed to collect baseline health data about the Inuit population that members of the IHS steering committee identified as important. Baseline data are gathered using the same measurements to provide a snapshot of a population at a single point in time. They are useful for measuring the improvement or lack of improvement in health status over time, for setting future health improvement targets, and for estimating future outcomes and planning appropriate interventions.

In order for the survey results to tell us about the health status of the entire Nunavut Inuit population, a sufficiently large sample of the population was needed. A total of 1,372 households and 1,923 individuals participated in the IHS, or about 12 per cent of the Nunavut Inuit population. In order to help achieve a sample of this size, individuals were compensated with \$25 for participating in the survey.¹⁸ This sample was sufficiently large to be able to generalize many of the survey results for the entire Nunavut Inuit population. Even though not all Nunavut Inuit households participated in the survey, for example, a large enough proportion of households indicated experiencing food insecurity for this number to tell us about the food security status for Nunavut Inuit as a whole.

Like the Nunavik survey, the IHS involved a team of nurses, researchers, interviewers, and interpreters travelling aboard the CCGS *Amundsen* to Nunavut's 24 coastal communities from Aug. 2007 to Aug. 2008, with a separate visit to the inland community Baker Lake in 2008. In each community, interviewers surveyed participating individuals from randomly selected households about household living conditions, including overcrowding, disabilities, and food security. This questionnaire was administered on land by the land team that arrived in each community ahead of the *Amundsen*. The land team was made up of a head nurse and assistants and was also responsible for scheduling appointments with participants to board the *Amundsen* when it arrived in the community. The land team was also responsible for making sure participants were transported to the vessel for their appointments at the designated time.

Once aboard the ship, interviewers administered an individual health survey looking at chronic disease risk, nutrition, physical activity, and mental health. Questionnaires regarding medicine and supplement use, community and personal wellness, and diet were also administered on board the *Amundsen*. Clinical



Community research assistants Bernice Aggarak of Igluigaarukjuk (Chesterfield Inlet) and Paul Onalik of Kimmirut enjoy a country food meal shared with members of the CCGS *Amundsen* crew.



measurements were completed during this time, including the taking of blood samples, blood pressure, pulse, height, and weight.

Participants' blood samples were later assessed to determine peoples' exposure to potentially harmful chemical contaminants such as mercury, lead, and polychlorinated biphenyls (PCBs).

Within five months, each participant received his or her clinical measurement results in the mail following analysis in the form of a booklet. These booklets showed height, weight, Body Mass Index, blood pressure, and blood work results. Cartoon faces expressing emotions within each booklet were also used to help communicate the meaning of participants' results, with a sad face indicating the need to go to the hospital. If participants had given permission to do so, their results were also sent to their community health care centre.¹⁹

The IHS steering committee successfully organized a project of significant scope involving cooperation among hundreds of people and dozens of communities within a short period of time. Inuit language interpreters, graduate student researchers, and the land team members responsible for briefing each community about the IHS prior to the *Amundsen's* arrival, all had to be assembled in less than a year. The logistical challenges associated with supplying the *Amundsen* (which was essentially a mobile clinic and laboratory) with the appropriate resources needed to complete the project were also daunting.

That said, the use of the *Amundsen* for this purpose has a dark parallel in history with another CCGS ship that carried out a similar function in the eastern Arctic during the 1950s and 1960s, the *C.D. Howe*. The *C.D. Howe* made annual trips to Inuit communities during this period to conduct medical and dental examinations that included screening for TB by administering chest x-rays. Like the *Amundsen*, Inuit boarded the *C.D. Howe* in the summer months for medical examinations, but unlike the *Amundsen*, some never returned to their families and communities. Inuit diagnosed with TB were immediately quarantined, then transported to TB sanatoria in southern Canada. People were not given the opportunity to settle their affairs or say goodbye to loved ones for fear of contamination. As discussed in the previous section, this was a traumatic experience for many people due to the culture shock of being transported to an alien environment, as well as the uncertainty many people felt about ever being able to return home.

There continues to be a lack of closure surrounding these events, and many families are still uncertain what became of relatives who were transported south. For this reason, the legacy of the *C.D. Howe's* impact on Nunavut families and communities, and the memories of disappeared relatives surfaced during the

Amundsen's stops in communities during the IHS. People in communities hosted ceremonies in remembrance of those who have been affected, including IHS staff members in Iqaluit in Sept. 2007.²⁰

This section provided brief background information about the IHS, including details about the process by which the survey was carried out. The following section highlights IHS findings and places these findings into their appropriate political and historical context.

Nunavut Inuit Child Health Survey

Grace Egeland was also the principal investigator for the IHS sister survey, the Nunavut Inuit Child Health Survey that was carried out in 16 Nunavut communities in 2007/08. This survey reached 388 preschool-aged children (ages 3 to 5). The survey was organized by the same IHS steering committee but was also an International Polar Year project but asked different questions and was not carried out aboard the *Amundsen*. The survey looked at growth and weight, vision, a blood test for weak blood (anemia) and vitamin D levels, bone health, health histories, mercury in hair, and a household questionnaire on smoking, crowding, and having enough food to eat.²¹ NTI cites statistics from the Nunavut Inuit Child Health Survey throughout this report in order to supplement our focus on the IHS.

Key IHS findings

IHS findings tell us that the health status of Inuit continues to be negatively impacted by policy decisions made by the GN and the Government of Canada that fall far short of meeting basic international human rights standards.

The issue of adequate household food security stands out because this has been an ongoing challenge since Inuit were relocated into permanent settlements. Despite food being recognized as a basic entitlement by the UN, the majority of Nunavut Inuit households do not get enough food. The following bullet points summarize key IHS findings about household food security:

- Aboriginal Affairs and Northern Development Canada modified the United States Department of Agriculture's (USDA) food security questionnaire, and this modified version of the questionnaire was used in the IHS. The USDA defines food security as "access by all people at all times to enough food for an active, healthy life."²²
- Survey participants were asked if in the last 12 months they had ever worried about running out of food for themselves

and their family before having enough money to buy more. They were also asked if in the last 12 months there were times when food for themselves and their family did not last and there was no money to buy more and if there were times when participants and their family could not afford to eat healthy food.

- Based on responses to these questions, the IHS revealed that 70.2 per cent of Inuit households overall are food insecure, and 71.4 per cent of households with children are food insecure.²³
- By contrast, only nine per cent of Canadian households were considered food insecure according to the 2004 *Canadian Community Health Survey*.²⁴

The long-term effects of household food insecurity on the healthy growth and development of very young children is especially concerning. The Nunavut Inuit Child Health Survey shows that about 34 per cent of homes with 3- to 5-year-old children report experiencing severe food insecurity (having to skip meals or eat small meals due to not having enough food).²⁵ Children need adequate amounts of nutritious foods to support their healthy development, foods that are too often out of reach due to outside factors.

The main factors contributing to food insecurity in Nunavut are unemployment, low income, and high food costs. Inuit account for 78 per cent of Nunavut's working-age population, yet on average make up only 64 per cent of employed people in the territory. Inuit outnumber non-Inuit by more than three to one, yet non-Inuit are nearly twice as likely to be employed: in 2011, 46.2 per cent of working-age Inuit were employed, compared with 89.2 per cent of non-Inuit.²⁶

Nunavut schools are also failing to adequately educate the majority of students, and this presents social and economic challenges that influence employment and health status. From 1999 to 2008, the average high school graduation rate for Nunavut students was just 27.5 per cent,²⁷ and less than 13 per cent of the population aged 25 to 64 possessed a university certificate or degree at the bachelor's level or above.²⁸

Consequently, most employed Inuit do not hold professional positions that require a high school diploma or university degree, limiting employment options and earnings. Nationwide, the median total income for Canadian families of two or more people is \$69,850, compared with \$62,680 in Nunavut, a difference of more than \$7,000.²⁹

Gaps in employment and earnings can be seen clearly in employment statistics from the GN, the largest employer in the

territory. The bulk of Inuit GN employees hold paraprofessional and administrative support positions that do not require a post-secondary education, with the overwhelming majority of professional, middle management, upper management, and executive positions held by educated non-Inuit.³⁰

Making matters more difficult, food costs in Nunavut are the highest in Canada, with families commonly paying at least double, if not triple, what people in southern Canada pay for food, despite significantly lower income levels. Families must also pay astronomically high prices for non-food necessities such as diapers, laundry detergent, and hygiene products.

The IHS looked at household expenditures for food, finding that the average household in Nunavut spent \$1,875 per month on food compared with \$609 for Canada as a whole, more than three times the amount.³¹

The combination of low educational attainment, low employment, and low income relative to high living costs contribute to the poverty crisis in Nunavut and changes in diet and health status for Inuit. The IHS shows that food insecurity as well as the shift away from country to store-bought foods is underway and that this change in diet presents many health concerns touched on in the following paragraphs.

The nutrition transition of Nunavut Inuit impacts health status

Asked about food preferences, about 20 per cent of IHS participants said they preferred mainly country food, while the rest preferred a mix of country and store-bought foods.³² Country foods include wild fish and game such as Arctic char, caribou, whale, and seal that are high in vitamins and healthy fats. These foods are thought to help protect from cardiovascular disease and diabetes due to their high levels of omega-3, unsaturated fatty acids, and low levels of omega-6 fatty acids. Country foods are also excellent sources of critical vitamins, minerals, and micronutrients that contribute to good health.³³

Even though 71 per cent of IHS participants consider country foods less expensive than store-bought foods, 81 per cent said they preferred to eat more country food than they could get.³⁴ The primary reasons given for not being able to acquire more country foods were a) no active hunter in the household, b) lack of transportation, and c) gas and supplies being too expensive.

In order to better understand dietary patterns, IHS participants were asked to recall their diets in the year leading up to the survey and in the past 24 hours. Participant responses show that the percentage of energy taken from country foods decreased



between 1999 (23.4 per cent of daily energy) and 2008 (16.1 per cent of daily energy), with older adults consistently consuming more country foods as a percentage of their diet than younger adults.³⁵ The decline in the percentage of energy taken from country foods between 1999 and 2008 was greater for women (an 11.3 per cent decline) than for men (2.9 per cent).

At the same time that country food consumption has declined among Inuit adults, consumption of sugar-sweetened drinks, sweets, granulated sugar, chips, and pasta increased between 1999 and 2008.³⁶ In the day prior to taking the IHS, men under 40 got 35.8 per cent of their calories from sugary foods, compared with 27.2 per cent for men over 40. For women, these numbers are 36.3 per cent and 29 per cent, respectively.³⁷

The percentage of daily energy intake from high sugar and high fat food and drink is similarly high for preschool-aged children, with about 35 per cent of daily energy intake coming from high sugar or high fat foods.³⁸

The transition from healthy country foods to greater consumption of energy dense, nutrient poor, store-bought foods high in sugar, saturated fats and sodium has contributed to Nunavut Inuit becoming heavier. The IHS measured the Body Mass Index of Inuit, which is a comparison of body weight to height. Based on this measure, 59 per cent of Inuit have a body weight relative to height that classifies them as overweight or obese.³⁹

People who are overweight or obese are at greater risk for nutritionally related diseases such as diabetes, cardiovascular disease, and some forms of cancer. In the past, an active lifestyle and a diet rich in healthy country foods helped protect Inuit from these diseases. However, the IHS tells a different story, with findings showing that the rate of diabetes for Inuit is now similar to the overall Canadian population across age groups.⁴⁰

Helga Saudny, Research Coordinator for the Centre for Indigenous Peoples' Nutrition and Environment at McGill University,



The Canadian Coast Guard Ship (CCGS) Amundsen.

helped plan and coordinate the IHS, in addition to working as a dispatcher coordinating participant interviews aboard the *Amundsen*. Saudny was surprised and concerned by these dietary changes. “Inuit were always thought to be protected [from nutritionally related diseases] because of their lifestyle and diet, but that no longer seems to be the case,” said Saudny, in an interview for this report. “And I think that is important to keep in mind for policy makers...If nothing is done, it’s going to get worse, so hopefully something will be done—that those rates don’t go up any higher.”⁴¹

Lowering rates of overweight, obesity, and nutritionally related diseases is challenging, in part because of economic barriers to acquiring nutritious foods, either at the store where fresh fruits and vegetables are expensive, scarce, and often of low quality, or on the land where hunting can be constrained by expensive resources. According to Helga Saudny,

Because of employment, [Inuit families] don’t have time to spend as much ... time on the land. Also the equipment is expensive. Unless you have a full-time job, you may not be able to afford it. If you don’t have a full-time job, you can’t afford it. Fuel is expensive; equipment is expensive, so there is this struggle going on: “Yes, we want to go onto the land, but we can’t because it’s expensive.”⁴²

Rates of overweight and obesity are also high among Inuit pre-school-age children. According to the Nunavut Inuit Child Health Survey, only one-third of children had healthy body weights for their age or height using International Obesity Task Force criteria for healthy body weights.⁴³ In developed countries like Canada and the US, the store-bought food choices people make are generally understood in terms of income and nutrition education, with high income levels linked to higher educational attainment and more nutritious diets, and low income levels linked to lower educational attainment and less nutritious diets.⁴⁴ This consumption pattern is commonly explained in terms of food costs because more nutritious store-bought foods, such as fresh fruits and vegetables, cost more on average than less nutritious store-bought food options, and are thus unaffordable for many low-income groups that often also lack nutrition education.⁴⁵ For this and related reasons, low-income populations tend to experience higher rates of overweight and obesity.

However, the IHS data show that this pattern is reversed among Inuit in Nunavut, Nunatsiavut, and the Inuvialuit Settlement Region. The data show that in a pattern matching that of developed countries, the odds of becoming overweight or obese for Inuit in these regions increase as income level increases and that factors such as higher education, employment, and private housing are also associated with overweight and obesity.⁴⁶ It is thought by some researchers that factors related to acculturation

contribute to this pattern, in which people with higher education levels and wage employment may be able to afford to live less active lives and consume more store-bought foods.⁴⁷

Global impacts on food security, diet, and nutrition

Making matters more complex are the effects of global factors, such as climate change and environmental contaminants, on Inuit food security, diet, and health. The effects of these global factors can be difficult to address through policy because responsibility lies with so many different entities.

Climate change is affecting animal migration, sea ice cover and thickness, and weather patterns, making it difficult for hunters to access game consistently. Barriers to country food access are a public health concern because, in addition to being healthier than store-bought food options, most IHS participants indicated that country foods are preferred and considered less expensive than store-bought options. Changes in sea ice conditions in particular can increase the danger of hunting, constrain access to hunting areas, affect the distribution of wildlife, and make hunting economically costlier when hunters must travel greater distances to find game. The overall effect of these changes can be an acute shortage of country foods in some households and communities.⁴⁸

Equally concerning are the effects of environmental contaminants in the Arctic ecosystem on Inuit health. Industrial contaminants that have migrated from warm climates are present in the country foods eaten by Inuit. The Contaminant Assessment portion of the IHS explains the extent to which contaminants exist in peoples’ bodies and what their potential effects are. Contaminants are thus an important part of the discussion about food security because they can limit safe food choices for Inuit.

Persistent Organic Pollutants (POPs) are highly toxic chemicals that are persistent in the environment, meaning they last for years or even decades before degrading into less dangerous forms. POPs are used as powerful insect pesticides for farming and serve a range of industrial purposes including use in the making of plastics and insulation fluids.⁴⁹ Heavy metals such as mercury and methyl mercury are found naturally in rocks and soils but can be released in the environment as a result of mining, smelting, and the burning of fossil fuels. Radionuclides, like cesium, polonium, and uranium, can be released into the environment as a result of nuclear activity but are less common.

POPs can pose health risks for Inuit because they evaporate into the atmosphere in warm climates and travel long distances in the air and water. In a process known as the grasshopper effect,



evaporated chemicals drift toward the earth's poles, where they settle to earth and enter the ecosystem after encountering cool, dry air.⁵⁰ The fatty bodies of Arctic animals are especially prone to contamination because POPs build up in the fatty tissue of animals. These contaminants are passed up the food chain to humans when country foods are consumed.

Fortunately, international measures have been taken to ban the use of the most dangerous POPs and gradually phase out the use and production of others. The most notable of these international measures is the *Stockholm Convention on Persistent Organic Pollutants*, an international treaty with over 90 parties that became international law in 2004.⁵¹ The convention holds governments accountable for regulating the use of POPs and helps identify safe alternatives.

The IHS looked for traces of contaminants in blood samples taken from Inuit adults. Blood test results show that most people should have minimal concern for contaminant-related effects from country food consumption and that the benefits and nutritional value of eating country foods outweigh the risks from contaminant exposure.⁵² Here are some highlights from the IHS contaminants report that give an overview of the situation:

- Concentrations of many POPs are declining in the Arctic due to efforts to ban their use, but a reduction in mercury levels in the ecosystem has not been observed and has, in some cases, increased.⁵³

- Blood concentrations of contaminants for Nunavut Inuit were higher than average levels for Canadians as a whole but below guideline levels set by Health Canada, the World Health Organization, the Centers for Disease Control, and the Occupational Safety and Health Administration. These guideline levels are used to screen populations and individuals for elevated contaminants exposure that can result in negative health outcomes.
- Age and sex differences exist for concentrations of contaminants in the bloodstream, with older participants having higher blood concentrations than younger participants of the following contaminants: mercury, lead, PCBs, DDT and DDE, taxaphene, and chlordan. Men were found to have higher concentrations of these contaminants than women.
- The IHS identified two areas in which human health effects should be considered in food and lifestyle choices: limiting exposure of women of child-bearing age to mercury through ringed seal liver consumption, and limiting exposure to cadmium by decreasing the number of cigarettes smoked.

The age and sex differences in concentrations of contaminants roughly correspond with patterns of country food consumption, with those consuming the most country foods tending to have the highest concentrations of contaminants in their bodies.



Community research assistant Christine Ekidlak of Sanikiluaq and nurse Kathy Morgan enjoy a lighter moment trying on the vision glasses during the Inuit Health Survey.

The average mercury blood levels for Inuit as a whole were higher than in the general population of Canada, but below individual and population guideline levels. However, women of childbearing age were an exception, with 43 per cent of women of childbearing age having mercury blood concentrations above Health Canada population guidelines. By looking at weekly country food intake, the IHS found that about half the mercury intake for women of childbearing age comes from ringed seal liver. This is a concern because fetuses and nursing infants are more sensitive to the effects of mercury than adults. In high doses, mercury can affect brain functions, weaken the immune system, and cause neurological damage.

Women of childbearing age who may become pregnant, are planning to become pregnant, or are pregnant are thus advised against eating ringed seal liver and encouraged to substitute ringed seal meat in order to cut this source of mercury out of the diet.

Also of significant concern were cadmium blood levels in the population, which were elevated above population and individual guideline levels for 73 per cent of participants. Cadmium is a naturally occurring metal used in batteries, some plastics, and metal coatings that can cause kidney and lung damage, fragile

bones, and an increased risk of certain cancers. It is also found in high levels in cigarette smoke. The IHS identifies smoking as the single largest cause for elevated cadmium blood concentrations among Inuit, due to the fact that 73 per cent of adult Inuit smoke. Some country foods contain small amounts of cadmium, but cigarette smoke can double the daily intake and the IHS recommends quitting smoking as the best way to decrease cadmium exposure and improve health.⁵⁴

Community wellness

In addition to looking at aspects of physical health, the IHS included a Community and Personal Wellness Survey taken by 1,710 people, 213 fewer than the total number of IHS participants. The sensitive nature of the topics dealt with in the survey may account for the lower participation. The survey asked participants about stress, sleep habits, and gambling. Participants were also asked about activities on the land, suicidal ideation, substance use, household violence, and sexual abuse. The results from the survey speak to the interrelatedness of many of Nunavut's social challenges and the need for public health policies that reflect this interrelatedness.



Community research assistant Theresa Kakkianium poses at the stern of the CCGS Amundsen.



Participants were asked if, in their opinion, their community was generally peaceful or affected by violence. Most respondents (69 per cent) said they thought their community was a very peaceful or moderately peaceful place to live, with more women (7 per cent) than men (2 per cent) categorizing their community as very violent. The vast majority (90 per cent) of people said that it was very or somewhat important for them to go out on the land, with fishing being the most common activity.⁵⁵ However, despite a relatively optimistic view of communities as peaceful, people's answers to questions about depression, suicidal thoughts, and abuse made it clear that there are issues within communities that people are struggling with.

Participants were asked how often they felt so depressed in the last month that nothing could help cheer them up. Nine per cent of participants said they felt this way all or most of the time, while 43 per cent said they felt this way some of the time.⁵⁶ About an even number of men and women responded this way. When asked about suicide, a startling number of people said they had considered or attempted suicide in their lifetime or in the last year:

- 48 per cent of survey participants said they had thought seriously about committing suicide in their lifetime, including 14 per cent in the last 12 months.
- 29 per cent reported having attempted suicide in their lifetime, including 5 per cent in the last 12 months.

Of those who had attempted suicide in their lifetime, women (31 per cent) were slightly more likely than men (25 per cent) to have attempted suicide, as were those under 50 (34 per cent).

Suicide is the second leading cause of death in the territory (heart disease is the second leading cause of death in every other province and territory), and young men are at the greatest risk of dying by suicide. The rate of death by suicide among 15- to 24-year-old Inuit men in Nunavut is 28 times that of this age group Canada-wide.⁵⁷

Participants were asked if they had experienced any form of physical violence or sexual assault when they were growing up or as an adult, with responses showing that a painful number of Nunavut Inuit have experienced violence and sexual assault in their lifetime:

- 41 per cent of participants indicated that they had experienced severe sexual abuse during childhood, which includes someone threatening to have sex with them, touching the sex parts of their body, trying to have sex with them, or sexually attacking them.⁵⁸

- Women (52 per cent) were more likely than men (22 per cent) to be survivors of severe sexual abuse during childhood.⁵⁹
- 50 per cent of participants experienced at least one form of physical abuse as an adult, with women (52 per cent) slightly more likely than men (46 per cent) to have experienced violence.⁶⁰
- 18 per cent of participants said they experienced a form of attempted forced sexual activity, with women (27 per cent) much more likely than men (5 per cent) to have experienced forced or attempted forced sexual activity.⁶¹

The fact that nearly half of survey respondents reported being severely sexually assaulted as children and that a large proportion of the population, particularly women, had experienced physical abuse and sexual assault as an adult, gives us an impression of the social environment in which other health issues related to nutrition, diet, and food security exist.

The IHS statistics described above, along with other research, show that Nunavut households are often violent and threatening places for adults and children to live. Statistics Canada keeps track of rates of family violence nationwide, with family violence defined as violence committed by spouses (legally married, separated, divorced, or common-law partners), parents, children, siblings, and extended family. The rate of police-reported family violence in Nunavut is higher than in any other province or territory,⁶² as is the rate of family violence against children and youth 0 to 17 years old.⁶³

In the following paragraphs, NTI uses what is known today about early childhood development to reflect on this information, and to show how stress from household and other forms of abuse can impact the healthy development of children. Without intervention, negative experiences in the early years of a child's life can translate into negative and unhealthy behaviours later in life, behaviours that can in turn negatively impact future generations. Understanding how this cycle works is critical to breaking it.

Effects of stress, violence and trauma on individuals and society

“The kids are exposed to violence. It happened to my kids when they were young, and it has had some influence, especially on my boy. The girls don’t seem to have been bothered that much, but my boy...I don’t know what it is. I try to understand him. I think he has anger. When someone bothers him, he lets his anger out easily. I see it in other kids, where the parents just keep fighting. That’s where it hurts the most...the children are caught. When they see anger between their parents, they get afraid and confused.”⁶⁴

“Geela,” Pangnirtung, Nunavut

NTI has used past reports to advocate for increased research and investment in programs and services that support early childhood development. NTI has shown that investing in programs and services that help create safe, healthy learning environments in the early years can have positive effects on the health and well-being of children that carry throughout their lives and into the lives of future generations. In the following paragraphs, several early childhood development concepts are introduced to provide a more thorough explanation of how lifelong health and well-being can be negatively influenced by early childhood experiences, especially stress, violence, and trauma. By doing so, NTI shows how adult and child health issues are connected and puts these concepts into the context of the IHS statistics described above.

When children witness or are the victims of violence or sexual abuse, they can experience a form of heightened or chronic stress that can make healthy development difficult. In the early years of a child’s life, the brain undergoes its most rapid development. The architecture of a child’s brain is still forming during this sensitive period. During this time, the healthy emotional and cognitive development of a child is shaped by responsive, dependable interactions with adults. When children experience heightened or chronic forms of stress in an environment that lacks responsive, dependable interactions with adults, normal brain development can be interrupted.⁶⁵ Three child development concepts are especially useful for understanding how this happens and are described below.

Chronic stress due to fear and anxiety can affect brain development in children: In the absence of a supportive adult, a child who experiences chronic or extreme adversity in the form of household violence or sexual abuse, for example, may experience a heightened form of stress called toxic stress. Toxic stress occurs when the body’s stress response system is activated

strongly for a prolonged period of time in response to stressful, uncontrollable events. Prolonged activation of the body’s stress response system can impact the formation of the brain’s architecture.⁶⁶ This is due to the over-activation of the hormone systems in the body that are responsible for helping us cope with stress. In large doses, the chemicals these hormone systems produce can harm the brain to such an extent that the part of the brain used for learning, memory, and controlling emotions can be impaired.⁶⁷ Toxic stress differs from the tolerable or positive forms of stress that many of us experience in our daily lives because these forms of stress are generally milder and occur for briefer periods of time, allowing us to recover. Children who experience toxic stress in response to prolonged fear and anxiety are thus at risk of experiencing a diminished ability to learn and engage in normal social interactions across the lifespan.⁶⁸

Stress can negatively impact the air traffic control system of the brain: The areas of the brain we use to control our impulses, hold onto and work with information, focus thinking, filter distractions, and switch gears have been likened to an “air traffic control system,” with dozens of flights arriving and departing at the same time.⁶⁹ These brain functions are known by scientists as executive function and self-regulation which begin developing in infancy, reaching maturity during young adulthood. We depend on executive function and self-regulation for strong working memory, cognitive self-control, and attention skills. These abilities are key to school readiness because they enable students to acquire knowledge and to participate in the school experience as actively engaged and competent learners.⁷⁰ Executive function and self-regulation are also important for social interactions, because we use these brain functions to stay focused, follow directions and resist the urge to respond impulsively.

Children develop in an environment of relationships, and the nature of these relationships shapes the development of executive function and self-regulation skills. Children are not born with these skills; they are shaped with guidance from adults through activities that gradually promote independence in safe, structured environments. However, the development of these executive function and self-regulation skills can be hampered in highly threatening or stressful environments. Toxic stress brought on by household violence, fear of violence, or sexual abuse, for example, can delay the development of or impair the neurons in the brain that we use when we try to keep information in working memory, inhibit a habitual action, or address problems in a flexible manner.⁷¹ When children experience severe stress for sustained periods of time, it makes it difficult for them to engage the executive functions needed to succeed, even in nonthreatening environments such as school. Thus, when executive function and self-regulation skills are developed successfully, individuals and societies are more likely to benefit. These benefits can include a better-educated population, more stable commu-



nities, reductions in crime, and a healthier population more capable of making positive choices about nutrition, exercise, and lifestyle choices.⁷² Fortunately, executive function and self-regulation can be enhanced in both children and adults through training and practice.

Maternal depression can undermine the development of young children: Maternal depression disproportionately affects low-income families, and mothers experiencing depression are often young, economically and educationally disadvantaged, and burdened by family conflict and a stressful life.⁷³ Depressed women produce higher levels of stress chemicals during pregnancy. These stress chemicals can affect the fetus similarly to the way toxic stress affects young children, such that an infant of a chronically depressed mother may have sustained effects on his or her stress response and immune system that make the child more vulnerable once he or she is born. Untreated depression can also lead to more hostile or withdrawn parenting during the most sensitive period of a child's development when stimulation and engagement are needed to strengthen brain circuitry.⁷⁴ These factors can combine to affect the development of executive function and self-regulation skills in young children, increasing the risk of children experiencing lifelong hardship.

Tying it all together: Early childhood development and adult health

Jack P. Shonkoff, M.D., is the director of the Center on the Developing Child at Harvard University and chairs the National Scientific Council on the Developing Child (US). The Center generates, translates, and applies knowledge in the service of improving life outcomes for children in the US and throughout the world that includes using scientific knowledge to inform child development policy and practice. In an interview for this report, NTI shared IHS statistics with Shonkoff that are relevant to his field of study. Shonkoff shared information from the frontiers of his field about the need for a two-generation focus in order to meet the needs of young children and their adult caregivers.

Shonkoff explained that it is important for those concerned about adult health to understand the science of early childhood development because “the origins of serious disparities in health outcomes and in educational achievement and in behaviour—the origins of those adult problems start very early.”⁷⁵ The science of early childhood development is useful because it provides a level of insight into how child development takes place, explains Shonkoff, and this insight can be used to develop innovative solutions for children and families facing adversity:

To have more information that just tells us that if you're very disadvantaged, you're going to have more risk for health problems doesn't really help. That's not new. But what's new about the science, and what's new about the early childhood piece of it is it's helping us understand how that happens. It's helping us look inside the body physiologically and understand how adversity can actually lead to disease and how it can lead to problems in learning. So, from my perspective, the reason this is so important is not just to make people more aware of focusing on young children, but [to] basically give us ideas about new strategies, new things we could do. And that's to me the most important thing, rather than [to] just keep documenting the problems.⁷⁶

NTI asked Shonkoff about areas in which investments in early childhood development are being made globally. Shonkoff stressed that cultural context matters for communities developing programs but that the ways early experiences shape brain development are biologically the same:

Cultural context matters a lot, in terms of the values behind the practices that guide the way people raise their kids. But there's also a common biology that is independent of culture that has to do with the way experience shapes brain circuits. I would say [that] what's common across the board is a growing understanding of the importance of early experience and a growing interest in providing some combination of rich learning experiences for children and education and support for their parents—parenting education and support for their families. That is actually a growing movement around the world. What that actually looks like will vary depending on culture.⁷⁷

During our discussion, Shonkoff also stressed that the quality of programs matters in order to build a strong foundation for positive lifelong outcomes in the early years: “It's not true that doing *anything* is going to make a big difference. The quality really matters. Partly, the quality is tied to what the needs are of the children and families.” In addition to quality, Shonkoff introduced the idea that a focus on children is not enough to prevent challenges later in life, and that a focus on adult needs is equally important:

There has to be a two-generation strategy...Prevention is so much more important than trying to fix things later. We know that the best prevention strategy is conceptually very simple—though it may be hard to implement. It's providing children with an environment that feels safe and predictable and that provides good opportunities for learning and developing skills and competencies. The protection piece is

critical because of all of the threats. But the only way to help kids when they're young is to build the capacities of the adults who are taking care of them. So, even if your interest is in the children...and not in adults, you can't help the children unless you meet the needs of the adults.⁷⁸

This two-generation approach, focusing on meeting the needs of children and their adult caregivers, must reach beyond what has traditionally been a focus on teaching parenting skills to include the basic, personal needs of parents. According to Shonkoff,

You can't parent if your own basic, personal needs aren't being met, regardless of how much money you have. So what really needs to happen in the field, I think, is to start to put more of our early childhood energies into meeting the needs of adults, who are the key caregivers for young children. It means meeting their need for sound mental health, for safety for themselves, for economic security, for having a future in terms of being able to build their own capacities.⁷⁹

The science of early childhood development sheds light on the interconnected challenges facing Inuit. These connections are between experiences in the early years of a child's life, the environments in which children grow up, and the lifelong outcomes that can result from these experiences and impact future gener-

ations. The science of early childhood development continues to evolve, but what is clear is that addressing issues that place stress on the adult caregivers of children, such as crowded housing, scarce employment, food insecurity, and poverty, is an equally if not more important step toward ending the cycle of intergenerational stress and trauma that many of our young people face.

Implementing a continuum of mental health services is an integral feature of this holistic approach to improving the health and well-being of our society. It is known from research and past experience that services that focus on prevention and intervention alone are not sufficient to meet the health needs of people who need a continuum of care, particularly when it comes to mental health. People who have experienced trauma such as domestic violence or sexual assault, for example, are at greater risk for suffering from psychiatric disorders or post-traumatic stress and often require a continuum of mental health services in order to recover and heal psychologically. A continuum of mental health services focuses on early diagnosis of mental health needs and may include clinical counselling and community-based healing; it is a well-integrated network of mental health services that prevents people from slipping through the cracks by filling gaps in services.

Looking at our health challenges in this way is a reminder that cooperative relationships are needed between Inuit organiza-



Community research assistant Oleepika Ikkidluak of Iqaluit interprets for Mayor Uriash Puqiqnak of Gjoa Haven during a shipboard visit.



tions and government that help foster innovative solutions that take the whole picture of Inuit health status into consideration. It is encouraging that, in recent years, these cooperative relationships have taken shape in the areas of suicide prevention and poverty reduction. NTI and the GN worked together on *The Makimaniq Plan* poverty reduction strategy as well as the *Nunavut Suicide Prevention Strategy* and *Nunavut Suicide Prevention Action Plan*. These documents recognize the links between challenges such as mental health services, suicide prevention, and poverty, and are promising indicators that there is a growing understanding of the ways mental, physical, and spiritual health are tied together, and effect the bigger picture of peoples' social, cultural, and economic status.

Conclusion to Part 1: Policy implications and moving forward

"The only way to really make a big difference for the kids is to make a big difference for the adults. If we don't make a big difference for the adults, we're not going to make a big difference for the kids."⁸⁰

Dr. Jack Shonkoff, Harvard University Center for the Developing Child

In Part 1, NTI highlighted what is perceived as the most urgent aspects of the IHS findings and placed these findings within the larger historical, social, and political contexts in which they exist. By doing so, readers are reminded of the historical and political backdrop for today's challenges and show that it isn't by chance that Inuit experience tremendous inequity compared with non-Aboriginal Canadians. Placed in this context, a different path is possible, one in which the human rights to food security, adequate housing, and quality education are met, and where the benefits associated with a two-generational approach to investing in children and adult health and well-being is understood and used to inform policy.

In summary, NTI briefly reiterates the key takeaways from the IHS below:

Food security and the nutrition transition jeopardize Inuit health. The IHS provides us with valuable information about the nutrition transition underway in Nunavut, showing that people are consuming less country foods and more store-bought foods than in the past. This is concerning because the store-bought foods people are eating tend to be less nutritious than country foods. Inuit are becoming heavier than in the past and have a

higher risk for developing type 2 diabetes and other diet related health diseases. People also said that store-bought foods tend to cost more than country foods, and this too is a concern in light of the intense financial strain that many families face.

The presence of environmental contaminants in country foods and the effects of climate change on country food harvesting are global pressures whose future effects on food security are difficult to foresee. Thankfully, blood work carried out as part of the IHS shows that with the exception of mercury levels in ringed seal liver, there do not appear to be immediate health risks for people consuming country foods.

Poverty, employment and education are connected. In our 2009/10 and 2010/11 *Annual Reports on the State of Inuit Culture and Society*, NTI stressed that employment and economic security will remain out of reach for too many Inuit without a strong education system. NTI described the policy changes needed to improve the existing education system. NTI would again like to restate our commitment to working in cooperation with the GN and other stakeholders to accomplish this shared goal.

Because the majority of Inuit leave high school before graduating, many adults lack employment and economic security, making it difficult for people to meet their own basic needs such as food security and adequate housing. Mental health issues, addictions, and household violence increase the stress these barriers place on people and their families and contribute to stressful or traumatic living environments for children.

Mental health can be improved and household violence, sexual assault, and child sexual abuse reduced through policies that focus on prevention. The responses of IHS participants to questions about their mental health show that a large number of people are suffering from severe depression and thoughts of suicide. NTI acknowledges that the GN is working hard to strengthen existing mental health services and cope with household violence, sexual assault, and child sexual abuse, but a long-term strategy is necessary.

Our theory of change in these areas is that mental health problems, violence, and sexual abuse recur in cycles from one generation to the next. These cycles must be broken through a focus on meeting the basic needs of adults so that they can meet the developmental needs of children in safe and predictable environments. These basic needs encompass the areas described above. In addition, using the science of early child development to inform early childhood education programs and services is needed to ensure that all children have access to safe learning environments.

Part 2:

INUIT SELF-DETERMINATION OVER RESEARCH

The second half of this report focuses on the process by which the IHS was carried out. It draws on conversations with researchers involved in the IHS to identify aspects of the research process that were successful, as well as aspects that could be improved in future research. This section also describes expectations for researchers and research institutions working with Inuit and Inuit communities in Nunavut and in doing so hopes to support a shift in the way Inuit have traditionally participated in the research process. This shift must entail Inuit participation and decision-making at every step of the research process and greater accountability by research institutions for the ethical conduct of research in Inuit communities. Encouragingly, this shift in the balance of power is already happening in many other Aboriginal communities and is quickly becoming the norm rather than the exception to Aboriginal Peoples' involvement in research.

Progress was made in the last decade with regard to the ways researchers and research institutions engage Inuit communities and organizations in research, but there are opportunities for continued improvement. The solutions put forward in this section about what is needed for improvement are not intended to devalue the role research, researchers, and research institutions have had and are playing in Nunavut. Research has the power to educate individuals and communities, as well as to inform policy-makers who make decisions that impact the lives of Inuit. NTI also recognizes that Inuit are far more likely to experience the positive effects of research if Inuit and communities are actively involved in decision-making about what is researched, the research process, and how information about Inuit and communities is used. Inuit involvement in research will help make research findings more useful to communities and policy-makers, translating more directly into positive impacts on the health and well-being of Inuit communities.



Community research assistant Oleepika Ikkiduak organizes participants in Kugluktuk, Nunavut.



A note on the legacy of research and researchers in Nunavut

Too often, relationships between researchers and Indigenous Peoples and communities are characterized by power imbalances. The nature of these power imbalances is such that non-Inuit researchers and research institutions have disproportionately benefited from research about Inuit and communities, with little to show in the way of improvements in the health and well-being of the population studied. Inuit are among the most studied people on earth, with nearly every facet of our lives having been documented and dissected by non-Inuit researchers. From traditional child rearing practices to sexual behaviour to country food harvesting, the study of our people has evolved into a source of professional and financial support for many non-Inuit researchers and research institutions.

Inuit communities are often in a vulnerable position when they engage with researchers and research institutions for several reasons. Most obviously, research projects in Nunavut are framed and then carried out almost exclusively by visiting non-Inuit who use their own cultural lens to interpret and reframe information extracted from Inuit communities. Yet at the same time, Inuit communities often need research that can inform policies that support positive change.

Because the majority of Inuit leave high school before graduating, few local people are equipped with the skills or resources needed to carry out research. Thus, many Inuit are seen as being unable to participate in the development of outside research proposals, supervise the implementation of research projects or help ensure that researchers meet their ethical responsibilities to individuals and communities. Consequently, Inuit recognize that research can help improve health, yet too often find themselves in a vulnerable position that can take away from the potentially positive impacts of research.

Part 2 of this report describes these and related concerns within the context of the IHS process and outlines NTI's expectations for researchers and research institutions going forward.

The IHS: What worked?

In the following paragraphs, IHS successes and shortcomings are highlighted. By doing so, NTI aims to show how research can better serve Inuit communities.

From a planning and implementation perspective, the IHS was largely successful. The Nunavut Steering Committee consisted of NTI, the GN, NAM, and principal investigators Grace Egeland and Kue Young. The committee worked together to

execute a project of considerable scope and complexity in a short amount of time. NAM consisted of Nunavut community mayors, each of whom acquired their respective hamlet council's consent for the IHS to take place in their communities after being presented with project details by Egeland and Young in Feb. 2007. By June 2007, the project received a research license from the Nunavut Research Institute, after having met McGill University's ethics approval, and a series of community-university agreements with McGill were signed with each hamlet.⁸¹

From a data-gathering standpoint, the Nunavut portion of the IHS was a success. The IHS provides a tremendous amount of information that, pieced together, tells part of the complex story of the health status of Nunavut Inuit. These data have great potential to inform our understanding of health challenges, as well as to inform public health policy and practice in Nunavut. In some cases this is already happening. GN Chief Medical Officer Geraldine Osborne told us about how IHS data about food security led to the establishment of the Nunavut Food Security Coalition in June 2012, as part of *The Makimaniq Plan* for poverty reduction. She also related how information about levels of overweight and obesity is being used to develop policy around chronic disease prevention.⁸²

The development of the Nutaqqavut Health Information System is another example of IHS data being put to good use. Data from the IHS and the companion Nunavut Inuit Child Health Survey contributed to the development of the GN's Nutaqqavut Health Information System. Nutaqqavut is an electronic database that centralizes maternal and child health care data from prenatal to preschool across the territory, enabling health care providers to better understand the determinants of health for infants and children. Laura Arbour, a professor in the Department of Medical Genetics at the University of British Columbia and an affiliate associate professor in the Division of Medical Sciences at the University of Victoria, worked with the GN chief medical officer to help develop Nutaqqavut. Nutaqqavut is the culmination of an intensive development effort based on inclusivity and a participatory process. Interviewed for this report, Arbour describes the ways IHS data contributed to the development of Nutaqqavut:

In order for...us to really understand what would be important for the Nutaqqavut Health Information System, the Inuit Health Survey was crucial in that. For instance, we would have never thought of asking what the height and weight of the father was, until we understood that obesity was a problem in young Inuit children. What we do know is that both parents' height and weight is important, not just the mother's, so that information is being asked in the health information system.⁸³

Arbour went on to describe some of the beneficial ways that IHS data are contributing to a more holistic understanding of Inuit health status. Being able to understand the relationships between multiple factors impacting health contributes to this more holistic understanding. Arbour's research focuses on folic acid intake among pregnant and nursing mothers. Folic acid is a natural nutrient that comes from plant foods, like broccoli, spinach, and seaweed, and helps prevent certain birth defects. Arbour explained to us that having information from the IHS about smoking and food security in mothers enhanced her understanding of folic acid intake:

Women who had been smoking for a longer period of time had lower red blood cell folate. Smoking interferes with the way folate is absorbed and that's another important health promotion bit of information...And also, women who have food insecurity—that means that they're really not able to afford food every day of the week or every day of the month—those women also have a lower level. So again it flagged for us the importance of really focusing on food security as an important way, of course, [of] just understanding the basic nutrients that are important for pregnant women.⁸⁴

Nutaqqavut is a commendable example of how research can be successfully used to develop policy solutions, and Arbour's ongoing research shows the potential for the same. Unfortunately there is some uncertainty about the future of Nutaqqavut.

Related to data, the publication of IHS summary reports successfully organized and presented the wide array of IHS data in a way that is easy to grasp. These reports include the Inuit Health Survey, the Nunavut Community and Personal Wellness Survey, and Contaminant Assessment in Nunavut, published in May 2010, June 2012, and August 2011 respectively.

The IHS: What could be improved?

Despite more than a dozen drafts, a memorandum of understanding (MOU) outlining the expectations, decision-making process, and responsibilities of each steering committee member was not signed. The lack of a signed MOU contributed to confusion about the responsibilities of steering committee members and a lack of transparency about how IHS data would be used. MOUs are valuable tools for clarifying the decision-making process among research project partners, as well as the roles and responsibilities of partners. The lack of a signed MOU clarifying expectations for steering committee members created an accountability vacuum and contributed to some of the oversights described in greater detail below.

A signed MOU would have supported a more transparent and cooperative research review process between academic institutions and NTI. For example, language within the most recent draft MOU clearly spells out the steering committee decision-making process with regard to the dissemination of research papers and presentations, requiring that steering committee members grant prior approval for the dissemination of publications and presentations. Consultation on matters relating to the dissemination of research is a bare minimum standard for the ethical conduct of research in Aboriginal communities. Instead, the lack of a clear research review protocol guided by an MOU contributed to a lack of transparency and consistency when it came to NTI review and approval of publications and presentations on IHS findings.

The departure of NAM midway through the IHS had a negative impact on its outcome. The resignation of NAM's chief executive officer in 2008 created a leadership vacuum that was not filled. As the steering committee member responsible for coordinating community logistics, NAM was unofficially expected to contribute to the research team's communications strategy following the completion of the IHS.⁸⁵ In a move indicative of poor research practice, planning for a communications strategy began to take shape in 2008 long after the IHS research had begun. NAM's departure from the steering committee contributed to the lack of clarity about steering committee responsibilities and a communications strategy was never finalized.

The manner in which IHS data were interpreted, managed, and disseminated to communities could have been improved. Dissemination is the process by which research results are communicated to research participants. It is generally at this stage that communities directly benefit from their participation in research. MOUs typically discuss roles and responsibilities related to research dissemination, such as the prior approval by all research project partners of any research papers or presentations being considered for publications. Research results are most commonly disseminated through written publications, often in the form of plain-language reports accessible to all citizens, in addition to peer-reviewed academic journal articles. It is becoming increasingly common for researchers who have carried out research in Aboriginal communities to return to the affected communities in order to present their findings and answer questions from community members.

The three IHS summary reports mentioned above and a series of academic papers constitute the extent to which IHS findings were disseminated to Nunavut citizens. NTI's concerns about the manner in which data ownership, access and dissemination were handled are listed below:



- IHS data were in the sole possession of the IHS steering committee's academic partners at McGill's Centre for Indigenous Peoples' Nutrition and Environment. McGill's centre had exclusive access and control over the use of IHS data until sharing them with GN Chief Medical Officer Geraldine Osborne in Aug. 2012. NTI does not yet have access to IHS data.
- The McGill Centre independently determined how IHS data would be used without consulting the IHS steering committee and was thus solely positioned to disseminate results.
- As of Aug. 2012, IHS principal investigators and more than a dozen researchers and students have used IHS data to publish 13 research papers in seven peer-reviewed academic journals and did not consistently consult steering committee members. Steering committee members did not always have an opportunity to review or provide input prior to the submission of manuscripts for publication, sometimes learning of them only after publication. A request by NTI for a complete list of all individuals, including students, working with IHS data went unheeded.
- Nunavut communities and IHS participants did not have a chance to engage directly with researchers about the meaning of either their individual results or the IHS as a whole because findings were not presented to communities by researchers.

Researchers affiliated with the IHS have indicated that they are aware of some of these concerns. IHS Principal Investigator Kue Young framed community-level dissemination as the responsibility of NTI, NAM, and the GN:

One thing we haven't done is gone back to each community, which I think it's really beyond our capacity to go back to each community, to report back. So we're relying on our partners to do that. But at least in (Inuvialuit Settlement Region) we were able to have a couple of meetings in Inuvik where we brought in people from the communities to actually listen to the report but that was because they're much smaller number of communities.⁸⁶

McGill's Helga Saudny expressed a similar viewpoint:

I think there were promises made [about dissemination]—I don't know by whom—and I think that communities expected the (principal investigators) or the research team to go back to communities and present the results. And I think that would have been ideal. However, the logistics and the expense—it's a question of funding...I know communities like it when they get the researcher back into the commu-

nity...I think this was a criticism that was levelled against a survey. Because a booklet arrives and is shelved somewhere. This is something that in the future, it is something that has to be discussed with the researchers: 'how are you bringing results back?'⁸⁷

Tracey Galloway, an assistant professor of anthropology at the University of Manitoba, co-authored the *Nunavut Community and Personal Wellness Summary Report* with Saudny. Asked what improvements she would make to a future IHS survey, Galloway identified the need for researchers to bring information back to communities:

One suggestion I might have is that, those of us who want to be involved in something in the future go back and present, again, what we found, because I think it's worth telling the story more than once and let people ask questions. We can actually use that as a form of data collection, too; let people have an opportunity to voice their impression of the results, and then let that information shape what we do next.⁸⁸

Galloway, whose research focuses on child obesity, explains how community feedback can put survey information into context. Galloway organized a focus group in Iqaluit to discuss the extraordinary overweight/obesity statistics from the Inuit Child Health Survey. Elders, Qikiqtani Inuit Association, and community health representatives participated. "[Participants] did not feel that obesity rates were that high among children, that these numbers may be misrepresenting actual obesity and health risk in these kids. So I do think we have a problem with our tools," Galloway said, referring to the North American child references that were used as a standard measure for height and weight. The same may be true for rates of overweight and obesity reported by the IHS:

For the adult data, what we found is that in terms of height, Inuit adults are still a shorter population than the American references that we use to assess them and that is probably affecting our...we are probably overestimating obesity rates in adults again because of poor tools.⁸⁹

Issues of data ownership, possession, and dissemination may have been avoided if a signed MOU was in place outlining the responsibilities of steering committee partners at each step of this project. However, even without an MOU in place, these ethical oversights are disappointing given national guidelines put in place to protect Aboriginal communities from unethical research practices.

The Government of Canada's three research agencies—the Canadian Institutes of Health Research, the Natural Sciences and Engineering Research Council of Canada, and the Social Sciences and Humanities Research Council of Canada collaborated to publish a national policy for ethical conduct of research involving humans: the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. The purpose of this policy is to “promote research that is conducted according to the highest ethical standards.”⁹⁰ The policy discusses ethical research practices in Aboriginal communities and includes a section about the interpretation and dissemination of research results. This section provides two guidelines that are relevant to this discussion:

- Researchers should afford community representatives engaged in collaborative research an opportunity to participate in the interpretation of the data and the review of research findings before the completion of the final report and before finalizing all relevant publications resulting from the research.
- Researchers and communities should clarify the extent to which research findings will require translation, plain language summaries, or oral presentations to community members, in order to make the research findings accessible to the community.

The Ownership, Control, Access and Possession (OCAP) principles also show that a higher standard exists for the ethical conduct of research than was used by the IHS's academic research team. The OCAP principles were originally developed in 1998 during the inception of the *First Nations and Inuit Regional Health Survey* (RHS).⁹¹ Incidentally, IHS Principal Investigator Kue Young acted as principal writer for that RHS, the project that is the basis for the OCAP principles in question.⁹²

The OCAP principles establish a precedent for research and researchers carrying out work in Aboriginal communities, affirming “the right of First Nations to exercise their voice and control over research, as well as make decisions on research that affects their communities.”⁹³ The OCAP principles are listed below in detail:⁹⁴

- **Ownership:** Refers to the relationship of a First Nations community to its cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns their personal information. It is distinct from stewardship [or possession].
- **Control:** The principle of control asserts that First Nations Peoples, their communities, and representative bodies are within their rights in seeking to control all aspects of re-

search and information management processes which impact them. First Nations control of research can include all stages of a particular research project—from conception to completion. The principle extends to the control of resources and review processes, the formulation of conceptual frameworks, data management, and so on.

- **Access:** First Nations people must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.
- **Possession:** While ownership identifies the relationship between a people and their data in principle, possession or stewardship is more literal. Although not a condition of ownership per se, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party are in the possession of another, there is a risk of breach or misuse. This is particularly important when trust is lacking between the owner and possessor.

The methods and avenues to assert the OCAP principles are left to individual First Nations, and communities are encouraged to develop community codes of research ethics and related processes. Put in the context of the *Tri-Council Policy Statement* and OCAP, it is clear that the IHS steering committee's academic partners fell short of meeting what are now entrenched, national standards for the ethical conduct of research in Aboriginal communities. These shortcomings are most apparent in the ways our academic partners regulated the access and use of IHS data once they were obtained, as well as the manner in which findings were disseminated to communities.

Alaska Native Tribal Health Consortium: A promising model for research review

Aboriginal communities and organizations are rejecting the power imbalances that have characterized research in Aboriginal communities for so long and developing their own research policies. These policies typically contain measures designed to put Aboriginal communities on an equal footing with researchers and prevent exploitative practices. As the *Tri-Council Policy Statement* and OCAP principles attest, it is no longer acceptable for researchers to be the sole beneficiaries of research through published articles and conference presentations about Aboriginal communities while these same communities are excluded from decision-making about data use and dissemination or lack the opportunity to

engage directly with researchers at each step of the research process. Below, an Aboriginal research policy from Alaska is profiled which reflects innovative ways that Aboriginal communities are asserting their rights to an equitable role in research.

The Alaska Native Tribal Health Consortium based in Anchorage, Alaska, has developed an instructive policy for health research review by tribal health organizations.

This policy is an example of an Aboriginal organization using its gatekeeper status to ensure that community safety and interests are protected in research, not just the safety and interests of the individual participant. In the pages that follow, this policy is examined in detail because it reflects NTH's aspirations for a more rigorous research review process that protects Inuit communities and individuals. A blueprint is provided for this research review process as a first step toward strengthening research review and collaboration.

The consortium manages statewide health services for Alaska Native Peoples. The consortium is made up of tribal and non-profit organizations that administer health services in Alaska's different cultural regions, with tertiary care provided in Anchorage (Alaska's largest city) by the Alaska Native Medical Center.

Each regional health provider has its own tribal review process for research proposals that apply to that region. For example,

the Yukon-Kuskokwim Health Corporation oversees the delivery of health care in the southwest region of Alaska and is responsible for reviewing research proposals for that region. Research must also be reviewed and approved by Alaska's statewide Institutional Review Board (the equivalent of a Research Ethics Board in Canada). Features of the different research review processes are listed below for clarity, followed by discussion:

- Researchers must obtain at least two and sometimes three levels of approval at the statewide, regional, and community levels in order to conduct research involving Alaska Native Peoples. This review process happens in the following order:

1) Statewide review and approval of research proposals must be obtained from the statewide Alaska Area Institutional Review Board (AAIRB).

2) If a proposal is approved by the AAIRB, it is directed to the appropriate tribal health organization with jurisdiction over the affected region for a second layer of review.

3) If approved by the appropriate tribal health organization, research proposals may then be reviewed by a community's tribal government, which may choose not to participate.



Community research assistant Bernice Aggarak conducts a household interview during the Inuit Health Survey.

- The Alaska Area Impact Review Board is administered through the Indian Health Service and helps ensure the protection of individual safety and rights in research. The regional-level tribal health organization and community-level tribal government review processes help ensure the protection of Alaska Native community safety and rights in research.
- Research projects reviewed and approved by the Alaska Area Impact Review Board cannot go forward without approval from the appropriate regional tribal health organization. Even after regional approval is obtained, individual communities may decide not to participate.
- When tribal health organizations approve a research project, they communicate their expectations for the review and approval of research manuscripts and/or conference abstracts prior to a manuscript or abstract being submitted for publication or conference presentation. Although not bound by a formal MOU, researchers wishing to conduct future research have an incentive to remain in good standing with tribal health organizations and tribal governments.

In order to understand the motivation behind the consortium's policy and its intended effects, Kathryn Koller, a research nurse supervisor at the consortium was interviewed. Koller explained how these steps protect community interests, and their importance for empowering communities in the research process:

Years ago, an (impact review board) alone could approve a study and there was no tribal oversight or required contact before investigators showed up to conduct the research... a group of researchers could just appear in a small village without warning—the village councils are very active and want to know who's coming in and out... They want to have some sort of control over outside activities taking place in their own communities. So now there's at least a process that, "Yes, we know about this research, this sounds like a great idea," or "This might not be the best time to do this type of research, maybe later, maybe we could do something different"—an opportunity to talk directly with the [Principal Investigator] and make changes. It opens up the opportunity for community-based say. Just because something is deemed by an (impact review board) as—it meets all the requirements for the safety of individuals, doesn't mean that it's a done deal. It means that now it goes to tribal leaders and they have the final say. So they hold the trump card. And that's empowering.⁹⁵

In the next section, NTI's ambitions and expectations for research and researchers in Nunavut are discussed.

NTI's expectations for researchers and research institutions in Nunavut

NTI recognizes that until more Inuit acquire the education and skills needed to carry out research by and for our own communities, researchers from outside Nunavut are needed to conduct research in Inuit communities. Given this reality, clear guidance from Inuit organizations such as NTI is necessary to help foster collaborative research practices that are based on equal partnerships. In order to help ensure the protection of Inuit and communities, partnerships must be premised on modern policies and principles for ethical research in Aboriginal communities. As the primary Inuit advocacy organization in Nunavut, NTI is concerned with protecting the individual and community interests of Inuit in research. NTI sees the following as being necessary in order to achieve this:

NTI expects to be an equal partner in research. NTI is commonly treated as a gatekeeper with a role limited to providing researchers and research institutions with the access needed to carry out research in Inuit communities. NTI expects to be an equal partner in research from the time NTI screens research license applications and provides feedback to researchers, to decision-making about dissemination of findings, manuscript publication, and conference presentations.

NTI has partnered with upstanding researchers and scholars on past projects. Research has a greater chance of positively affecting our communities when power is shared between researchers and communities. When this happens, those involved have a personal stake in the research outcomes and in the policy changes that can result from these outcomes. Having this kind of buy-in is important because it ensures that there will not be a communication gap between researchers and research and policy-makers who have the power to affect programs and services that contribute to people's health and well-being.

Former NTI employee Laakkuluk Williamson Bathory explained this gap in clear terms, "I think that the problem for research and policy, in general, is that researchers don't know how to speak to policy-makers and policy-makers don't know necessarily how to pick up a research paper and interpret it."⁹⁶

This gap can be filled when community members play a strong role in shaping and helping carry out research and when Inuit organizations and government have an intimate understanding of the purpose of research and are in conversation with each other about it. When good research informs the development of policy that is responsive to people's needs, our entire society benefits.



NTI expects researchers and research institutions to follow national guidelines and principles for ethical research in Aboriginal communities. Specifically, NTI expects researchers and research institutions to abide by the *Tri-Council Policy Statement's* framework for the ethical conduct of research in Aboriginal communities, as well as the Regional Health Survey OCAP principles.

The *Tri-Council Policy Statement* and OCAP principles are clear national standards that set the foundation for NTI's engagement with researchers and research institutions. In order to provide an overview of these guidelines, key articles and themes are presented in Figure 2.

Figure 2. *Tri-Council Policy Statement*⁹⁷ and OCAP principles⁹⁸: Core themes

<p><i>Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans</i></p> <p>Purpose: "to ensure, to the extent possible, that research involving Aboriginal peoples is premised on respectful relationships. It also encourages collaboration and engagement between researchers and participants."</p>		
(9.1) In cases where the welfare of an Aboriginal community may be affected, researchers shall seek engagement with the relevant community.	(9.4) For the purposes of community engagement and collaboration in research undertakings, researchers and Research Ethics Boards shall recognize Aboriginal organizations...as communities.	(9.11) Where a community has formally engaged with a researcher or research team through a designated representative, the terms and undertakings of both the researcher and the community should be set out in a research agreement before participants are recruited.
(9.12) Researchers and communities should consider applying a collaborative and participatory approach as appropriate to the nature of the research, and the level of ongoing engagement desired by the community.	(9.13) Where possible, research should be relevant to community needs and priorities while benefiting the participating community (e.g., training, local hiring, recognition of contributors, return of results).	(9.14) Supports capacity building through enhancement of the skills of community personnel in research methods, project management, and ethical review and oversight.
(9.15) Researchers should engage the community in identifying Elders or other recognized knowledge holders to participate in the design and execution of research, and the interpretation of findings in the context of cultural norms and traditional knowledge.	(9.17) Researchers should afford community representatives engaged in collaborative research an opportunity to participate in the interpretation of the data and the review of research findings before the completion of the final report, and before finalizing all relevant publications resulting from the research.	(9.18) The assignment of rights, or the grant of licenses and interests in material that may flow from the research, should be specified in a research agreement (as appropriate) before the research is conducted.
<p><i>OCAP: Ownership, Control, Access and Possession</i></p> <p>Purpose: "a comprehensive framework developed by First Nations to bring self-determination into the realm of research and information management."</p>		
Applies to all research, data or information initiatives that involve First Nations, and encompasses all aspects of research (including funding and review), monitoring, statistics, cultural knowledge and so on.	A community or group owns information collectively in the same way that an individual owns their personal information. It is distinct from stewardship [or possession].	First Nations Peoples, their communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes that impact them.
First Nations communities and organizations have the right to manage and make decisions regarding access to their collective information.	In addition to ownership, First Nations communities and organizations have the right to possess collective information about them.	OCAP stands to benefit governments, researchers, First Nations Peoples and their communities, as well as researchers and information management practices.

These documents are empowering for NTI and other Aboriginal organizations because they assert that Aboriginal communities benefit from research when they are on an equal footing with researchers.

NTI expects researchers and research institutions to work with NTI to craft MOUs or partnership agreements. MOUs or partnership agreements are essential tools for establishing shared expectations and responsibilities between parties and for protecting the interests of individuals and communities. Too often, NTI has negotiated MOUs and/or partnership agreements with researchers and research institutions while research is in progress or after it has concluded. This contributes to confusion over expectations, inconsistent research practices, and a general lack of transparency. MOUs and partnership agreements are tools used to clarify expectations and responsibilities with researchers and research institutions prior to any research moving forward and to ensure that research practices are consistent with national standards for the ethical conduct of research in Aboriginal communities.

NTI expects to play a stronger role in the screening and licensing of research project proposals submitted to the Nunavut Research Institute (NRI). It is not possible to conduct social sciences or health research in Nunavut without a research license issued by the NRI. NRI is responsible for coordinating the screening process for research license applications under the 1988 *Scientists Act* consolidated from the NT. Submitted applications are circulated for screening and comment to the appropriate communities, organizations, and agencies affected by the proposed research. These screeners may include representatives from the municipal councils, hunters and trappers organizations, land claims organizations, Inuit associations, territorial government departments, institutions of public government, district education authorities, as well as other groups who may have an interest in the proposed research.

NTI is involved with screening the majority of research license applications submitted to NRI that deal with social sciences and health research but lacks the authority to veto research license applications (NRI is enabled to grant or revoke licenses under the *Scientists Act*).⁹⁹ NTI's lack of self-determination over research in Inuit communities within the current research review process creates a weak foundation for cooperative research, and is at odds with the spirit and intent of the *Tri-Council Policy Statement* and OCAP principles.

In the short term, it is possible for NTI to play an expanded role within the current research review framework if the current criteria for granting research licenses are more narrowly defined and tied closely to feedback provided by application screeners. Doing so could enable screeners to play an expanded role in reviewing research while preserving NRI's license granting authority under the *Scientists Act*.

NRI's current standard for conferring research licenses is lenient, and this presents challenges: research licenses are not granted if a proposed research project is deemed a social or environmental threat. As a consequence, it is exceptionally rare for NRI not to grant a research license.

The current research review process is having the dual effect of inundating Nunavut with researchers while preventing NTI and other Inuit organizations from exercising self-determination over research in communities. For example, many communities do not see a need for more research about food security, but because such research is not considered a social or environmental threat, it is able to proceed.

NTI views Alaska's multilayer review process as a useful model for improving NRI's research license screening process. NTI and Nunavut communities lack the power that Alaska Native communities have in self-determining whether or not research should proceed in their communities. Although NTI provides a form of consultation, NTI relies on NRI to determine for Inuit whether or not a research project is in the best interests of Inuit. NTI views this as old fashioned and believes Inuit self-determination over research can be strengthened through an alternative research review model. What stands out about the consortium's model is that it empowers communities and regional health organizations to use their own criteria for reviewing research, allowing reviewers to serve their communities' unique needs. This guarantees Alaska Native Peoples a strong voice in the entire research process that Inuit lack.



Conclusion to Part 2: The future of Inuit voices in research and policy

As shown in Part 2 of this report, research is a powerful tool that can be used to document Inuit reality, and to educate people who have the power to make decisions about how to improve our reality. It is crucial for Inuit and all Aboriginal Peoples to be involved in research because these decisions can directly impact our peoples' health and well-being. Research can also be used as a tool to educate our people, giving citizens a richer understanding of society and their place in it, as well as new understandings on which to base their life choices.

In the past, the vulnerability of Aboriginal communities made them easy targets for exploitation by researchers who wished to advance their own interests. As the IHS demonstrates, there is still tension between research as an occupation that directly benefits researchers and the need for Inuit to participate in research in order to understand the needs of our communities more completely. The second half of this report has focused on the nature of that participation, showing how Aboriginal communities in North America are being empowered by research policies and guidelines that recognize the value of Aboriginal Peoples as equal partners in research with the authority to self-determine the way in which research is carried out. These policies and guidelines, placed in the context of the IHS and Nunavut's research review process, throw Inuit participation in research in stark relief and call for a paradigm shift.

There is an urgent need to turn a new page in the way in which knowledge about Inuit is produced and used by researchers and research institutions that come to Nunavut. NTI has presented expectations for the ethical conduct of researchers and research institutions working in Inuit communities in this report. NTI is confident these expectations will be conducive to the cooperative relationships needed between NTI and the research community in order for Inuit to experience the full benefits of research with and about Inuit.



Gjoa Haven community research assistant Simon Okpakok.

APPENDIX I

Nunavut Inuit Health Survey highlighted findings

Food security		
70.2 percent of Inuit households overall are food insecure, and 71.4 percent of households with children are food insecure. ¹⁰⁰	By contrast, only nine percent of Canadian households were considered food insecure according to the 2004 <i>Canadian Community Health Survey</i> . ¹⁰¹	Inuit adults see unemployment, low income and high food costs as the biggest contributing factors to food insecurity. ¹⁰²
Inuit account for 78 percent of Nunavut's working-age population, yet on average make up only 64 percent of employed people in the territory. ¹⁰³	Nationwide, the median total income for Canadian families of two or more people is \$69,850, compared to \$62,680 in Nunavut, a difference of more than \$7,000. ¹⁰⁴	The average household expenditure for food in Nunavut is more than three times the average household expenditure for Canada as a whole. ¹⁰⁵
Nutrition and diet		
20 percent of IHS participants said they preferred mainly country food, while the rest preferred a mix of country and store-bought foods. ¹⁰⁶	81 percent of IHS participants said they preferred to eat more country food than they could get. ¹⁰⁷	Between 1999 and 2008, the percentage of energy taken from country foods declined for men and women, with the greatest declines among women. ¹⁰⁸
Consumption of sugar-sweetened drinks, sweets, granulated sugar, chips and pasta increased between 1999 and 2008. ¹⁰⁹	59 percent of Inuit have a body weight relative to height that classifies them as overweight or obese. ¹¹⁰	Today, the rate of diabetes for Inuit is similar to the overall Canadian population across age groups, having increased due to changes in diet. ¹¹¹
Community wellness ¹¹²		
Most people (69 percent) said they thought their community was a very peaceful or moderately peaceful place to live, with more women (7 percent) than men (2 percent) categorizing their community as "very violent".	48 percent of survey participants said they had thought seriously about committing suicide in their lifetime, including 14 percent in the last twelve months.	Women (31 percent) were slightly more likely than men (25 percent) to have attempted suicide in their lifetime, as were those under 50 (34 percent).
41 percent of participants indicated that they had experienced severe sexual abuse during childhood.	18 percent of participants said they had experienced any form of attempted forced sexual activity, with women (27 percent) much more likely than men (5 percent) to have experienced forced or attempted forced sexual activity.	50 percent of participants had experienced at least one form of physical abuse as an adult, with women slightly more likely than men to experience violence.



Notes

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¹³ Tester, McNicoll, and Irniq, "Writing for Our Lives," 24.

¹⁴ Qikiqtani Truth Commission, *QTC Final Report*, 22.

¹⁵ T. Kue Young (Professor of Epidemiology, Dalla Lana School of Public Health), interview by Natan Obed and Timothy H. Argetsinger, August 7, 2012, available from Nunavut Tunngavik, Department of Social and Cultural Development.

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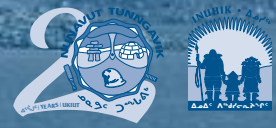
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