

**The Burden of Acute Gastrointestinal Illness  
and Health Research Knowledge Translation in Inuit Communities**

by  
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## **ABSTRACT**

### **THE BURDEN OF ACUTE GASTROINTESTINAL ILLNESS AND HEALTH RESEARCH KNOWLEDGE TRANSLATION IN INUIT COMMUNITIES**

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This thesis research sought to answer two questions: “What is the burden of acute gastrointestinal illness (AGI) for Inuit in Iqaluit, Nunavut?” and “What does the literature tell us about knowledge translation (KT) in Inuit communities in the Circumpolar North?” Data analysis from two population-level surveys in Iqaluit found the Inuit-specific annual incidence of AGI was higher than both national and international annual incidences, but comparable to population-level (Inuit and non-Inuit) assessments in Iqaluit. Variables associated with increased odds of AGI differed from the Iqaluit population-level assessment, highlighting how factors for AGI can differ for sub-populations. Scoping literature review thematic analysis results indicate community engagement, context, and cohesive messaging are necessary for KT. Community engagement in KT is critical; however, more discussion on challenges and opportunities for improvement is necessary. Similarly, formal evaluation of health research KT on its success or failure to elicit its intended action is necessary.

## **DEDICATION**

This thesis is dedicated with loving memory to my friend and teacher

**Isabel MacDonald**

1918-2014

who did not live to see this work completed.

Isabel had a great gift for telling stories. She instilled in me at a very young age the importance of oral knowledge transmission from person to person – from generation to generation. She inspired me to learn through listening, and as such has been the greatest teacher in my life. She lived her entire life caring for and comforting others. With an open heart and open mind, her selflessness and compassion were uncompromising.

Isabel's memory lives within the supporting pillars of who I am today,

and all those who had the pleasure of knowing her.

While she is no longer with us, her stories remain.

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## STATEMENT OF WORK

Ellen McDonald prepared the primary thesis draft and led editing. Drs. Andrew Papadopoulos, Sherilee Harper, Victoria Edge, and James Ford contributed to manuscript editing. The committee provided guidance by contributing to and commenting on the thesis design and throughout the entire research process.

Ellen McDonald, Drs. Papadopoulos, Harper, Edge, Ford, M. Kate Thomas, and the Indigenous Health Adaptation to Climate Change (IHACC) Research Group developed the burden of gastrointestinal illness for Inuit in Iqaluit project. Dr. Harper co-designed the questionnaires with community stakeholders. Ellen McDonald was involved in the collection of data in Iqaluit, Nunavut, and coded all data used in the study. Ellen McDonald analyzed the data and interpreted the results. Drs. Papadopoulos and Harper co-supervised the data analyses and interpretation of results. Authorships on this project included: M. Ellen McDonald, Andrew Papadopoulos, Victoria L. Edge, James Ford, M. Kate Thomas, IHACC Research Team, Sherilee L. Harper.

Ellen McDonald developed the scoping review project and built the study design. Ellen McDonald built the search string, with guidance from a library scientist, and also developed the relevance screening, and data charting forms. Ellen McDonald and Alison Sumner independently reviewed articles captured in the search at the abstract level. Ellen McDonald reviewed articles at the full-text level, and charted relevant articles. Ellen McDonald collated, summarized, and thematically analyzed charted material. Drs. Papadopoulos and Harper co-supervised data analyses and interpretation

of results. Authorships for this chapter included: M. Ellen McDonald, Andrew Papadopoulos, Victoria L. Edge, James Ford, IHACC Research Team, Alison Sumner, Sherilee L. Harper.

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# CHAPTER ONE: INTRODUCTION, LITERATURE REVIEW, & STUDY RATIONALES

## Introduction

Health disparities are associated with social, economic, cultural, and political inequities. Further, the legacy of Indigenous colonial history, including loss of lands and autonomy continues to cause health disparities among this subpopulation.<sup>1</sup> In Canada, the health status of many Indigenous people, including Inuit, is well below that of the rest of Canada.<sup>1,2</sup> For instance, Inuit experience lower life expectancy, higher infant mortality rates, and lower birth weights than their non-Inuit Canadian counterparts at the national, provincial, and territorial level.<sup>2</sup> Suicide is the leading cause of potential years of life lost – with mental health and suicide prevention named the number one health concern for Inuit by Inuit Tapiriit Kanatami.<sup>2</sup> Tuberculosis is 17 times higher in Canada's Inuit than in the non-Inuit population<sup>2</sup> and sexually-transmitted infections such as genital chlamydia and HIV are higher in Inuit as well.<sup>2</sup> Infectious enteric illness is also higher in Northern Canada than southern locales.<sup>3,4</sup> For instance, a recent population health study investigating the burden of acute gastrointestinal illness (AGI) for both Inuit and non-Inuit residents in Iqaluit (the capital city of Nunavut) (Figure 1.1), found health disparity in AGI incidences.<sup>3</sup> The annual incidence of AGI in Iqaluit was three times higher than national incidences. This study did not examine the annual incidence and factors for AGI specifically among the community's Inuit population, as such it is unknown if incidences and factors identified in the study are applicable to Inuit as a subpopulation in Iqaluit.

Many social determinants of health such as education, employment, and housing contribute to Inuit population health disparities.<sup>1</sup> In 2006, approximately half of the Inuit population had less than a high school diploma.<sup>5</sup> One reason for the lack of formal education in Inuit populations is that a curriculum developed in Southern Canada may lack cultural relevance.<sup>5</sup> Until recently, the majority of Inuit education took place informally on the land as traditional and ecological knowledge is incredibly important in this population for continuation of culture and subsistence in Arctic climates.<sup>5-8</sup> In 2006, the unemployment rate for Inuit at working age was four times higher than their non-Indigenous Canadian counterparts.<sup>5</sup> There is a housing shortage within Inuit populations, including Iqaluit, Nunavut, with approximately 38% of the Inuit population living in over-crowded homes.<sup>5</sup> In the last four decades, Inuit cultural, political, social, and economical autonomy has been slowly building again, with a series of land claim agreements and self-government in four Inuit regions in Canada: the Territory of Nunavut, as well as Nunavik (Quebec), the Inuvialuit Settlement Region (Northwest Territories), and Nunatsiavut (Labrador).<sup>9</sup>

While Inuit experience many disparities in health, they have a strong, unique culture with close ties to the land, devotion to community, commitment to the tradition of sharing, and a strong sense independence, innovation, and patience.<sup>10</sup> Inuit have experienced rapid and expansive change in the last few decades, but have shown incredible resilience as they begin to reclaim self-governance, and structures to ensure Inuktitut language and culture are kept strong.<sup>10</sup>



The purpose of applied research that examines the biological, social, cultural, and environmental interactions that influence human health is to improve the health of populations.<sup>11</sup> Many health research funding agencies have recognized the necessity for transmission and exchange of new and existing health knowledge between researchers and end-users such as other researchers, practitioners, policy-makers, and community members.<sup>12-14</sup> Ideally, the best method to facilitate the uptake of research results is determined by the needs of stakeholders involved, and also the nature of the health research.<sup>15-17</sup> Furthermore, differential social and cultural mechanisms of communication, along with historical, political, and economic contexts within any given population, including Inuit populations, may necessitate unique approaches to transmission and exchange of health knowledge specific to particular contexts.<sup>15,18</sup> Inuit continue to experience health inequities compared to the Canadian population in general;<sup>19,20</sup> as such, health research efforts in Inuit communities should include KT to move research results into action as it may contribute to reducing health inequities.<sup>1,2,21-</sup>

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Considering the disparities in health and the role that KT could play in reducing health inequities, the objectives of this literature review are as follows:

1. Summarize the agents, hosts, and environments that lead to symptoms of AGI;
2. To investigate underreporting of AGI and the need for burden of illness studies to capture AGI cases in Inuit populations;

3. To explore the burden of AGI in Canadian Inuit communities in the context of national and international burden of illness studies;
4. To describe the Inuit way of life, and how this may affect the Inuit-specific burden of AGI;
5. To understand the population level assessment of AGI in Iqaluit, Nunavut, Canada;
6. To define KT and summarize common terminology used to describe KT; and
7. To conceptualize KT in the context of the Inuit way of life.

## **Acute Gastrointestinal Illness**

### **Methods and Numerical Results for Acute Gastrointestinal Illness Literature Search**

To develop a search query, a preliminary search of general AGI articles was conducted to better understand terminology used in peer-reviewed literature and to create a broad list of potentially relevant terms. A library scientist assisted in developing various combinations of terms to develop a search string that included outcome terms (e.g., “gastrointestinal”, “diarr\*”, and “vomiting”), population terms (e.g., “Canada” [Mesh] “British Columbia”, etc.), and restrictive terms (e.g., NOT “chemotherapy”, “radiation”, etc.).

The final search string (Table 1.1) was used to search MEDLINE/PubMed (1946-present). The search was then filtered by publication date (previous ten years), and

species (humans). To ensure the species filter did not exclude articles based on animal terms used in the text of the article as potential factors, 15 articles known to the author as relevant were checked in the reference list.

All references were imported into the online bibliographic management program RefWorks©. Titles and abstracts were screened and recorded in a Microsoft® Excel® for Mac 2011 (Version 14.4.5) spreadsheet. Articles were excluded if the title and abstract described non-human study populations, were not Canadian, or the AGI was not infectious. Any articles that were relevant, or where relevance was uncertain based on title and abstract alone, were screened based on the full article, and those relevant articles were summarized. A snowball approach was then used to identify further articles on relevant article reference lists (not limited by date) and all relevant articles were summarized.

This search string generated 1,667 hits. A total of 64 articles were deemed relevant from the MEDLINE/PubMed search, and an additional 66 articles were deemed relevant as a result of snowballing of reference lists. A total of 130 articles were summarized. The summary of these articles formed the basis of the literature review.

### **Acute Gastrointestinal Illness Symptoms and Transmission**

There are a wide range of symptoms associated with AGI, they can include diarrhea and/or vomiting, fever, abdominal cramps, and nausea. Symptoms of AGI are caused by the ingestion of a pathogen (virus, bacteria, or parasites) through routes such as

drinking contaminated water, eating contaminated food, or through direct contact such as by cross-contamination via unclean hands. The epidemiology of AGI can be complicated as humans are exposed to many possible risks and through several transmission routes such as water, food, contact with infected individuals, contact with animals, and through their environment. The cause of AGI may be identified, such as a specific contaminated food or water source. For example, in 2002, 13 cases of *Escherichia coli* O157:H7 hemorrhagic colitis were reported in Edmonton, Alberta through notifiable disease surveillance.<sup>25</sup> Twelve of 13 outbreak cases had consumed the same unpasteurized Gouda cheese within the incubation period, days prior to become symptomatic; indicating the cause of AGI was specific to the consumption of this Gouda cheese.<sup>25</sup> In Walkerton, Ontario in 2000, the cause of an outbreak of waterborne AGI had many contributing factors including lack of source water protection and inadequate drinking water treatment.<sup>26,27</sup>

### **Acute Gastrointestinal Illness Agents**

Bacterial pathogens that can cause symptoms of AGI include *Escherichia coli* (EHEC), *Salmonella* spp., *Shigella* spp., *Francisella tularensis*, *Campylobacter* spp., *Yersinia enterocolitica*, *Clostridium difficile*, *Clostridium difficile tcd*, *Brucella*, *Coxiella burnetii*, *Listeria monocytogenes*, and *Vibrio parahaemolyticus* (Table 1.2).<sup>3,4,28</sup> Viral pathogens that can cause symptoms of AGI include Norovirus group, Rotaviruses, Astroviruses, Adenoviruses, hepatitis virus, and Sapoviruses (Table 1.2).<sup>3,28,29</sup> Parasitic pathogens that can cause symptoms of AGI include *Giardia lamblia*, *Entamoeba*, *Tapeworm*, *Trichinella*, and *Cryptosporidium* (Table 1.2).<sup>3,28,30,31</sup>

There are multiple methods to identify a case of AGI including self-reporting,<sup>3,28</sup> pathogen testing,<sup>4,31-39</sup> and evaluating clinical records for signs and symptoms of diarrhea and/or vomiting.<sup>29,40-43</sup> In self-reported AGI studies, and in evaluating clinical records where a laboratory pathogen test has not been conducted, the pathogen itself is not known. A ten-year retrospective study from 1995-2004, using the Canadian Institute for Health Information (CIHI) hospital administrative data found that 78.3% of hospitalizations for AGI in Canada the pathogen was unknown; the laboratory confirmed that 11.6% were viral infections, 9.7% were bacterial infections, and 0.3% were parasitic infections.<sup>44</sup> In the Canadian Arctic, conventional microbiological assessment can be compromised as a result of the often long distance that specimens travel from the collection point to a testing laboratory.<sup>31</sup> Additionally, the remote location of many communities in the Canadian Arctic may limit access to health care influencing health care seeking behaviours of residents<sup>29</sup> thereby reducing the number of microbiological assessments conducted. Nonetheless, many studies have characterized pathogens in the Canadian Arctic.<sup>4,28,31,33,36,45-48</sup> A study conducted in the Northwest Territories from January 1991 to December 2008, looked at laboratory confirmed cases of AGI data from the Northwest Territories Communicable Disease Registry, found 64.7% of confirmed cases had bacterial infections, and 33.9% and 1.4% had parasitic and viral infections respectively.<sup>4</sup> The most frequently reported gastrointestinal illnesses to the Northwest Territories Communicable Disease Registry, and integrated Public Health Information System (Ontario) were campylobacteriosis, salmonellosis, and giardiasis.<sup>4,45</sup> Conversely, a study by Iqbal *et al*

(2015) tested diarrheal stool specimens submitted to a hospital in the Qikiqtani Region of Nunavut and found that the number of cases of *Cryptosporidium* (15.7%) infection was higher than the number of cases of *Giardia* infection.<sup>46</sup>

Bacterial gastroenteritis outbreaks as a result of enterohaemorrhagic *E. coli* (EHEC) O157:H7 have also been reported in northern communities.<sup>36</sup> In 86 stool specimens collected in a community hospital in Nunavut, 50 pathogens were detected with one or more pathogens detected in 46.5% of stool specimens, including *Cryptosporidium*, *C. difficile*, *Campylobacter*, *Salmonella*, astroviruses, noroviruses, rotavirus, *Shigella*, and *Giardia*.<sup>31</sup> A study comparing rates and factors of diarrhea in northern and southern communities found that rotavirus infection in neonates was significantly higher in northern communities.<sup>28</sup> In 2010, the National Enteric Surveillance Program Summary indicated that Nunavut had a higher rate of reportable *E. coli* infection than all of the provinces/territories except for Manitoba, a much higher reportable rate of *Salmonella* infection than the rest of the provinces/territories, and a higher reportable rate of *Vibrio* infection than the rest of the provinces.<sup>48</sup>

### **Acute Gastrointestinal Illness Host Factors**

#### **AGE**

In Canada, the incidence of AGI was found to be higher in children and elderly<sup>44,49,50</sup> with the burden often highest among children.<sup>45,49,51-53</sup> The increase in AGI incidence within these groups could be as a result of immune status that is underdeveloped in children<sup>54</sup> and depressed in elderly,<sup>55</sup> decreased hygiene practices in children,<sup>56</sup> as well

as increased interaction with other children in daycare and early school years<sup>56</sup> or among elderly in healthcare facilities.<sup>57</sup> In British Columbia, physicians were more likely to request stool samples from older individuals, which may result in an over-estimation of incidence rates and prevalence of AGI in older individuals in studies done using the passive surveillance system.<sup>58</sup> It is also possible, however, that an underestimation of the burden of AGI in elderly occurs, as some population-based surveys inadvertently select for healthier individuals in the elderly category when they do not include individuals in institutions such as hospitals or nursing.<sup>52</sup> Pathogen-specific studies have documented children as having an increased risk for AGI especially those involving rotavirus,<sup>31,59</sup> and adenovirus.<sup>60</sup> In a study looking at diarrhea among infants and young children in Northern Canada, rotavirus infection was the pathogen most often identified, and was significantly more common among neonates in two Inuit communities (Eskimo Point and Berens River) than in Winnipeg.<sup>28</sup> In Canada, studies have also found a higher rate of AGI in young adults.<sup>3,52</sup> In Rigolet, Nunatsiavut, Northern Labrador, it was found that the odds of AGI in the 20-55 year old age group was greater than in those in the 0-19 years age group.<sup>3</sup> This particular age group could be at higher risk of AGI as they are often involved in food preparation where they may come into contact with contaminated food more often, and they are more likely to care for sick children and elders.<sup>3</sup>

#### GENDER/SEX

There does not seem to be unanimity across Canadian literature on the effect of gender/sex on the risk of AGI. In studies using both passive surveillance data<sup>44,50</sup> and

self-reported AGI surveys,<sup>51,52,61,62</sup> the burden of AGI was higher in females than males. In passive surveillance, this could be as a result of sex bias on admission,<sup>44,50</sup> with females often more likely to visit a hospital for AGI symptoms than males.<sup>44,50</sup> Another study looking at a variety of demographic factors, found that women in low-income categories had a much higher risk of AGI, but that for males the risk of AGI was similar across income levels.<sup>52</sup> An increase in self-reported or laboratory confirmed cases of AGI in females compared to males could also be due to biological differences that might affect severity, or difference in exposure routes as a result of gender roles such as food preparation, and contact with children (especially middle aged women).<sup>52</sup> Conversely, studies have found incidence of AGI to be higher in men when looking at specific pathogens such as *Giardia* and *Cryptosporidium* in laboratory confirmed passive disease surveillance.<sup>45,63,64</sup> It is unclear why males have a higher rate of giardiasis and cryptosporidiosis in these studies; however, sex/gender may be a proxy for host- or environment-related factors.<sup>62</sup> A *Giardia* study from 1990-1998 using the Ontario Reportable Disease Information System (RDIS) found males had a higher mean annual incidence than females in all age groups.<sup>64</sup> Another study done by Majowicz *et al.*, looking at reported endemic cryptosporidiosis cases in Ontario in 1996 and 1997, reported that males had a higher mean annual incidence than females except in the group consisting of 15-19 year-old individuals.<sup>63</sup> Additionally, a study conducted in Ontario from 2007 to 2009 using data obtained from Ontario's passive reportable disease surveillance system found that there were significantly more male (54.8%,  $p < 0.001$ ) cases of AGI than females, specifically males experienced more cases of amebiasis (71.1%), campylobacteriosis (55.0%), giardiasis (58.8%), shigellosis



(57.2%), and yersiniosis (54.4%).<sup>45</sup> Overall, a trend in the literature appears to be that when AGI in general is studied, the burden of AGI is higher in females than males, but when specific pathogens are assessed the burden of AGI is higher in males than females.

### **Acute Gastrointestinal Illness Environment Factors**

#### **FOOD**

According to the Public Health Agency of Canada, every year approximately four million people - one in eight people - are sick with domestically acquired foodborne illness that cause symptoms of AGI.<sup>65</sup> In Canada, from 2000 to 2010 the leading known pathogens of foodborne illness from were Norovirus, *Clostridium perfringens*, *Campylobacter*, and nontyphoidal *Salmonella*.<sup>65</sup>

In the Canadian North, particularly in Inuit communities, country food plays an important role both physically and culturally, and is often favoured over retail food.<sup>30,66</sup> Country foods are foods harvested from the land and water, including wild game (e.g., caribou, muskox), sea mammals (e.g., seal, walrus, beluga whale), fish (e.g., char, cod, salmon, trout), birds (e.g., geese, ducks, eggs), as well as some vegetation (e.g., mushrooms, berries, teas).<sup>30,66</sup> Traditional knowledge is shared between Inuit hunters across generations, about the environment and wildlife that inhabits it, providing a wealth of knowledge on selection, examination, rejection, and preparation of country foods.<sup>32</sup> In many Inuit communities, including Iqaluit, consumption of raw, frozen, fermented, and dried meat from fish, and marine and terrestrial mammals is common

and important for culture, providing strong connection to the land, community, and past. Country foods are also important to physical health for Inuit, as they are nutrient-dense and contain high levels of antioxidants, omega-3- fatty acids, monounsaturated fatty acids, and protein.<sup>67,68</sup> Additionally, retail food in Inuit communities tend to be expensive, and high in fats, sugar, and salt.<sup>67,69</sup> There is, however, a risk of exposure and infection from foodborne pathogens in country foods that can cause symptoms of AGI.<sup>34,35,70,71</sup>

There does not seem to be unanimity across Canadian literature in regard to which animals commonly carry zoonotic pathogens. For instance, in a study conducted between from August 2007 to July 2009 in Nunavik, Nunavut, and Nunatsiavut, *Anisakis simplex* and *Pseudoterranova decipens* were found in fish (Atlantic tomcod, polar cod, and sculpins), ringed seals, bearded seals, and beluga whales.<sup>71</sup> In the Canadian North, it is thought that *E. coli*, *Salmonella*, and *Campylobacter* infections sometimes occur through the storage, preparation, and consumption of country food.<sup>33</sup> *Giardia duodenalis* and *Cryptosporidium* were also found in both ringed and bearded seals that were harvested for food in Nunavik.<sup>72</sup> *Giardia* has also been reported in ringed seals in the western Canadian Arctic,<sup>47</sup> as well as in harp, grey, and harbor seals on the east coast of Canada.<sup>73</sup>

While country food could increase the risk of AGI, some studies have shown the opposite. In Nunavik, for instance a study found consumption of seal meat to be slightly protective against gastroenteritis at the univariate analysis level.<sup>49</sup> Further, a

study attempting to determine the prevalence of *E. coli* O157:H7 and *Salmonella* in traditional meats from the eastern Canadian Arctic tested 129 samples of arctic mammals, fowl, fish, and environmental swabs from community freezers and found no *E. coli* or *Salmonella* present in any of the samples.<sup>70</sup>

A study in Nunavik found a positive association between consumption of marine mammals, fish, and gastroenteritis;<sup>49</sup> however, a limitation of cross-sectional study designs, as used in this study, is temporality.<sup>3</sup> For instance, Inuit often consume certain foods to settle upset stomachs (e.g., in Iqaluit consumption of frozen fish); therefore, while it could be that consumption of fish was causing AGI, it could also be that symptoms of AGI were already present, and therefore fish was consumed.<sup>3</sup> Another study suggested it is possible that country food could have a protective effect against AGI; however, also indicated that increased trapping and consumption of traditional foods could be a surrogate for a decrease in consumption of retail food, which may also lead to a decreased risk of AGI.<sup>34</sup> In a series of interviews done in Rigolet, Nunatsiavut, community participants perceived retail food to be an important factor for AGI.<sup>30</sup> Their concern may be warranted, as many communities in the Canadian North are incredibly remote requiring increased travel distance for food, making it more difficult to ensure the food is in good condition upon arrival.<sup>4,33,74</sup> Little research was found on pathogen specific contamination of retail food in the Canadian North.

## WATER

Consumption of contaminated drinking water causing symptoms of AGI is a recurrent threat in developed and under-developed countries.<sup>4,29,32,50,53,55,75-88</sup> With the main pathogens in outbreaks in Canada being *Giardia*, *Campylobacter*, *Cryptosporidium*, *Salmonella*, pathogenic *E. coli*, and Norwalk-like viruses.<sup>75,89,90</sup> In rural and remote communities, reliable safe drinking water can have additional challenges as well-resourced treatment plants are rare, and highly trained personnel are limited.<sup>76</sup> Factors contributing to unsafe drinking water include insufficient disinfection or filtration, contamination from wastewater or animal fecal material, inadequate knowledge of source water risks, failures in safe distribution and storage of water, or in treatment plant maintenance, as well as extreme weather events (e.g., flooding, high volumes of precipitation, and/or snowmelt).<sup>75</sup> For instance the waterborne outbreak in Walkerton, Ontario in 2000, was a result of failures in multiple barriers (i.e., source, treatment, distribution, monitoring, and response) in providing safe drinking water.<sup>27</sup>

Water security in Inuit communities is a function of accessibility, availability, safety, quality, and preference.<sup>91</sup> While most Inuit homes have access to treated drinking water, many Inuit prefer to drink untreated water directly from untreated surface water sources such as lakes, rivers, and streams.<sup>3,29,30,49,91</sup> One study that included all fourteen communities in Nunavik found that in both the summer and winter months, about a third of households' primary water consumption was from untreated surface water sources such as lakes, rivers, streams, and melted snow or ice.<sup>49</sup> This practice could reflect cultural preferences and community norms, but could also be as a result of

mistrust of treated piped water.<sup>49</sup> A study conducted on preferences and perceptions of drinking water in Rigolet and Nain, Nunatsiavut found that the taste and smell of chlorine, and additional aesthetic issues (e.g., colour) were common reasons for preference of untreated surface water sources over tap water.<sup>91</sup> Between 9% and 43% of Inuit adults living in Labrador, Nunavik, Nunavut, and the Inuvialuit Region believed water quality in their community was unsafe for consumption.<sup>92</sup> Concern regarding the safety of treated drinking water in many Inuit communities may be warranted as sampling has found water quality issues.<sup>1</sup> Other sources of contaminated drinking water could include domestic water reservoirs as one study found the prevalence of diarrhea cases to be higher in households who clean their reservoirs less often than those who clean their tank every two to six months.<sup>49</sup> A later study found contradictory results that cleaning of the domestic reservoir once a month or more was associated with a seropositive result for *E. granulosus*, suggesting that cleaning frequency and adequacy of domestic water reservoirs must be better defined.<sup>32</sup> Consumption of untreated water could increase the risk of AGI.<sup>3,29,30,49</sup> For example, in Rigolet, Nunatsiavut, consumption of tap water alternatives (e.g., untreated brook water) was significantly associated with increased odds of AGI.<sup>3</sup>

Additionally, increased precipitation often has been associated with outbreaks of waterborne AGI.<sup>29,51,75,84</sup> In a Canadian Inuit community, two and four weeks after heavy rainfall and snowmelt there was significantly higher numbers of AGI clinic visits.<sup>29</sup>

## ANIMAL EXPOSURE

Exposure to animals (pets, livestock, wildlife) carrying AGI pathogens can increase the risk of disease in humans.<sup>3,93,94</sup> A large part of Inuit subsistence and culture involves hunting, trapping, and fishing where contact with wildlife is common.<sup>6-8,66,95</sup> Although wildlife exposure has been proposed as a vehicle for pathogen transmission associated with AGI,<sup>34</sup> a study investigating the seroprevalence of pathogens in Nunavik did not find an association between wildlife exposure and symptoms of AGI.<sup>32</sup> Exposure to pets may also pose an increased risk in exposure to pathogens that cause AGI. Exposure to puppies was associated with an increased odds of AGI in Rigolet, Nunatsiavut, and exposure to cats was associated with an increased odds of AGI in Iqaluit, Nunavut.<sup>3</sup>

## PERSON-TO-PERSON TRANSMISSION

Many pathogens causing AGI can be passed from person-to-person (Table 1.2). Frequency and severity of infectious disease often increases when population density is high,<sup>34,96</sup> which could include crowded living conditions. Indeed, over-crowded households have been associated with increased odds of AGI in Iqaluit, Nunavut.<sup>3</sup> However, a study by Messier *et al.*, (2007) across Nunavik found no significant association between prevalence of diarrhea and crowded living conditions; however, it was stated that a recall bias may have occurred as a result of the primary respondents being third parties (e.g., may not remember symptoms of AGI for another person).<sup>49</sup> The International Polar Year Inuit Health Survey 2007-2008 reported that 30% of households were crowded in Nunavut, and in both Nunatsiavut and the Inuvialuit Settlement Region of the Northwest Territories 12% of households were crowded.<sup>97</sup>

## **Acute Gastrointestinal Illness Burden**

Diarrheal disease remains a major global public health challenge as the fifth most frequent cause of death world-wide, surpassed only by ischaemic heart disease, cerebrovascular disease, lower-respiratory infections, and chronic obstructive pulmonary disease.<sup>98</sup> Although in developed countries, AGI is usually mild and self-limiting, in developing countries mortality associated with diarrheal disease is still high, and to kill 2.2 million people annually.<sup>98</sup> Still, diarrheal diseases, including AGI, are not a challenge that only developing countries face. An example highlighting the high burden of AGI in Canada is a ten-year retrospective study from 1995-2004 indicating there are at least 92,765 hospital admissions per year in Canada for AGI compared to 181,177 hospital admissions per year for AGI in the United States (whose population is 10 times larger than that of Canada).<sup>44</sup> Moreover, AGI contributes to a significant societal burden through morbidity and economic loss.<sup>62,99</sup> A cross-sectional telephone survey in British Columbia investigating the burden of self-reported AGI, found that of those who had AGI who were older than 17 years and were employed, 32.5% took time off work as a result of their illness, and 43.5% lost income.<sup>51</sup> In 2004, an estimation of the cost of AGI in British Columbia, Canada found the mean annual cost per capita of AGI to be CAN\$128.61. In the province of British Columbia alone, it was found that loss of productivity as a result of AGI resulted in a mean economic annual burden of CAN\$514.2 million.<sup>99</sup>

## **Acute Gastrointestinal Illness Underreporting**

A well-known limitation of studies done on the burden of AGI using passive surveillance system data is the rate of underreporting. To capture a case of AGI, the individual must seek medical care, the healthcare provider must ask for a stool sample, the patient must agree to give a stool sample, the stool sample must test positive in the laboratory, and must be reported (Figure 1.2).<sup>4,32,58,100,101</sup> Thus, there are many steps in the reporting process where a case of AGI might not be captured. Often individuals experiencing AGI will not seek medical care as a result of it being mild and self-limiting.<sup>58,100,101</sup> Population level self-reported AGI studies have indicated that between 14-25% of all community cases of AGI will seek health care.<sup>32,51,53,61,62,102</sup> Many laboratories in Canada still use electron microscopy for viral detection for example, which has a low sensitivity compared to molecular methods (e.g., PCR) allowing the potential for false negatives to occur.<sup>31</sup> As a result of this wide array of scenarios causing underreporting, incidence rates and prevalence of AGI in passive surveillance system data are an underestimation of the true scale of the burden of AGI.<sup>58,61,100</sup> Studies estimating the magnitude of underreporting of AGI in British Columbia and Ontario have suggested that for every case of AGI, 313 and 347 community cases respectively are not reported.<sup>58,100</sup>

Nationally, underreporting in surveillance data on the burden of AGI is high and may be increased in rural and remote areas of Canada including northern communities. In many northern communities, especially those small and remote, accessibility and availability of healthcare, available laboratory equipment or transportation of



specimens, as well as use of traditional medicine all hinder the ability of the surveillance system to capture AGI cases.<sup>3</sup> For instance, the proportion of AGI cases in Rigolet, Northern Labrador, and Iqaluit, Nunavut seeking medical services were 1.3 to 3.8 times lower than other national incidences.<sup>30</sup> This difference in reported AGI cases, if only using passive surveillance data, can lead to an under-representation of the true burden of AGI in northern communities.<sup>4,31,33,40</sup> Therefore, comparing surveillance data on the burden of AGI in the Canadian North and other national incidences does not provide a true comparison of the burden of AGI as a result of differential underreporting rates.

### **Burden of Illness Surveys**

To describe and quantify the underreporting of AGI, further understand factors for AGI, and generate baseline period prevalence rates of self reported AGI, burden of illness surveys are conducted at the community level to assess the burden of self-reported AGI, as well as accompanying factors. In Canada, three 12-month population surveys have been administered via telephone surveys, in Hamilton, Ontario,<sup>62,102</sup> three regions of British Columbia,<sup>51</sup> and the province of Ontario<sup>61</sup> with annual incidence rates between 0.99 and 1.30 cases per person-year (Table 1.3). Similar burden of illness studies were conducted in Rigolet in Northern Labrador, and in Iqaluit, Nunavut<sup>3</sup> (Table 1.3) with tools and processes that would allow for a degree of comparability of results between the Canadian studies. In Rigolet and Iqaluit, the survey results showed annual incident rates between 1.9 and 4.1 cases per person-year.<sup>3</sup>

## **Acute Gastrointestinal Illness Burden in Iqaluit: Population Level Assessment**

Iqaluit, Nunavut is located in Arctic Canada, on the south coast of Baffin Island, at the head of Frobisher Bay (Figure 1.1). Iqaluit is the territorial capital and largest city in Nunavut with just under 7,000 people. Of Iqaluit's population, approximately 60% self-identify as Indigenous (First Nations, Métis, or Inuit), with the majority being Inuit. Approximately seven in ten Inuit have knowledge of at least one of the Inuit languages.<sup>5</sup> Iqaluit is unique compared to other capital cities in Canada in that it has a mixed wage and traditional economy, which means that many individuals still take part in traditional hunting and fishing for subsistence, but a wage economy also exists, with many employment opportunities for wage-based work in Iqaluit coming from the government sector.

Until recently, little research has documented the burden of AGI in Inuit communities. Many studies, however, have indicated environmental conditions in rural and remote communities, and particularly Indigenous communities, across Canada may increase the risk of AGI including over-crowded households, drastic changes in climate, and inaccessibility and availability of safe drinking water.<sup>1,29,40,75,76</sup> To address this gap in research, the Public Health Agency of Canada and the Indigenous Health Adaptation to Climate Change Project conducted a series of retrospective cross-sectional surveys to investigate the burden of AGI in two Inuit communities, Rigolet, Nunatsiavut, and Iqaluit, Nunavut, in Canada (2011-2013).<sup>3,30</sup> The research design was adapted from other national and international burden of illness surveys for comparability.<sup>3</sup> In particular, the study design used was very similar (modifications were necessary to be

relevant to the local context) to designs in studies conducted in Hamilton, Ontario,<sup>62</sup> three regions of British Columbia,<sup>51</sup> and the province of Ontario (Table 1.3).<sup>61</sup>

The case definition for AGI used was “self-reported vomiting and/or diarrhea (any loose stool) in the past 14 days (September and May) as well as the past 28 days (May), excluding cases who reported vomiting or diarrhea due to pregnancy, medication use, alcohol/drug use, or diagnosed chronic conditions (e.g., colitis, diverticulitis, Crohn's disease, irritable bowel syndrome, *Helicobacter pylori*, or other diagnosed chronic conditions)”.<sup>3,30</sup> Two surveys took place in Iqaluit, Nunavut, one in September 2012, and another in May 2013. In September 2012 and May 2013, 532 (response rate= 75%), and 523 (response rate= 55%) questionnaires were completed, respectively. In both cases, these numbers exceeded the target sample size of 498 participants in a population of 6,184 people.<sup>30</sup> Burden of illness surveys captured data regarding self-reported AGI, potential factors (e.g., food and water consumption, social-economic levels, animal exposures, demographics), and health seeking behaviours.<sup>3</sup> To-date a population-level (e.g., Inuit and non-Inuit) assessment of these data have been done.

Using a 14-day recall period, the age-adjusted annual incidence rate was 3.8 and 2.8 episodes per person per year in September 2012, and May 2013, respectively.<sup>3</sup> These incidences are approximately three times higher than other national incidences (Table 1.3).

In September, those who consumed country fish in half or more than half of their meals, had exposure to cats, were employed, and did not wash counter with soap after preparing raw meat were significantly associated with an increased odds of AGI in the multivariable exact logistic regression model.<sup>3</sup> In May, those who had a homeless person staying in the home were significantly associated with an increased odds of AGI in the multivariable exact logistic regression model.<sup>3</sup>

## **Knowledge Translation**

### **Knowledge Translation Defined**

The transmission and exchange of new and existing knowledge between researchers and end-users is of paramount importance in the successful application of research results.<sup>103,104</sup> Knowledge translation (KT) is a widely used term for the movement of research evidence to practical action. There are, however, many other terms used in health research for this type of knowledge-sharing whose true functions are similar, such as “knowledge transfer,” “knowledge exchange,” “dissemination,” and “results sharing.”<sup>16,17</sup> The term KT will be used in this literature review as an all-encompassing term for those knowledge-sharing activities involving research-to-action in some capacity in any part of the research process.

### **Knowledge Translation at Canadian Institutes of Health Research**

The Canadian Institutes of Health Research (CIHR) is the chief federal agency responsible for funding health research in Canada, and “is recognized within Canada and internationally for leading and funding the advancement of KT science and

practice.”<sup>105,p.1</sup> For this reason, inquiry into CIHR’s KT initiatives provided a good base to begin understanding the KT process. The CIHR aims to create new knowledge through research, and to ensure this knowledge is translated into real-world applications.<sup>12</sup> In order to fulfill the aim to increase research-to-practice/action, CIHR works with researchers, healthcare practitioners, and policymakers to create research agendas that are harmonious with Canada’s health priorities.<sup>12</sup> Crucial to improving the overall health of Canadians is moving knowledge found through these research agendas into tangible applications in real-world settings.<sup>12</sup> The CIHR defines KT as “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system.”<sup>106,para.1</sup>

The concept of KT is very broad and can involve stakeholders or end-users throughout the research process, or simply end-of-grant KT whereby the researcher informs users of the knowledge gained from the research.<sup>106</sup> The CIHR describes KT as including,

“knowledge dissemination, technology transfer, consideration of the ethical context, knowledge management, knowledge utilization, the two-way exchange between researchers and those who apply knowledge, implementation research, technology assessment, synthesis of results within a global context, and the development of consensus guidelines.”<sup>12,p.2</sup>

Utilization of these KT pathways in order to facilitate the uptake of research is determined by the needs of the stakeholders or end-users involved, and also the nature of the health research.<sup>15-17</sup>

### **Knowledge Translation in Canadian Inuit Populations**

In Canada, despite a large amount of research on the health of Indigenous populations, improvements to health have been slow but steady.<sup>22</sup> Indeed, the creation of new knowledge from research is unlikely, on its own, to lead to implementation or improvement of population health; therefore, a process to translate knowledge into practical action is necessary.<sup>106</sup> One of the reasons for the lack of improvement in health is that in the decades of research on Indigenous peoples, academic researchers have often “parachuted” into communities to collect data (historically, often without consent) with little to no KT before, during, or after the study process involving community stakeholders.<sup>21,107-111</sup> Involvement of Inuit, in an environment of mutual respect and meaningful collaboration, throughout research in their communities “increases relevancy, facilitates community support, increases community knowledge, builds capacity, and encourages sustainability.”<sup>15,p.4</sup> In order to increase local uptake of research in Inuit communities it is important to understand how KT has been, or can be, successfully adapted to better suit the needs of Inuit communities. Where KT methods have been adapted to suit Indigenous groups in the context of their environment (social, cultural, economic, and political) an increase in local uptake of research has been documented.<sup>112</sup>

## Thesis Research Goals and Objectives

Acute gastrointestinal illness (AGI) is an important global public health challenge in Canada.<sup>52,61,98,99</sup> Insufficient quality and quantity of surveillance data has led to little knowledge of the burden of AGI in the Canadian North.<sup>40</sup> While the burden of AGI for all residents in Iqaluit is high,<sup>3</sup> the Inuit-specific burden of AGI in Iqaluit is currently unknown. It is hypothesized that Inuit might have unique factors for AGI due to differential social, economic, cultural, and political conditions often found in Indigenous communities.<sup>1</sup> The analysis of Inuit-specific annual incidence, and an increased understanding of the associated factors for AGI in Iqaluit is intended to inform evidence-based policy and practice to reduce the impact of AGI in these communities. The inclusion of many stakeholders is intended to ensure effective KT by employing an ongoing exchange with the community. In the Circumpolar North<sup>a</sup>, where a majority of the Inuit population resides, differential social, economic, cultural, and political conditions may require unique KT practices within these communities. It is important to determine, summarize, and disseminate what is known from existing literature in order to examine what underpins successful KT activities in Inuit communities in the Circumpolar North. This thesis research sought to answer two questions: “What is the burden of acute gastrointestinal illness (AGI) for Inuit in Iqaluit, Nunavut?” and “What does the literature tell us about knowledge translation (KT) in Inuit communities in the Circumpolar North?”

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<sup>a</sup> **Circumpolar North** including parts of Canada, Alaska (United States), Greenland, and Chukotka (Russia).<sup>114-116</sup>

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## Tables

Table 1.1 Pubmed search query breakdown for literature review of acute gastrointestinal illness (AGI) in Canada including "Population Terms", "Connecting Term", "Outcome Terms", "Connection Term", and "Restrictive Terms".

Research Topic	Population Terms	Connecting Term	Outcome Terms	Connecting Term	Restrictive Terms
Burden of acute gastro-intestinal illness in Canada	("Canada" [Mesh] OR "Canadian" OR "British Columbia" OR "Alberta" OR "Manitoba" OR "Saskatchewan" OR "Ontario" OR "Quebec" OR "New Brunswick" OR "Nova Scotia" OR "Prince Edward Island" OR "Newfoundland" OR "Labrador" OR "Newfoundland and Labrador" OR "Yukon" OR "Northwest Territories" OR "Nunavut")	AND	("gastrointestinal" OR "diarr*" OR "vomiting")	NOT	("chemotherapy" OR "radiation" OR "cancer" OR "bulimia" OR "anorexia" OR "gastric bypass" OR "migraine" OR "postoperative" OR "postsurgical" OR "preoperative" OR "presurgical" OR "anaesthesia")

Table 1.2 Pathogen information associated with AGI in Canadian literature search including name, type, the disease they cause, general symptoms, incubation period, and transmission routes.<sup>113</sup>

Pathogen Name	Pathogen Type	Disease	General Symptoms	Incubation Period	Transmission
<i>Astroviruses</i>	Virus	Norwalk virus	<ul style="list-style-type: none"> <li>• diarrhea</li> <li>• vomiting</li> <li>• abdominal cramps</li> </ul>	10-60 hrs	<ul style="list-style-type: none"> <li>• fecal-oral</li> <li>• water</li> <li>• food (shellfish and salads)</li> <li>• aerosol</li> <li>• fomites</li> </ul>
<i>Campylobacter jejuni</i>	Bacteria	Campylobacteriosis	<ul style="list-style-type: none"> <li>• diarrhea (sometimes bloody)</li> <li>• abdominal pain</li> <li>• fever</li> <li>• malaise</li> <li>• nausea</li> <li>• vomiting</li> </ul>	1-10 days	<ul style="list-style-type: none"> <li>• fecal-oral transmission (e.g., chicken or drinking water)</li> <li>• contact with animal faeces</li> <li>• low person-to-person transmission</li> </ul>
<i>Clostridium botulinum</i>	Bacteria	Botulism	<ul style="list-style-type: none"> <li>• double vision</li> <li>• drooping eyelids</li> <li>• slurred speech</li> <li>• difficulty swallowing</li> <li>• muscle weakness</li> <li>• constipation</li> </ul>	12-72 hrs	<ul style="list-style-type: none"> <li>• ingestion of toxin (commercially processed goods that had undergone poor processing, storage, and improper preservation)</li> </ul>
<i>Clostridium difficile</i>	Bacteria	C. difficile	<ul style="list-style-type: none"> <li>• antibiotic associated diarrhea</li> </ul>	Not known	<ul style="list-style-type: none"> <li>• opportunistic pathogen that thrives in individuals whose gut flora has been compromised i.e., cancer patients receiving chemotherapy, or patients on antibiotics</li> </ul>
<i>Cryptosporidium parvum</i>	Protozoa	Cryptosporidiosis	<ul style="list-style-type: none"> <li>• profuse, watery diarrhea</li> <li>• cramping</li> <li>• abdominal pains</li> <li>• weight loss</li> <li>• anorexia</li> <li>• flatulence</li> <li>• malaise</li> <li>• nausea</li> <li>• vomiting</li> <li>• fever</li> <li>• myalgias</li> </ul>	1-12 days	<ul style="list-style-type: none"> <li>• fecal-oral route (person-to-person, animal-to-person, food and waterborne transmission)</li> </ul>
<i>Entamoeba</i>	Parasite	-	<ul style="list-style-type: none"> <li>• asymptomatic (except sometimes debilitated, pregnant or immunosuppressed individuals may have abrupt onset of fever, abdominal cramps, profuse bloody diarrhea and tenesmus)</li> </ul>	few days – several months	<ul style="list-style-type: none"> <li>• fecal-oral route (person-to-person, animal-to-person, food and waterborne transmission)</li> <li>• oral-anal sexual contact</li> </ul>
<i>Escherichia coli</i>	Bacteria	-	<i>Enterohemorrhagic</i> <ul style="list-style-type: none"> <li>• cramps</li> <li>• abdominal pain</li> <li>• watery followed by bloody diarrhea</li> <li>• low grade fever</li> </ul>	2-8 days	<ul style="list-style-type: none"> <li>• Ingestion of contaminated food</li> <li>• fecal-oral transmission</li> <li>• person-to-person transmission (extremely high)</li> </ul>
			<i>Enteroinvasive</i> <ul style="list-style-type: none"> <li>• watery diarrhea (might be bloody)</li> <li>• fever</li> <li>• abdominal cramps</li> </ul>	2-48 hours	<ul style="list-style-type: none"> <li>• fecal-oral route (ingestion of contaminated food and water)</li> <li>• person-to-person transmission can also occur</li> </ul>
			<i>Enteropathogenic</i> <ul style="list-style-type: none"> <li>• acute, profuse, watery diarrhea</li> <li>• low grade fever</li> <li>• nausea</li> <li>• vomiting</li> </ul>	6-48 hours	<ul style="list-style-type: none"> <li>• fecal-oral (ingestion of contaminated food, water, and fomites)</li> </ul>
			<i>Enterotoxigenic</i> <ul style="list-style-type: none"> <li>• watery diarrhea</li> <li>• low-grade fever</li> <li>• nausea</li> </ul>	14-30 hours	<ul style="list-style-type: none"> <li>• fecal-oral route (most commonly improperly treated drinking water)</li> <li>• person-to-person transmission is possible</li> </ul>

<i>Giardia lamblia</i>	Parasite	Giardiasis	<ul style="list-style-type: none"> <li>• abdominal pain</li> <li>• asymptomatic</li> <li>• nausea</li> <li>• chills</li> <li>• low grade fever</li> <li>• epigastric pain</li> <li>• sudden onset of watery diarrhea</li> </ul>	7-14 days	<ul style="list-style-type: none"> <li>• fecal-oral route (person-to-person, animal-to-person, food and waterborne transmission)</li> </ul>
<i>Listeria monocytogenes</i>	Bacteria	Listeriosis	<i>Febrile gastroenteritis:</i> <ul style="list-style-type: none"> <li>• fever</li> <li>• diarrhea</li> <li>• vomiting</li> </ul>	1-4 weeks	<ul style="list-style-type: none"> <li>• ingestion of contaminated foods</li> <li>• Nosocomial infections and person-to-person transmission are rare</li> </ul>
Human rotavirus	Virus	-	<ul style="list-style-type: none"> <li>• fever</li> <li>• vomiting</li> <li>• non-bloody-diarrhea (often watery and explosive)</li> </ul>	1-3 days	<ul style="list-style-type: none"> <li>• fecal-oral route (person-to-person or contaminated environmental surfaces)</li> <li>• food and waterborne transmission also exists</li> </ul>
<i>Salmonella enterica spp.</i>	Bacteria	Salmonellosis	<i>Gastroenteritis</i> <ul style="list-style-type: none"> <li>• nausea</li> <li>• vomiting</li> <li>• abdominal cramps</li> <li>• diarrhea</li> <li>• headache</li> <li>• chills</li> <li>• fever</li> </ul>	5-72 hours	<ul style="list-style-type: none"> <li>• consuming contaminated foods and water</li> <li>• contact with infected feces</li> <li>• contact with infected animals, animal feed, or humans</li> <li>• <i>High Risk Foods</i> (meat, poultry, milk products, and egg products)</li> </ul>
<i>Shigella spp.</i>	Bacteria	Shigellosis	<ul style="list-style-type: none"> <li>• mild &amp; asymptomatic</li> <li>• mild watery diarrhea to severe inflammatory bacillary dysentery or shigellosis (severe abdominal cramps, nausea and vomiting, fever, tenesmus, anorexia, and stool contain blood and mucus)</li> </ul>	1-7 days	<ul style="list-style-type: none"> <li>• fecal-oral route (person-to-person, food and waterborne transmission)</li> </ul>
<i>Trichinella spp.</i>	Parasitic	Trichinellosis	<ul style="list-style-type: none"> <li>• nausea</li> <li>• vomiting</li> <li>• epigastric pains</li> <li>• diarrhea and/or constipation</li> <li>• fever</li> <li>• oedema</li> <li>• myalgia</li> <li>• peripheral eosinophilia</li> </ul>	1-3 weeks	<ul style="list-style-type: none"> <li>• consumption of raw or undercooked meat of infected animals</li> </ul>
<i>Yersinia enterocolitica</i>	Bacteria	Yersiniosis	<ul style="list-style-type: none"> <li>• enteritis</li> <li>• enterocolitis</li> <li>• fever</li> <li>• watery stools</li> <li>• abdominal pain</li> <li>• acute mesenteric lymphadenitis</li> </ul>	3-10 days	<ul style="list-style-type: none"> <li>• fecal-oral route (person-to-person, animal-to-person, food and waterborne transmission)</li> <li>• blood transfusion</li> </ul>

Table 1.3 Summary of results from community level self-reported burden of illness studies in Canada.

Location	Study Period	Case-definition	Recall Period (days)	Sample size	Response Rate	Annual Incidence Rate (cases/person/year)	Ref.
Hamilton, Ontario	Feb. 2001-Feb. 2002	Any Diarrhea and/or Vomiting	28	3496	36.6%	1.30	<sup>62</sup>
Hamilton, Ontario	Feb. 2001-Feb. 2002	≥3 Diarrhea and/or Vomiting	28	3496	34.7%	0.99	<sup>62</sup>
Ontario	May 2005-Apr. 2006	Any Diarrhea and/or Vomiting	28	2090	36.6%	1.17	<sup>61</sup>
British Columbia	Jun 2002-Jun 2003	Any Diarrhea and/or Vomiting	28	4612	44.3%	1.30	<sup>61</sup>
Nunavik	Sept. 2004	≥3 Diarrhea and/or Vomiting	30	2550	54.0%	1.23	<sup>62</sup>
Quebec	Apr. 2007-Apr. 2008	≥3 Diarrhea and/or Vomiting	28	7006	56.7%	0.73	<sup>63</sup>
Rigolet, Nunatsiavut	Sept. 2012	Any Diarrhea and/or Vomiting	14	226	92.0%	3.6	<sup>3</sup>
Rigolet, Nunatsiavut	Sept. 2012	≥3 Diarrhea and/or Vomiting	14	226	92.0%	1.9	<sup>3</sup>
Rigolet, Nunatsiavut	May 2013	Any Diarrhea and/or Vomiting	14	249	95.0%	4.1	<sup>3</sup>
Rigolet, Nunatsiavut	May 2013	≥3 Diarrhea and/or Vomiting	14	249	95.0%	3.1	<sup>3</sup>
Rigolet, Nunatsiavut	May 2013	Any Diarrhea and/or Vomiting	28	249	95.0%	3.0	<sup>3</sup>
Rigolet, Nunatsiavut	May 2013	≥3 Diarrhea and/or Vomiting	28	249	95.0%	3.0	<sup>3</sup>
Iqaluit, Nunavut	Sept. 2012	Any Diarrhea and/or Vomiting	14	532	75.0%	4.1	<sup>3</sup>
Iqaluit, Nunavut	Sept. 2012	≥3 Diarrhea and/or Vomiting	14	532	75.0%	3.6	<sup>3</sup>
Iqaluit, Nunavut	May 2013	Any Diarrhea and/or Vomiting	14	523	55.0%	2.8	<sup>3</sup>
Iqaluit, Nunavut	May 2013	≥3 Diarrhea and/or Vomiting	14	523	55.0%	2.2	<sup>3</sup>
Iqaluit, Nunavut	May 2013	Any Diarrhea and/or Vomiting	28	523	55.0%	3.1	<sup>3</sup>
Iqaluit, Nunavut	May 2013	≥3 Diarrhea and/or Vomiting	28	523	55.0%	3.1	<sup>3</sup>

## Figures



Figure 1.1 Iqaluit, Nunavut's location in relation to North America (adapted from Google).

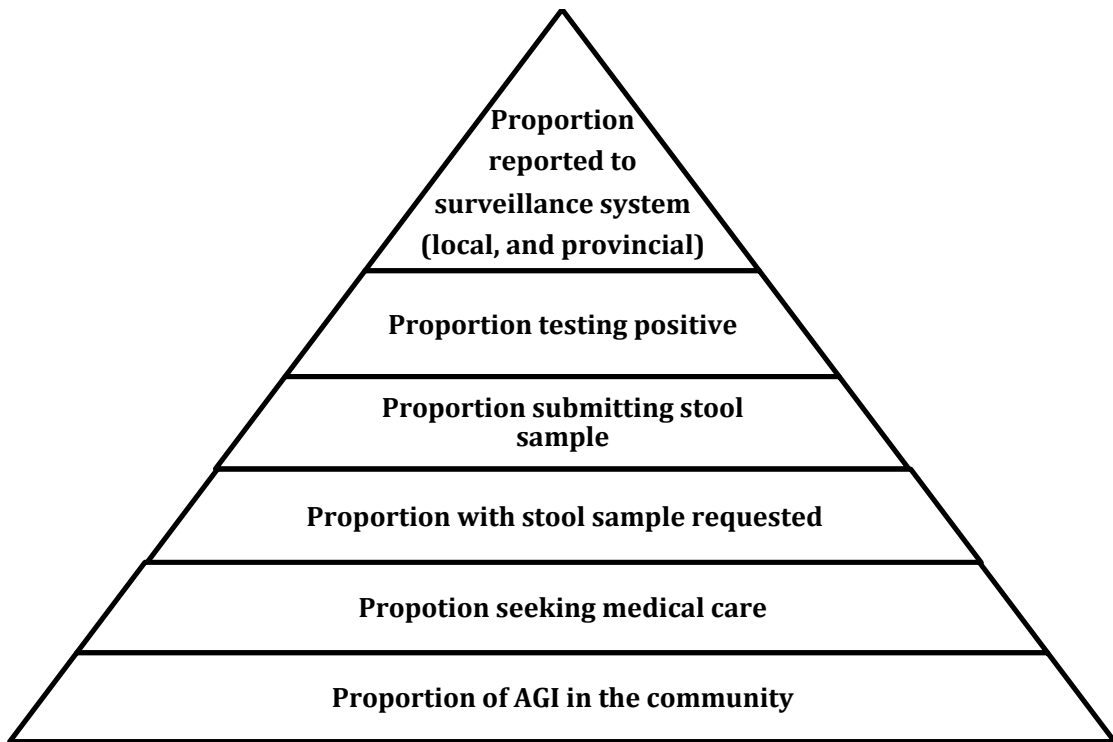


Figure 1.2 Underreporting pyramid for acute gastrointestinal illness (AGI) adapted from MacDougal *et al*, 2008.

## **CHAPTER TWO: THE BURDEN OF ACUTE GASTROINTESTINAL ILLNESS (AGI) FOR INUIT IN IQALUIT, NUNAVUT, CANADA**

### **Abstract**

Canadian Inuit communities have higher incidences of self-reported acute gastrointestinal illness (AGI) than non-Inuit Canadian communities. This study found the annual incidence of self-reported AGI, and identified factors associated with AGI for Inuit in Iqaluit, Nunavut, Canada. International burden of illness study methods were modified to reflect Inuit culture and Northern context of this study. A population level assessment, including Inuit and non-Inuit individuals, was conducted using two retrospective, cross-sectional surveys in Iqaluit in 2012 and 2013; a sub-set of these data was used in this study. Of the 1,055 survey participants in Iqaluit, 663 self-identified as Inuit, which formed the basis of the analysis. The annual incidence of self-reported AGI was found using a case definition of diarrhea and/or vomiting in the past 14-days not due to pregnancy, drug or alcohol use, or diagnosed chronic conditions. Multivariable logistic regression was used to identify factors associated with AGI. The Inuit-specific age-adjusted annual incidence was 3.2 episodes per person-year (95% CI: 2.0 - 4.4). Females, and households where those responsible for food preparation were employed were significantly associated with increased odds of AGI. Consumption of country fish and consumption of raw meat were also associated with increased odds of AGI. Additionally, the perception of 'fair', 'poor', or 'very poor' water quality was significantly associated with increased odds of AGI. This study found the Inuit-specific

annual incidence of AGI to be higher than both national and international population level incidences from studies done in a comparable way, but similar to previous assessments in the Canadian North. Variables associated with increased odds of AGI were identified that differed from the population level assessment in Iqaluit, highlighting how factors for AGI can differ for sub-populations within the same community.

**Keywords:** acute gastrointestinal illness, Aboriginal, Inuit, Indigenous, Iqaluit, Nunavut, infectious disease, burden of illness.

## **Introduction**

Diarrhea is the fifth most frequent cause of death worldwide, and remains a major global public health challenge.<sup>1</sup> In Canada, it is approximately 4 million Canadians acquire foodborne illness (that can result in diarrhea and vomiting) every year,<sup>2</sup> which results in sizeable morbidity, and economic loss.<sup>3-7</sup> As such, acute gastrointestinal illness (AGI) surveillance is an important public health activity that can detect and control outbreaks, monitor AGI burden of illness, and inform and help evaluate measures of control. Underreporting of illness in a population is a by-product of passive surveillance systems, and this may generate an under-estimate of the true magnitude of the AGI burden.<sup>4,8,9</sup> Situations that contribute to underreporting could include patients not seeking healthcare for AGI symptoms, healthcare providers not requesting a stool sample for laboratory testing, patients not providing a stool sample, false negative stool sample, or stool samples are returned negative but the individual is infected with a different pathogen than was tested.<sup>2,8,10</sup> To examine the level of



underreporting and adjust surveillance numbers accordingly, surveys can be conducted to find the self-reported incidence of AGI at the community-level.<sup>4,6,11-15</sup>

Many communities in northern Canada face additional challenges hindering the ability of passive surveillance systems to capture AGI cases, including constraints concerning the accessibility and availability of healthcare, as well as availability of laboratory equipment or timely and secure transportation of specimens.<sup>7,16</sup> Additionally, many Inuit communities have a greater use of traditional medicine (e.g., teas) and practices (e.g., consuming country foods for healing) instead of seeking Western healthcare services, which can further increase underreporting.<sup>7,16</sup> These factors highlight the necessity for community level studies that identify the magnitude of AGI in remote communities in northern Canada.

An international effort to decrease the magnitude and burden of AGI has been coordinated by the World Health Organization in collaboration with national public health agencies, beginning in 2004.<sup>17</sup> A number of studies internationally have used comparable methodology (i.e., case definition, questionnaire design, and analysis), to find the community level burden of self-reported AGI.<sup>11-13,15,18-23</sup> Similar burden of AGI studies conducted in Canada include the city of Hamilton, Ontario (2001-2002),<sup>3</sup> the province of Ontario as a whole (2005-2006),<sup>4</sup> parts of the province of British Columbia (2002-2003), and the community of Rigolet, Nunatsiavut (2012-2013).<sup>7</sup>

Most studies on AGI in Canada's North have focused on small, remote communities where the population is almost entirely Inuit.<sup>7,24</sup> While these studies have contributed to our understanding of AGI, limited research has been conducted on Inuit populations living in larger northern settlements. These rapidly growing urban centres are home to almost one-fifth of all Canadian Inuit, and differ in socio-economic demographic structure from smaller communities.<sup>25</sup> For instance, Iqaluit, Nunavut is the territorial capital, and largest city in Nunavut with just under 7,000 people.<sup>26</sup> Of those 7,000 people, approximately 60% self-identify as Indigenous (First Nations, Inuit, and Métis), with the majority being Inuit.<sup>26</sup> Iqaluit is unique compared to other capital cities in Canada in that it has a mixed wage and traditional economy. Mixed wage and traditional economy means that many individuals still rely on traditional hunting, fishing, and trapping for subsistence but that the use of a wage economy (individual is employed with a salary) also exists, with many employment opportunities for wage-based work in Iqaluit coming from the government sector.<sup>27</sup> Inuit have a profoundly deep relationship with the land, water/ice, and animals that inhabit it.<sup>28-32</sup> In many Inuit communities, including Iqaluit, consumption of untreated water from rivers, creeks, and streams is common.<sup>33</sup> Also common in Inuit communities is the consumption of country food (e.g., foods harvested, hunted, fished, or trapped on the land, sea, or fresh water) including cooked, raw, frozen, fermented, and dried meat from fish, marine and terrestrial mammals.<sup>33</sup> For many Inuit communities social cohesion and cultural continuity relies on hunting, harvesting, and sharing of country food.<sup>34</sup>

A recent population level assessment of the burden of AGI for both Inuit and non-Inuit residents in Iqaluit, Nunavut, found the annual incidence of AGI to be three times higher than national incidences,<sup>32</sup> but the study did not examine the annual incidence and factors for AGI specifically among the community's Inuit population. As such it is unknown if incidences and factors identified in the study are applicable to Inuit as a subpopulation in Iqaluit. It is important to consider Inuit separately given their unique cultural, political, economic, and social conditions that may result in differing annual incidences and factors for AGI. In this context, the goal of this study was to better understand the Inuit-specific burden of AGI in Iqaluit by identifying the Inuit-specific annual incidence of AGI and factors that may be associated with AGI.

## **Methods**

### **Selection and Description of Participants**

This study took place in Iqaluit, Nunavut (See Figure 2.1). In the 2011 Statistics Canada Census Iqaluit had a population of 6,699, 59% (3,952) of whom identified as single-identity Inuk (singular for Inuit).<sup>26</sup> Fifty-two percent of Inuit in Iqaluit are female.<sup>26</sup> The Inuit population in Iqaluit is very young compared to Canada as a whole with a median age of 23.0<sup>26</sup> as compared to 39.9 in Canada.<sup>35</sup>

This research project was initiated in response to a request from a Northern partner to analyze an Inuit-specific subset of data collected as part of large retrospective, cross-sectional, door-to-door survey conducted between September 15 – October 5, 2012 and May 18 – June 2, 2013.<sup>7</sup> The research team collaborated with local partners throughout

the design of the survey, data collection, results interpretation, and results dissemination.<sup>32</sup> In particular, local partners provided invaluable guidance and knowledge regarding cultural appropriateness of survey questionnaires. Participants (non-Inuit and Inuit) in the original survey were identified using a random sample of the population using a two-step process. First, random blocks of households were selected and a census of each of those blocks was attempted. Each house was attempted twice at different times of the day. Then, in each household, the individual who had celebrated their birthday most recently was asked to participate. The subset of Inuit-specific data was extracted from the full database of all participants.

### **Data Collection**

Study methodology and previously validated questionnaires used in other AGI burden of illness studies were adapted and pre-tested to better capture relevant data for the Iqaluit location.<sup>3,5,7,32,36</sup> Data were gathered on self-reported AGI, demographic information, socio-economic levels, food consumed, water consumed, and exposure to animals (Table 2.1). In this study, two recall periods were used: (1) diarrhea and/or vomiting over the past 14 days (September and May survey), and (2) diarrhea and/or vomiting over the past 28 days (May survey only). In both cases, diarrhea and/or vomiting as a result of self-identified pregnancy, drug or alcohol use, medication, or any kind of chronic condition (i.e., Crohn's Disease, Irritable Bowel Syndrome, etc.) were excluded. Community members were trained to administer the private and confidential questionnaire using iSurveySoft© software (version 2.8.3) with iPads. One of the questions on the survey was whether the individual self-identified as Inuit.

A participant consent video was developed and presented as an option to each participant using a tablet. Participants could view the video, ask any questions and then provide oral consent to participate in the study. The questionnaire was offered in English, French, and Inuktitut. Assenting participants under 18 years of age required parental/guardian consent. Additionally, potential participants under 12 years of age required a parent/guardian to answer the questionnaire on behalf of the child. The ability to involve human participants in research was cleared by the research ethics boards of the University of Guelph (REB: 11JL004), McGill University (REB: 180-1212), and Health Canada (REB 2011-0012). The Nunavut Research Institute granted the research team a research license under the Nunavut Scientist Act (REB: 01 014 13R-M).

### **Data Analysis**

Data were exported from iSurveySoft© software (version 2.8.3) into Excel© (version 14.2.5). All statistical analyses were conducted using STATA InterCooled (version 11.0 for Mac). Data from participants responding “Unsure” or “Refuse to answer” were excluded from the analysis of that question. Pearson  $\chi^2$  tests were used to compare sample population demographics to census demographics.<sup>37</sup> The annual incidence rate and annual incidence proportion were calculated (Appendix 1).<sup>38</sup>

Causal diagrams were built with hypothesized associations. Models were built from each of the September 2012 dataset, the May 2013 dataset, and a combined September

2012 and May 2013 dataset. Descriptive statistics (e.g., means, variances, percentiles for continuous variables and frequency tabulations for categorical variables) were used to identify potential variables to be precluded from the analysis due to lack of variability (e.g., if almost all the participants in the study have cats, adding cats as an exposure variable is unlikely to be helpful) or categories containing few observations.<sup>38</sup> Then, univariable logistic regression analyses were conducted to evaluate potential unconditional associations between individual predictor variables and the outcome variable.<sup>38</sup> A null hypothesis of no association between AGI (based on 14 day period prevalence) and potential factors of interest was used. Collinearity among predictor variables was assessed using the Spearman's Rank correlation.<sup>38</sup> Correlations above 0.8 (i.e.,  $\rho > |0.80|$ ) were assessed and the variable with the most biological plausibility based on previous literature, and/or most observations was considered in the multivariable model.<sup>38</sup> All significant variables ( $\alpha=0.20$ ) from the univariable analyses were considered in a multivariable logistic regression model.<sup>38</sup> Multivariable logistic models were built from each of the September 2012 dataset, the May 2013 dataset, and a combined September 2012 and May 2013 dataset. A 'month' variable, defined as either September or May (to identify the month the observations took place) was included as a fixed effect in the combined September and May model. A manual backward stepwise model building approach was used, with independent variables removed one at a time from the full (main effects) models starting with the variable with the highest p-value until all remaining variables were significant ( $\alpha=0.05$ ).<sup>38</sup> The resulting changes in coefficients (natural log odds) were evaluated and where removal of a variable resulted in a change greater than 20% in a coefficient (natural log odds),

the variable was considered a confounder.<sup>38</sup> After assessing confounders for biological plausibility based on previous literature, confounding variables were kept in the model regardless of statistical significance to diminish its bias on the measure of association between true exposure and outcome variables.<sup>38</sup> All of the potential interactions between significant variables in the multivariable model were assessed one at a time by adding each interaction into the main effects model and removing it if not significant ( $\alpha=0.05$ ).<sup>38</sup> Pearson and deviance chi-squared goodness-of-fit tests were used to assess the fit of the final logistic models.<sup>38</sup> Leverage as well as deviance, Pearson, and standardized Pearson residuals were plotted and assessed visually for model fit and outliers.<sup>38</sup> The model was assessed with and without each covariance pattern to determine if any major changes occurred in the model coefficients.<sup>38</sup>

## **Results**

The overall response rate including non-Inuit and Inuit individuals was 75% in the September 2012 survey, and 55% in the May 2013 survey.<sup>7</sup> This study examined only those survey participants who self-identified as Inuit (n=663). The proportion of Inuit respondents out of all survey respondents was 64.1% (341) in September 2012, and 61.6% (322) in May 2013. Males and individuals from 0-19 years of age who self-identified as Inuit were significantly under-represented ( $p<0.05$ ) in the September 2012, and May 2013 surveys when compared to the 2011 National Household Census Survey for the Inuit population in Iqaluit (Table 2.2).

### **AGI Annual Incidence and Proportion for Inuit in Iqaluit**

In Iqaluit, the proportion of Inuit individuals who stated that they had symptoms of AGI in the course of one year was 96.2%. Using combined data (September 2012 and May 2013) and a 14-day recall period the Inuit-specific annual incidence and Inuit-specific age-adjusted annual incidence were 3.2 (95% CI: 2.0-4.5) and 3.2 (95% CI: 2.0- 4.4) episodes per person-year respectively (Table 2.3).

### **AGI Factors for Inuit in Iqaluit**

In the combined 2012-2013 multivariable logistic regression model, consumption of country fish, and consumption of raw meat were associated with increased odds of AGI (Table 2.4). Furthermore, females, and households where those responsible for food preparation were employed were also significantly associated with increased odds of AGI. Perception of 'fair', 'poor', or 'very poor' water quality was significantly associated with increased odds of AGI. The month variable (i.e., September/May) was not significant in the combined 2012-2013 analysis.

The September 2012 and May 2013 models had differing independent variables that were significantly associated with AGI. In September 2012, consumption of country fish, females, and households where those responsible for food preparation are employed were all significantly associated with increased the odds AGI (Table 2.5). In May 2013, consumption of dried meat, and a homeless person staying in the home were significantly associated increased the odds of AGI (Table 2.6).



## Discussion

The annual incidence results were consistent between Inuit and non-Inuit populations in this Iqaluit based study, and also comparable to results found in Rigolet, an Inuit community in Nunatsiavut (Northern Labrador)<sup>7</sup> where 85% of the population is Inuit.<sup>39</sup> We found Inuit-specific annual incidences of AGI in Iqaluit to be approximately three times higher than those reported in other studies nationally using similar methodology using both broad and specific case definitions (Figure 2.2).<sup>3-5,36,40</sup> Similar study methodologies were used to find annual AGI incidence in Argentina,<sup>15</sup> Australia,<sup>18</sup> Cuba,<sup>19</sup> Denmark,<sup>20</sup> Hong Kong,<sup>21</sup> Italy,<sup>13</sup> Malta,<sup>22</sup> Netherlands,<sup>23</sup> Poland,<sup>12</sup> and the United States.<sup>11</sup> Each of these international studies reported lower annual incidences than this study. The higher rates of AGI for Inuit in Iqaluit compared to other national and international incidences highlight the need to review current community-level health strategies and to discuss ways to help reduce this burden. In both Rigolet and Iqaluit, where a large proportion of the populations are Inuit, continued efforts to incorporate Inuit-specific factors for AGI as well as cultural, social, political, and economical experiences into health strategies may help reduce this burden.<sup>41</sup>

The annual incidences were not significantly different between Inuit and non-Inuit populations, but factors significantly associated with AGI differed between Inuit and non-Inuit populations in Iqaluit. Previous studies have found differing factors among subpopulations for infectious disease, including AGI;<sup>42,43</sup> however, often differing factors are accompanied by differing incidences between subpopulations.<sup>42,43</sup> This may

be as a result of a common unknown exposure that is creating spurious associated factors for each subpopulation, or may simply mean that there are differing pathways, both creating similar annual incidences of AGI in Iqaluit. Further exploration of mutual and differing behaviours between Inuit and non-Inuit populations in Iqaluit is warranted to better understand these differences.

Consumption of country fish, and households where those responsible for food preparation were employed were significantly associated with increased odds of AGI in both the Inuit-specific analysis with this study and previous analyses in Iqaluit (both Inuit and non-Inuit) at the population level.<sup>7</sup> The perception of ‘fair’, ‘poor’, or ‘very poor’ water quality, being female, consumption of raw meat, as well as consumption of dried meat were all associated with an increased odds of AGI at the Inuit specific-level but were not significantly associated with an increase in AGI in the whole population assessment in Iqaluit.<sup>7</sup>

Pathogens can contaminate both store bought and country meat at many stages, including during harvesting, slaughtering, processing, storing, or transporting.<sup>44</sup> Consumption of raw meat in general is a factor for AGI consistent with literature.<sup>24,45-49</sup> Any raw meat consumption, including country meat, can increase the risk of exposure to foodborne pathogens that can cause symptoms of AGI.<sup>24,45-49</sup> For many Inuit, consumption of raw country meat including marine mammals (e.g., seals, walrus, narwhal) and land mammals (e.g., caribou, muskox)<sup>27</sup> is common practice. Ringed and bearded seals harvested for consumption were found to be contaminated with *Giardia*

*duodenalis* and *Cryptosporidium* spp. in Nunavik.<sup>50</sup> In Nunavut, five outbreaks of trichinosis were attributed to the consumption of raw walrus and seal meat, as well as polar bear meat.<sup>48</sup> The consumption of raw meat is a tradition important for food security and culture within the Inuit population.<sup>7,28–30,46,51–53</sup> Inuit knowledge of choosing, inspecting, and rejecting animals and meat for consumption is traditionally passed down through generations.<sup>51</sup> More research on how the safe consumption and handling of raw meats from hunted animals can be adapted to fit local needs that reduce the potential of the burden of AGI and respect Inuit culture is warranted. A better understanding of how Inuit conduct the selection, inspection, preparation, consumption, and storage of country meat and blending this knowledge with safe raw meat consumption practices<sup>54</sup> in order to prevent AGI may be beneficial. It is mandatory that this work be conducted with local partners. More detailed food safety guidelines applicable to Inuit culture could be used in any Inuit community in Canada where regular consumption of country foods occurs. It is important that food safety guidelines include community specific context to increase local uptake of these results.<sup>55</sup> According to the health belief model, behaviours that influence health are greatly affected by community and personal context, and are determined by personal perceptions about a disease and the strategies available to decrease its occurrence.<sup>41</sup> If messages are able to capture context, and elicit social modeling, whereby an observer can relate to the proposed behavioural change, health promotion strategies may be more successful in influencing health behaviour.<sup>55</sup> In particular, adaptations to food safety guidelines that reflect local perceptions (in both Inuit and non-Inuit communities) may increase local understanding of exposures to pathogens that can cause symptoms of

AGI. These guidelines may aid in development of more suitable health promotion strategies at the community level in order to elicit the intended health behavioural changes to reduce exposures to pathogens that can cause symptoms of AGI.

A higher odds of AGI in females is an association documented in studies across Canada.<sup>3-5,36,56,57</sup> In Canada as a whole, this is generally considered to be because females are often responsible for household food preparation,<sup>58</sup> and thus have the potential for greater exposure to foodborne pathogens through increased food handling of uncooked foods and through cross-contamination of working surfaces.<sup>36,59</sup> This same situation exists within Inuit homes, where women are habitually responsible for food preparation.<sup>27</sup> In northern regions in Canada, previous studies found more females were infected with *Echinococcus granulosus*,<sup>51</sup> had salmonellosis,<sup>33</sup> as well as have higher seroprevalence of *Toxoplasma gondii*<sup>51</sup> compared to men, while more men had giardiasis,<sup>33</sup> campylobacteriosis,<sup>33</sup> and *Helicobacter pylori* infections.<sup>60</sup> This observation could be indicative of a differing level of risk as a result of gender roles with women being exposed to foodborne pathogens more often during food preparation,<sup>3</sup> and as the primary preparer of raw meat<sup>51</sup> in the home, while men are exposed to different pathogens on the land while hunting, fishing, and trapping.<sup>51</sup> Furthermore, Canadian women, including Inuit, often bear the primary responsibilities for childrearing both in the household and community.<sup>58</sup> It is possible children could be a source for person-to-person transmission of diarrheal pathogens to women caring for them, as children are at increased risk of exposure to pathogens via person-to-person contact (e.g., daycare) and environmental transmission in conjunction with undeveloped hand hygiene

practices.<sup>18,61,62</sup> An Australian study demonstrated a higher rate of AGI in women (ages 20 to 40 years) was associated with living in a household with a child under five years and suggested transmission between caregiver and child may occur.<sup>18</sup> Inuit culture places childrearing as a highly meaningful part of the female identity, as such Inuit women are often actively engaged in childrearing duties within their households.<sup>63</sup> In the sense of greater exposure to children who are carrying infections, this places women at a higher risk of AGI through person-to-person contact. The potential for exposure to pathogens through food handling, as well as interacting with children could explain why women were associated with higher odds of AGI among Inuit in Iqaluit. Further research is warranted on unique Inuit gender roles, particularly females, and pathways of exposure and infection including laboratory-based pathogen testing to better understand the type and scope of infective agents behind the burden of AGI for Inuit females in Iqaluit.

There were several limitations to this study. Males and individuals from 0-19 years of age were significantly under-represented which provides the potential for gender and age biases. All diagnosed chronic illness cases of gastrointestinal illness were excluded, but there exists the potential for undiagnosed chronic diseases to be included (i.e., misclassified as an AGI case), and the potential of participants with a known chronic illness or condition to non-disclose, and thus annual incidences and proportions may be overestimates of the true incidence of AGI. As well, a study in a number of locales in the Canadian Arctic on Inuit identified a genetic mutation that causes congenital sucrase-isomaltase deficiency that also causes AGI symptoms, affecting an

approximately 5-10% of Inuit.<sup>64</sup> It is unknown if and how this might have impacted this study. There may be underestimates of the true incidence of AGI as a result of recall bias.<sup>65</sup> We can only comment on associations between potential factors and AGI symptoms, but not the direct cause of AGI as we did not test for pathogens. As with any cross-sectional study, associations can be made between potential factors and AGI; however, we cannot know if the factor came before AGI, and thus cannot assume causation.<sup>38</sup> Lastly, an attempt to assess seasonality of AGI was made through inclusion of month as a fixed effect variable without significant findings. We found different factors in both the September and May models; however, in the combined model the variable for month was not significant. Although there were different factors significantly associated with an increase in AGI in each survey month, the statistics do not support that it was as a result of month, but due to other factors. We were unable to assess trends of annual incidence of AGI due to lack of longitudinal community level data in Iqaluit and therefore, unable to assess whether the high incidence we found is trending downward or upward. Long-term community level surveillance would add a time dimension to aid in the overall picture of the burden of AGI for Inuit in Iqaluit.

This study found Inuit-specific AGI incidence at the community level in Iqaluit, and found a higher annual incidence of AGI in this subpopulation than similar studies both nationally, and internationally, but similar to non-Inuit assessments in Iqaluit. This study also identified several unique factors associated with increased odds of AGI within this sub-population compared to the Iqaluit population as a whole, highlighting how factors for AGI can differ for sub-populations within the same geographical

location. Results from this study, with continued Northern partners' collaboration, can advance important information for public health planning, prioritization, and programming for Inuit in Iqaluit and potentially in other Inuit communities.

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## Tables

Table 2.1 Summary of the information gathered in the September 2012 and May 2013 burden of illness surveys in Iqaluit, Nunavut.

Questionnaire Category	Data Collected
Acute Gastrointestinal Illness	<ul style="list-style-type: none"> <li>• Primary and secondary symptoms</li> <li>• Symptom severity</li> <li>• Healthcare seeking behaviour</li> </ul>
Demographic Information	<ul style="list-style-type: none"> <li>• Gender/Sex</li> <li>• Age</li> </ul>
Socioeconomic	<ul style="list-style-type: none"> <li>• Education</li> <li>• Household crowding</li> <li>• Employment</li> <li>• Household expenses</li> <li>• Household items</li> </ul>
Food Consumed	<ul style="list-style-type: none"> <li>• Food Security</li> <li>• Type of food</li> <li>• Source of food</li> <li>• Frequency of food consumed</li> <li>• Preparation and food handling behaviours</li> </ul>
Water Consumed	<ul style="list-style-type: none"> <li>• Primary and secondary sources of drinking water</li> <li>• Piped versus trucked water</li> <li>• Amount consumed</li> <li>• Secondary treatment</li> <li>• Storage of water</li> <li>• Perceived water quality</li> </ul>
Exposure to Animals	<ul style="list-style-type: none"> <li>• Pets</li> <li>• Working animals</li> <li>• Wild animals</li> <li>• Animals in the home</li> </ul>

Table 2.2 Demographics of Inuit in Iqaluit based on 2011 National Household Survey and September 2012 and May 2013 survey responses in Iqaluit, Nunavut, Canada.<sup>66</sup>

Variable	Iqaluit 2011 National Household Survey (No.%)	Sept 2012 Survey Participants (No.%)	May 2013 Survey Participants (No.%)	Combined 2012-2013 Survey Participants (No.%)
Sex	n=3900	n=338	n=317	n=655
Male	1,875 (48.1)	121 (35.8)	124 (39.1)	245 (37.4)
Female	2,025 (51.9)	217 (64.2)	193 (60.9)	410 (62.6)
Age	n=3905	n=338	n=317	n=655
0-19	1715 (43.9)	56 (16.7)	70 (22.1)	126 (19.3)
20-54	1895 (48.5)	221 (66.0)	197 (62.1)	418 (64.1)
55+	295 (7.6)	58 (17.3)	50 (15.8)	108 (16.6)

Table 2.3 Incidences for acute gastrointestinal illness (AGI) for Iqaluit, Nunavut in September 2012, May 2013, and combined 2012-2013.

AGI Incidence	September Inuit 2012	May Inuit 2013	Combined Inuit 2012-2013	Combined Non-Inuit 2012-2013
<i>Study Case Definition: 14-day recall period</i>	n=41	n=36	n=77	n=47
Annual Incidence Rate (episodes/person/year)	3.4 (2.5,4.3)	3.1 (2.3,4.0)	3.2 (2.0,4.5)	3.4 (2.5,4.4)
Age-adjusted Annual Incidence Rate (episodes/person/year)	3.6 (2.7,4.5)	3.0 (2.2,3.9)	3.2 (2.0,4.4)	4.11 (3.1,5.1)
Annual Incidence Proportion	96.6%	95.7%	96.2%	96.7%
<i>Study Case Definition: 28-day recall period</i>				
Annual Incidence Rate (episodes/person/year)	N/A	2.9 (2.4,3.5)	-	-
Age-adjusted Annual Incidence Rate (episodes/person/year)	N/A	2.8 (2.2,3.3)	-	-
Annual Incidence Proportion	N/A	94.7%	-	-

Table 2.4 Univariable and multivariable logistic regression results for combined September 2012 and May 2013 dataset assessing potential factor impact on the odds of acute gastrointestinal illness (AGI) for Inuit in Iqaluit, Nunavut.

Combined 2012-2013 Model		Univariable Analysis <sup>i</sup>			Multivariable Analysis <sup>ii</sup>		
n	Odds Ratio	P	Confidence Interval OR (95%)	Odds Ratio	P	Confidence Interval OR (95%)	
<i>Perception of water quality</i>							
Very poor, Poor, or Fair	140	ref <sup>iii</sup>		ref			
Good, or Very good	501	0.48	0.005	0.28, 0.83	0.42	0.002	0.24, 0.738
<i>Consumption of country fish</i>							
< Half of the meals	545	ref		ref			
Half or more of the meals	103	2.15	0.008	1.22, 3.77	2.81	0.001	1.55, 5.08
<i>Sex</i>							
Male	245	ref		ref			
Female	410	1.82	0.029	1.06, 3.11	2.05	0.014	1.16, 3.64
<i>Employment of person responsible for food preparation</i>							
Not employed	364	ref		ref			
Employed	288	1.60	0.052	0.99, 2.59	1.95	0.010	1.17, 3.25
<i>Consumption of raw meat</i>							
No	294	ref		ref			
Yes	358	1.47	0.126	0.90, 2.41	1.77	0.035	1.04, 3.01
<i>Consumption of raw fish</i>							
No	373	ref					
Yes	280	1.51	0.09	0.94, 2.44	-	-	-

<sup>i</sup> The results from the univariable analysis are only presented for variables with  $p < 0.10$ , unless they were significant ( $p < 0.05$ ) at the multivariable level, however all variables with  $p < 0.20$  were assessed in the multivariable model.

<sup>ii</sup> The results from the multivariable model are only presented for variables  $p < 0.05$ .

<sup>iii</sup> "ref" is an abbreviation of "referent"

Table 2.5 Univariable and multivariable logistic regression results for September 2012 dataset assessing potential factor impact on the odds of acute gastrointestinal illness (AGI) for Inuit in Iqaluit, Nunavut.

September 2012 Model	n	Univariable Analysis <sup>i</sup>			Multivariable Analysis <sup>ii</sup>		
		Odds Ratio	P	Confidence Interval OR (95%)	Odds Ratio	P	Confidence Interval OR (95%)
<i>Country fish consumption</i>							
< Half of the meals	277	ref <sup>iii</sup>			ref		
Half or more of the meals	58	3.50	0.002	1.58, 7.56	4.75	<0.001	2.13, 10.59
<i>Employment of person responsible for food preparation</i>							
Not employed	198	ref			ref		
Employed	139	2.49	0.012	1.22, 5.22	3.18	0.002	1.53, 6.61
<i>Perception of water quality</i>							
Very poor, Poor, or Fair	73	ref			ref		
Good, or Very good	259	0.38	0.013	0.18, 0.82	0.31	0.003	0.14, 0.67
<i>Sex</i>							
Male	121	ref			ref		
Female	217	2.15	0.066	0.96, 5.31	2.39	0.039	1.05, 5.46
<i>Consumption of frozen fish<sup>iv</sup></i>							
No	153	ref			ref		
Yes	184	1.71	0.126	0.86, 3.39	1.33	0.454	0.63, 2.84
<i>Washing counter with disinfectant</i>							
No	516	ref					
Yes	133	2.20	0.067	0.95, 4.84	-	-	-
<i>Exposure to cats in past month</i>							
No	329	ref					
Yes	29	3.18	0.029	1.13, 8.21	-	-	-

<sup>i</sup> The results from the univariable analysis are only presented for variables with  $p < 0.10$ , however all variables with  $p < 0.20$  were assessed in the multivariable model.

<sup>ii</sup> The results from the multivariable model are only presented for variables  $p < 0.05$  or if a confounder.

<sup>iii</sup> "ref" is an abbreviation of "referent"

<sup>iv</sup> Confounding variables are displayed with an\* and also presented in the table regardless of statistical significance.



Table 2.6 Univariable and multivariable logistic regression results for May 2013 dataset assessing potential factor impact on the odds of acute gastrointestinal illness (AGI) for Inuit in Iqaluit, Nunavut.

May 2013 Model	n	Univariable Analysis <sup>i</sup>			Multivariable Analysis <sup>ii</sup>		
		Odds Ratio	P	Confidence Interval OR (95%)	Odds Ratio	P	Confidence Interval OR (95%)
<i>Dried meat consumption</i>							
Less than half of the meals	192	ref <sup>iii</sup>			ref		
Half or more of the meals	124	2.12	0.036	1.05, 4.26	2.25	0.025	1.10, 4.57
<i>Homeless person staying in house</i>							
No	159	ref			ref		
Yes	156	0.58	0.133	0.28, 1.18	2.12	0.044	1.10, 4.57
<i>Dairy consumption</i>							
Less than half of the meals	123	ref					
Half or more of the meals	192	2.07	0.071	0.94, 4.57	-	-	-
<i>Country meat consumption</i>							
Less than half of the meals	229	ref					
Half or more of the meals	85	1.95	0.071	0.94, 4.04	-	-	-
<i>Washing hands before food preparation</i>							
No, not 100% of the time	84	ref					
Yes, 100% of the time	231	0.53	0.082	0.26, 1.08	-	-	-
<i>Exposure to birds in past month</i>							
No	266	ref					
Yes	51	1.94	0.071	0.95, 3.99	-	-	-

<sup>i</sup> The results from the univariable analysis are only presented for variables with  $p < 0.10$ , however all variables with  $p < 0.20$  were assessed in the multivariable model.

<sup>ii</sup> The results from the multivariable model are only presented for variables  $p < 0.05$ . There were no confounding variables in this model, and thus none are included in this table.

<sup>iii</sup> “ref” is an abbreviation of “referent”

## Figures

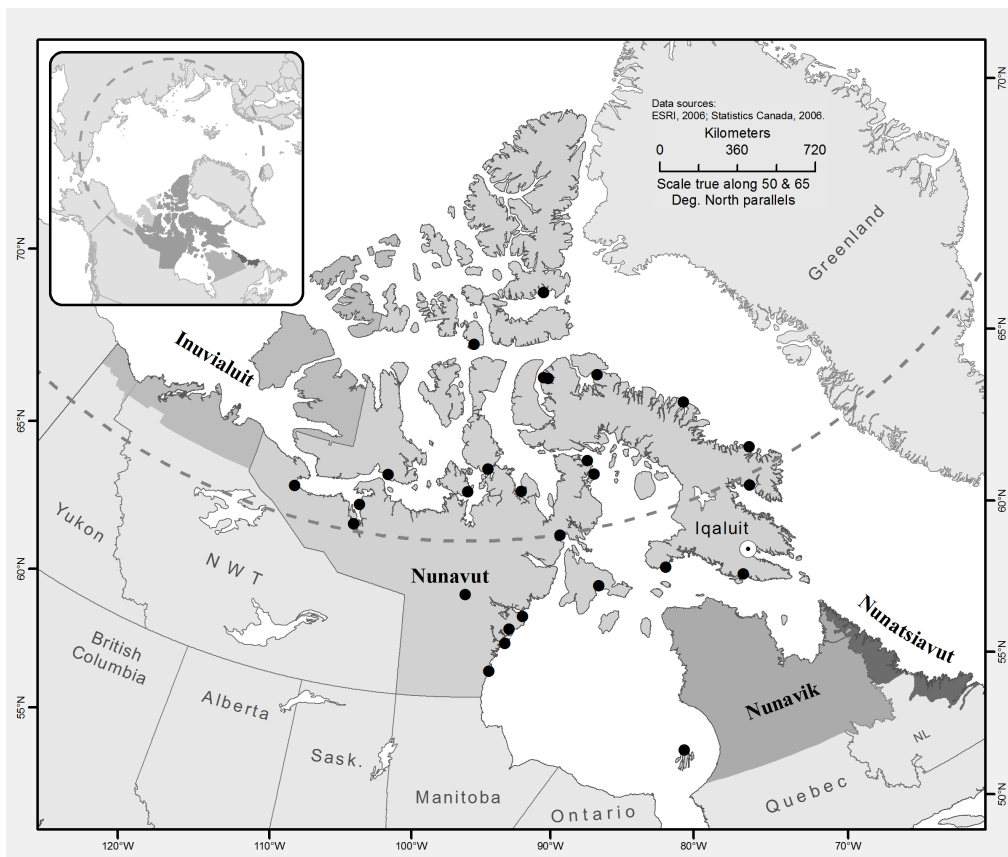


Figure 2.1 Iqaluit, Nunavut's location in the context of Canada and Greenland.

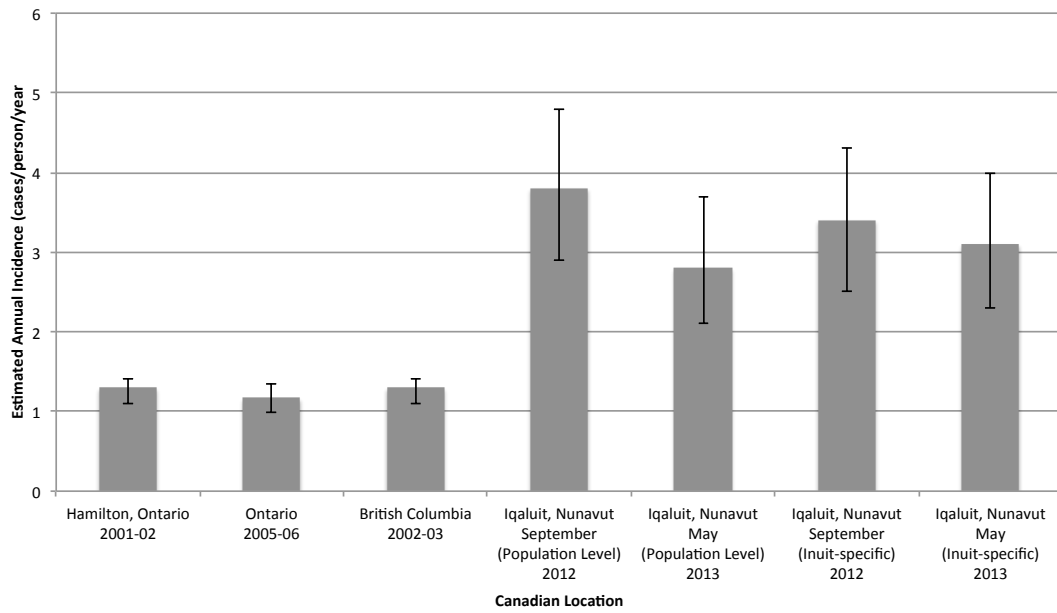


Figure 2.2 A bar plot of select annual incidences of AGI in Canada.<sup>3-5,7,36,40</sup>

# **CHAPTER THREE: RESULTS FROM A SCOPING REVIEW: CONTEXT, COMMUNITY ENGAGEMENT, AND COHESIVE MESSAGING IN HEALTH RESEARCH KNOWLEDGE TRANSLATION IN INUIT COMMUNITIES**

## **Abstract**

### **Background**

In applied health research, knowledge translation (KT) it is important to improve population health outcomes. For Inuit communities, differential social, geographical, and cultural contexts may require unique KT practices compared to methods commonly used in non-Inuit populations.

### **Purpose & Objectives**

The purpose of this scoping review was to better understand health research KT in Inuit communities in the Circumpolar North. This scoping review (1) examined the extent, range, and nature of existing health-related KT literature; and (2) identified common themes presented in literature involving health-related KT assessment activities in Inuit communities in the Circumpolar North.

### **Methods**

A scoping review was conducted by first constructing a search string, which was used to search two English aggregator databases, ProQuest and EBSCOhost, on March 12, 2015. Additionally, 3 key English journals were hand-searched for relevant articles,

including *International Journal of Circumpolar Health*, *Arctic*, and *Inuit Studies*. To be included, studies had to assess KT methods and approaches that were used to share human health research results in Inuit communities in the Circumpolar North. Study selection was conducted, based on inclusion and exclusion criteria, by two independent reviewers using relevance screening forms. Finally, relevant articles were charted and thematically analysed.

## **Results**

From 680 unique records identified in the initial search, 11 met the inclusion criteria and were retained for analysis, and an additional 6 were identified through the hand search of journals. Thematic analysis identified three themes: the value of community stakeholders as active members in the research process; the importance of context in tailoring KT strategies and messaging; and one subtheme indicated challenges with varying and contradictory messaging in KT. A crosscutting gap in the literature, however, included a lack of critical assessment of community involvement in research. The review also identified a gap in assessments of KT in the literature; generally, assessments were not focused on whether research had successfully elicited its intended action but instead focused on whether KT methods fit with cultural, social, and geographical needs of the community.

## **Conclusions**

Results from this review on this small, but burgeoning area of research, call for future KT in health research to be formally evaluated on its success or failure to elicit its

intended action. Further, it is important to continue to work toward actively deconstructing power dynamics in the KT process between researchers and researched. Community engagement is important; however, more discussion and discourse on the tensions, challenges, and opportunities for improvement is necessary.

**Keywords:**

Inuit, Circumpolar North, knowledge translation, knowledge transfer, knowledge exchange, dissemination, results sharing, health, public health messaging, stakeholder, community, scoping review

**Introduction**

The purpose of applied research that examines biological, social, cultural, and environmental interactions influencing human health is to contribute to the development of actions that will improve the health of populations.<sup>1</sup> In an effort to fulfill this purpose, many health research funding agencies have recognized the importance and necessity of the transmission and exchange of new and existing health knowledge between researchers and community stakeholders (e.g., other researchers, practitioners, policy-makers, community members).<sup>2-4</sup> Indeed, the creation of new knowledge from research is, on its own, unlikely to lead to implementation or improvement of population health; therefore, a process to translate knowledge into practical action is necessary.<sup>5</sup> Additionally, there is increased pressure from the public on government research funding agencies for accountability through evidence of the benefit of investment in health research.<sup>5</sup> Knowledge translation (KT) is a widely used

term that describes the attempt to move research results into practical action. There are, however, many other terms used in health research to describe knowledge-sharing with similar functions, such as “knowledge transfer,” “knowledge exchange,” “dissemination,” “results sharing,” among others (Table 3.1).<sup>6,7</sup> The concept of KT is broad and commonly involves “end of grant” KT, whereby KT researchers inform community stakeholders of the knowledge gained from research.<sup>5</sup> More recently there has been a move toward “integrated KT”, whereby community stakeholders are involved throughout the research process,<sup>8,9</sup> working together to build the research question, develop the methods and data collection tools, as well as being involved actively in data collection, results interpretation, and results dissemination.<sup>5</sup> For the purpose of this paper, the term KT will serve as an all-encompassing term for those knowledge-sharing activities that involve moving research results to practical action in some capacity, ranging from KT approaches that are integrated throughout the research process (e.g., integrated KT), to research results dissemination (e.g., end of grant KT).

Methods for KT are diverse and growing.<sup>6</sup> The KT methods used to facilitate the uptake of research results are ideally determined by the needs of community stakeholders involved and the nature of the health research.<sup>6,7,10</sup> For instance, differential social and cultural mechanisms of communication, along with historical, political, and economic contexts within Indigenous<sup>i</sup> populations, may necessitate unique approaches to transmission and exchange of health knowledge.<sup>9,10</sup> In the Circumpolar North (Figure

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<sup>i</sup>An internationally recognized description of the term “Indigenous” through the United Nations (UN) includes individuals self-identifying as Indigenous with strong connections to the natural environment, and unique social, economic and political systems. Indigenous peoples have unique language and culture, and are minority groups wishing to maintain their distinct ancestral environment and systems.<sup>79</sup>

3.1), where a majority of the Inuit<sup>i</sup> population resides, local uptake of research results is particularly important because Inuit continue to experience health inequities compared to non-Inuit (e.g., lower life expectancies, higher infant mortality rates, higher infectious and chronic disease rates, and more mental health and wellness challenges).<sup>11,12</sup> As such, health research KT in Inuit communities is particularly important to move research results into practical action.<sup>13-18</sup>

It is important to understand how approaches to KT of Inuit health research do or do not reflect differential cultural, political, economic, and social norms within Inuit communities to increase local uptake of research results. Further, it is important that health researchers assess the success or failure of their KT to elicit its intended action. As such, the purpose of this scoping review was to better understand health research KT conducted within Inuit communities in the Circumpolar North. Specifically, the scoping review (1) examined the extent, range, and nature of existing health-related KT literature; and (2) identified common themes in health-related KT assessment activities in Inuit communities in the Circumpolar North.

## **Methods**

Five key stages were used in this scoping review: (1) research question identification and search query development; (2) relevant study identification; (3) study selection; (4) data charting; and (5) results collation, summarization, thematic analysis, and reporting.<sup>19,20</sup>

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<sup>i</sup> Peoples described as “Inuit” include individuals self-identifying as Inupiat, Yupik (Alaska), Inuit, Inuvialuit (Canada), Kalaallit (Greenland) and Yupik (Russia).<sup>23</sup>



### **Research Question Development, Data Sources, and Search Strategy**

The research question identified was “What does the literature tell us about knowledge translation in Inuit communities in the Circumpolar North?” To develop a search query to investigate this question, a preliminary search of general KT articles was conducted to better understand terminology used in published papers and to create a broad list of potentially relevant terms. A library scientist assisted in developing various combinations of terms to develop a search string that included concepts (e.g., KT terms), populations (e.g., Inuit in Circumpolar locations), and outcomes (e.g., health and wellbeing). The final search string (Table 3.2) was used to search EBSCOHost and ProQuest® aggregator databases with select electronic databases (Table 3.3), including peer-reviewed and grey literature. Searches were conducted on March 12, 2015, and limited to English language publications. The searches were not limited by year (except for restrictions on database capacity). In addition to the database searches, three key journals (*International Journal of Circumpolar Health*, *Arctic*, and *Inuit Studies*) were hand-searched for relevant articles published in the last decade (March 2005 to March 2015). All returned citations from database searches were exported into RefWorks© online research management tool, and then exported into the systematic review software DistillerSR where all duplicates were removed.

### **Eligibility Criteria**

To be included, studies had to assess KT methods and approaches used to share human health research results in Inuit communities in the Circumpolar North. Specifically, KT

activities had to include some form of assessment (e.g., quantitative and/or qualitative evaluations, and/or reflections) of those knowledge-sharing activities (i.e., integrated KT and/or KT involving results dissemination). The World Health Organization's definition of health was used to define human health, which involves a holistic understanding of health (i.e., physical, mental, and social well-being) and not simply the absence of disease.<sup>21,22</sup> Therefore, the health research topic had to include an investigation of the physical, mental, or social well-being of humans to be considered. Research results being shared about the environmental impact on human health were considered, but those focused solely on the health of the environment were excluded. Studies had to focus on peoples originating from Thule culture, using the Inuit Circumpolar Council definition, including Inupiat, Yupik (Alaska), Inuit, Inuvialuit (Canada), Kalaallit (Greenland) and Yupik (Russia).<sup>23,24</sup> In particular, this review considered articles that engaged Inuit in the KT activity itself (i.e., Inuit were transferring, exchanging, or receiving knowledge). Strategies for KT with a non-Inuit target audience (e.g., academic poster presentations targeting southern scientists) and studies that used pan-Indigenous (e.g., combining First Nation, Métis, and Inuit populations together) instead of Inuit-specific approaches were excluded. Studies conducted in countries in the Circumpolar North where Inuit live were considered, which includes parts of Canada, Alaska (United States), Greenland, and Chukotka (Russia).<sup>23-25</sup>

### **Relevance Screening**

To identify relevant articles, a two-stage screening process was used. First, two independent reviewers screened the title and abstracts of all returned citations using a form developed in advance of the review (Appendix 2). Then, the relevant citations were reviewed in full for relevance using a form developed prior to the review by the same two independent reviewers (Appendix 3). To be included in the review analysis, all inclusion criteria needed to be met at both levels (title/abstract, and then full text) by both reviewers. Conflicts were discussed between reviewers; if a consensus could not be reached, a third reviewer decided if the study would be included. The degree of agreement between reviewers was assessed (i.e., inter-rater agreement via Cohen's Kappa) for both stages of screening (i.e., title/abstract, and full-text). The hand-search of the three key journals used the same inclusion/exclusion criteria as database searches.

### **Data Extraction and Synthesis**

Data were extracted from the included studies using a charting form to capture both descriptive numerical information, as well as study results.<sup>20</sup> Descriptive information extracted included author(s), year of publication, year of study, location of study within the Circumpolar North, type of document (e.g., journal article, thesis), specific health subfield, and health outcome studied (Table 3.4). The methodology for KT was also charted, including the KT method used, method of KT assessment, and outcome measures of KT success. The charting form also captured information on important results described in the studies regarding KT (Table 3.4).

## **Thematic Analysis**

Thematic analysis was conducted by one reviewer.<sup>26</sup> Charted data were repeatedly read and actively searched for potential patterns, and an initial list of potential codes was developed, prior to commencing manual inductive coding of excerpts from charted data.<sup>26</sup> Themes were created by grouping common codes, and then collapsing (i.e., two subthemes collapsed into a broader common theme), and discarding (i.e., not enough data to support theme, or data were too diverse).<sup>26</sup> When themes were finalized, entire studies were reread and excerpts missed in original coding were added.<sup>26</sup>

## **Results**

### **Descriptive Numerical Summary: Characteristics of Included Studies**

From 680 unique records identified in the initial search, 11 articles met the inclusion criteria and were retained for analysis, and an additional 6 were identified through the hand search of journals (Table 3.5, Figure 3.2). There was strong agreement between reviewers at the title/abstract level (inter-rater reliability was high at  $k = 0.82$ ) and full-article screening level (inter-rater reliability was high at  $k = 0.84$ ). Most articles described studies conducted in Canada, and all studies were published between 2005 and 2013 (Figure 3.3).

There was a wide variety of KT methods assessed in the articles (Figure 3.4).<sup>27</sup>

Fourteen studies (82.4%)<sup>27-40</sup> used oral KT methods (e.g., radio, presentation, open house, meeting) in conjunction with, or instead of, written KT methods (e.g., poster,

report). A wide variety of health outcomes were discussed in the studies, including environmental health,<sup>34,38,40</sup> diet and nutrition,<sup>27,31,37</sup> drinking water,<sup>41</sup> zoonotic parasites,<sup>35</sup> epidemiology,<sup>42</sup> substance misuse (i.e., drugs and alcohol) and fetal alcohol spectrum disorder (FASD),<sup>32</sup> lifestyle behaviours,<sup>27,32,36</sup> contaminants,<sup>28,29,36</sup> sexual health,<sup>11</sup> heart and vascular disease,<sup>33</sup> as well as genetics.<sup>27,30</sup>

Assessment of KT activities in reviewed studies ranged from reflections on the KT process (e.g., author of the article commented on what did or did not work in the KT strategy used in their study without any formal assessment), to quantitative evaluations (e.g., Likert scale questions, independent and paired t-tests) (Figure 3.5a). Reflection on the KT strategy was used as the sole assessment tool in 10 studies (58.8%).<sup>27,28,30-33,36,38-40</sup> Qualitative evaluation were used in four (23.5%),<sup>34,35,41,42</sup> and mixed quantitative and qualitative evaluations were used in three (17.6%)<sup>27,29,37</sup> studies. Thirteen (76.5%) studies assessed whether KT methods fit with social, political, and cultural needs or preferences of communities.<sup>11,27,30,32,34-42</sup> For example, one study examined preferences of KT methods through interviews with community stakeholders to obtain recommendations for effective and appropriate dissemination strategies and found KT methods that were interactive, oral-visual, and presented in both English and Inuktitut were preferred.<sup>35</sup> Seven (41.2%) studies<sup>11,29,34,37,40</sup> assessed whether the research evidence had effectively moved to action through their assessment of the extent of local uptake, and implementation of policy outcomes. For example, local uptake of information was assessed in one study, which formally evaluated whether Elder stories on DVD were successful in transferring traditional knowledge about

nutrition to youth using a comparison of pre and post DVD questionnaires distributed to youth (e.g., independent and paired t-test, content analysis, Likert scale interpretation).<sup>37</sup>

### **Themes Identified in the KT Literature**

#### VALUE OF COMMUNITY STAKEHOLDERS AS ACTIVE MEMBERS IN THE RESEARCH PROCESS

All studies indicated the necessity of community involvement (29.4%),<sup>27,31,37-39</sup> importance of context (29.4%),<sup>28,29,34,41,42</sup> or both (41.2%) for KT in Inuit communities in the Circumpolar North (Figure 3.5b).<sup>11,30,32,33,35,36,40</sup> Involvement of community stakeholders in the original research was described as a contributing factor to the success of integrated KT throughout the research process in 12 (70.6%) studies.<sup>11,27,30-33,35-40</sup> One study informally reflected that the development of Inuit ownership of the research project seemed to increase KT success.<sup>39</sup> Another study reflected that the overall success of integrated KT was attributed to developing trusting partnerships with stakeholders, which appeared to allow researchers to anticipate and avoid potential problems and misunderstandings.<sup>27</sup> Indeed, other studies echoed similar findings, reflecting that their partnership with community-based researchers was central to the success of integrated KT efforts throughout the research process, increasing the validity and relevance of research results improving the potential for local uptake of research.<sup>35,36,38,40</sup> For instance, one study reflected that consultation with community stakeholders helped improve appropriateness of both content and delivery of KT efforts.<sup>36</sup> Studies reported that approaches to KT were strengthened when local

participants directed and disseminated communication of research results.<sup>34,35,37</sup> For example, a study indicated that involvement of specific groups – such as youth – in the communication of research results was viewed as advantageous for uptake by local research partners especially for parents of the youth.<sup>35</sup> In an online community of interest that was developed to serve as a KT platform, participants in the online community of interest believed that they could have further enhanced KT by helping to develop the platform itself to increase the validity and relevancy of the KT method.<sup>42</sup> All 12 studies<sup>11,27,30–33,35–40</sup> that discussed community involvement in the research process, stated that engaging community members was key to the success of KT; however, they did not evaluate the impact, if any, that this approach had on local uptake of research results. Furthermore, minimal analysis of the tensions and challenges (if any), or opportunities for improvement was included in the KT assessments. None discussed a decision-making process to decide when, and how much community involvement should occur, or to decide which community stakeholders should be involved. None assessed the appropriateness of varying involvement of community stakeholders and the effect on successful KT. Yet, there were obvious variances in community involvement between studies based on the nature of the project and purpose of the KT. For instance, one study engaged women of child-rearing age to determine best pathways for dissemination of environmental health risk messages to women of child-rearing age.<sup>34</sup> Another study found that engagement of community leaders in the research processes seemed to enhance and expedite research to policy in mandating changes to reduce *trans*-fat intakes in Northern Québec.<sup>31</sup>

## IMPORTANCE OF CONTEXT IN TAILORING KT STRATEGIES AND MESSAGING

Attention to local community context (e.g., cultural, social, and geographical environments) and target audiences (e.g., community specific, women of child-rearing age) were identified as an important consideration for successful KT in twelve studies (70.6%).<sup>11,28–30,32–36,40–42</sup> For example, young females were interviewed about past and future food contaminant messaging, and identified that “if the material was deemed irrelevant to their setting and the food choice options they have, it may be disregarded no matter how clear or otherwise balanced the message is.”<sup>34,p.105</sup> The study discussed that KT efforts may be fruitless if local challenges in making the intended behavioural change in response to health research are not understood (e.g., suggesting to young women not to eat a particular food when other options are limited; suggesting not to eat a particular food, if it has important cultural implications).<sup>34</sup> The young female interviewees also suggested attention to social context (e.g., influential KT brokers, sharing networks, pathways of communication used in a particular subgroup) plays a role in successful KT strategies; in particular, many informal pathways (e.g., family, friends) were preferred for transmission of nutritional issues.<sup>34</sup> Indeed, another study found that youth are influential KT brokers, as focus groups and key informant interviewees preferred dissemination strategies where “children were identified as key elements of KT efforts because their involvement in the delivery of research results would increase impact of the message due to their influential role in the community, especially their parents.”<sup>35,p.107-108</sup>



Geographical location was described in one study as an aspect of local context that must be considered in some KT processes.<sup>41</sup> Community stakeholder interviewees in one study, identified remoteness of target communities (e.g., “communities with less than 150 people per square kilometer”)<sup>43,para1</sup> as a barrier to effective KT; remoteness was reported as especially problematic for KT involving training programs (e.g., employee training for small community drinking water facility in response to new research amending regulatory oversight).<sup>41</sup> Interviewees in the same study described distance, weather, and lack of roads going into the community as major obstacles in holding training courses, and suggested adaptations to in-person KT approaches, such as training videos or call centres may help to overcome these barriers.<sup>41</sup>

Many of the studies that suggested the importance of context in KT came from community stakeholders via interviews<sup>11,34,35,41,42</sup> and focus groups.<sup>11,34,35,41,42</sup> Other studies included extensive reflections based on the researchers’ active participation in activities such as workshops, open houses, community meetings, and household visits.<sup>30,33,36</sup> There were, however, a few KT assessments that highlighted the importance of local context in the form of informal reflections with no analysis.<sup>28,32</sup> For instance, in one study the KT method used was described as successful based on a single positive email from a participant.<sup>32</sup>

#### CHALLENGES WITH VARYING AND CONTRADICTORY MESSAGING IN KT

A challenge discussed by three (17.6%) of the studies was the lack consolidation of KT efforts between research groups and organizations, leading to varying and sometimes

contradictory messaging causing confusion among target audiences.<sup>29,31,34</sup> These three studies were all related to KT of dietary nutrition or contaminant research.<sup>29,31,34</sup> One study conducted a survey to evaluate the degree to which community stakeholders had been exposed to and comprehended messages about contaminants in country food, and reported that the information had not been broadly received.<sup>29</sup> The author of the study discussed that one of the reasons Inuit “reception, acceptance, and understanding”<sup>29,p.58</sup> of contaminants in country food was low may be due to changing and conflicting messages over the years from KT efforts (e.g., “contaminants are bad for them; but country food is the best food; they are being “poisoned” by southern pollution, but are blessed by a strong, nutritious, culturally valued, country food tradition”<sup>29, p.57</sup>). The complexity of the science behind nutrition and contaminants, along with lack of coordination in messaging between studies was believed to lead to confusion around consumption of country food and therefore, confusion around appropriate behavioural changes that needed to be made.<sup>29,31,34</sup> Another study, however, found that interviews with key informants, focus groups, and content of documents in a community indicated the majority of information on contaminants was presented to the community in a balanced way, displaying both risks and benefits for consumption of country foods. Participants indicated that presenting risks and benefits resulted in confusion and “the recipients of the messages on contaminants and wildfood show[ed] some confusion over “the bottom line” around consumption of wildfood(s)- is it safe to eat? Is it not safe to eat?”<sup>34,p.75</sup> The authors further noted that outreach messaging was more successful, clearer, and easier to understand when organizations presented a joint

message (e.g., cohesiveness of the message from trusted organizations made the intent of the message easier to base decisions upon).<sup>34</sup>

## **Discussion**

The small, but burgeoning number of assessments of health-related KT in peer-reviewed publications suggests there is still much to be studied about KT in the Circumpolar North. This small number of Inuit KT assessments reflects an international trend of small but increasing growth in the KT field.<sup>7</sup> For instance, a study, not restricted to Indigenous populations, investigated health research funding agencies' support and promotion of KT through semi-structured interviews with key informants from 33 agencies from Australia, Canada, France, Netherlands, Scandinavian Countries, the United Kingdom, and the United States.<sup>7</sup> The study found that despite recent interest in KT, the concept of KT seemed to be relatively new to the agencies in the study; however, international funding agencies perceived themselves as having generally increasing but variable roles in KT.<sup>7</sup> To learn from past successes or failures in KT, it is strongly suggested assessment of the KT process take place, and that researchers disseminate the KT assessment results in a format that is accessible and available to future projects and researchers (e.g., peer-reviewed journal article). Researcher reflections on their own experience with KT methods can be useful for developing KT strategies; however, critical assessment of tensions and challenges (if any), or opportunities for improvement in various stages throughout KT is necessary. Although KT method(s) should fit the needs and preferences of the community,<sup>11,28-30,32-36,40-42</sup> few assessments of KT in this review measured local uptake of research, or

the efficacy of moving research results to practical action in some way. Assessments need to formally evaluate KT success or failure in eliciting its intended action. Given the often negative history of Indigenous health research,<sup>13,44-48</sup> it is important that promises of action are kept, so as to strengthen the Inuit/non-Inuit relationship further.<sup>49</sup> There is still a lot to learn about moving research results into practical action – especially in Inuit communities where little is known about local uptake of research results within Inuit knowledge sharing systems and ways of knowing.<sup>36,50,51</sup>

The timing and large proportion of studies conducted in Canada could be due partially to endorsement of KT from major Canadian government agencies such as Canadian Institutes of Health Research (CIHR)<sup>11,31,34,35,37,40,41,52</sup> and Health Canada.<sup>32,36</sup> Indeed, the increase of published KT literature in Canada came one year after the CIHR released a Knowledge Translation Strategy in 2004 with specific objectives to fund grants that support KT research.<sup>53</sup> Furthermore, another study stated that “CIHR is recognized within Canada and internationally for leading and funding the advancement of KT science and practice,”<sup>54,p.1</sup> which could help explain the predominantly Canadian papers identified in this review. While fewer studies were captured from the United States<sup>27,30,33</sup> and Greenland,<sup>11</sup> KT is still recognized as important by the US National Institutes of Health,<sup>27,30,33</sup> and Greenlandic Medical Research Council.<sup>11</sup> The limited studies included from Russia, USA, and Greenland does not necessarily mean assessments of KT are not being done in these countries, but could also be a result of our English-only search strategy, and/or lack of peer-review publications of such assessments from these countries.<sup>19,20,55</sup>

Indigenous research, including the KT process, can be met with skepticism and resentment of non-Indigenous academic researchers by Indigenous peoples in some communities.<sup>13,44-48</sup> In decades of research on Indigenous peoples, academic researchers have “parachuted” into communities to collect data (historically, often without consent) with little to no KT involving community stakeholders before, during, or after the study process.<sup>13,44-48</sup> Attempts have been made to improve research methods by focusing on community participation, capacity development, and social equity;<sup>44,47</sup> however, there continue to be embedded power dynamics such as conflicting goals between universities and communities, hierarchy of scientific knowledge over Indigenous knowledge, and the production of knowledge by researchers that has little to no value to the community.<sup>13,44-48</sup> We found that interactive oral KT compared to written or less interactive KT was most commonly used in Inuit communities, which is supported by the extended literature as a preference by Inuit and other Indigenous groups.<sup>56,57</sup> Future health research projects in Inuit communities should consider the incorporation of oral methods when building KT strategies as Inuit have a strong oral history and culture.<sup>47</sup> While oral methods are appropriate for cultural and historical reasons, they may not be sufficient in improving embedded power dynamics between researchers and researched. Narrative or story-based approaches to data collection have been characterized as being less exploitive than other forms of data collection, and could be expanded to approaches in KT,<sup>47</sup> providing a method for giving voice to Indigenous communities through sharing stories.<sup>45,47,58</sup> Influence from non-Inuit researchers on the stories shared through narrative or story-based approaches (e.g.,

selection and interpretation of stories shared), however, can perpetuate these power dynamics despite attempts to avoid this; as such, they should be used with caution.<sup>47</sup> One way researchers have attempted to diminish power dynamics in data collection is through methods such as digital storytelling, where Inuit are able to create and control their own research framework, in their own voices.<sup>47</sup> If methods such as digital storytelling can decrease power imbalances in primary data collection, then perhaps it could also reduce power imbalances in KT, whereby knowledge is generated by the community and disseminated through methods untouched by non-Inuit researchers. It may be necessary to rebuild the KT methodological framework for Inuit communities, such that it is grounded in Inuit oral histories and cultural practices, and based on actively attempting to deconstruct power dynamics in the KT process between researchers and researched, and Inuit and non-Inuit.<sup>47</sup>

Community participation as a driver for successful KT was a theme echoed by the findings of van der Velde *et al.*,<sup>59</sup> in their assessment of participatory action research (PAR) in the context of multiethnic mental health research and KT. The researchers examined the degree of success relative to the four main tenets of PAR – empowerment, social change, participation, and learning (or KT), and found that success in each of the tenets was dependent on the level of community stakeholder participation in the research process.<sup>59</sup> Participation was viewed as the ‘gateway’ for engaging in PAR, while successful KT, opportunities for learning, and empowerment supported continued engagement in the research process.<sup>59</sup> The inclusion of community stakeholders and community research assistants in the study process allowed integrated,

and often informal KT between external and internal community researchers, which can aid in the integration of community values, knowledge, and technical assessments in KT processes.<sup>60</sup> This engagement with community researchers can lead to a more informed and culturally-relevant KT strategy, which promotes successful dissemination and utilization of research.<sup>57</sup> Indeed, in a study that examined factors that influence environmental health KT processes in Canadian Indigenous communities (i.e., Inuit, First Nations, and Metis), decision making actors identified participatory processes as fundamental to successful dissemination and utilization of research.<sup>57</sup> Recently, literature has questioned whether or not engagement of community stakeholders in the entire research project is appropriate in all projects at all times.<sup>49,61-63</sup> There is a need to move beyond uncritically advocating for community engagement, towards discussion and discourse on the tensions, challenges, and opportunities for improvement in community engagement.<sup>49</sup> Similarly, assessments of KT should include a critical discussion of the role of community engagement and its affect on whether the KT outcome was achieved. Development of guidelines for the decision-making process around when and how much community involvement should occur, and by which community stakeholders would be useful in building strategies for appropriate community engagement.<sup>49</sup>

There are strong arguments for research, particularly in Indigenous populations, that is self-determined (e.g., owned, controlled, accessed, possessed) by Indigenous communities;<sup>64</sup> however, the review only captured one study that explicitly indicated that the community had taken ownership over the entire research process, including

KT.<sup>39</sup> One method of facilitating community ownership of KT processes throughout the research project, is through the use of negotiated Indigenous research agreements as a natural extension of participatory research.<sup>9,65</sup> For instance, the Canadian Tri-Council,<sup>65</sup> as well as the Australian Institute of Aboriginal and Torres Strait Islander Studies<sup>9</sup> created a set of guidelines for conducting research with Indigenous partners, whereby complete ownership of the data by Indigenous partners is considered a major principle. These agreements could be advantageous to KT in some communities; however, for other communities these types of formal research negotiations may hold negative connotations stemming from periods during colonization when forceful signing of contracts took place.<sup>66</sup> In communities where formal signed research negotiations hold negative connotations, oral negotiations may be more appropriate.<sup>66</sup> It is important to ensure clarity of KT expectations (before, during, and after the study) of all concerned (e.g., funders, researchers, community). It is essential that research bodies in the Circumpolar North continue to commit to equitable research including KT with Indigenous communities, by thinking critically about equitable ownership of research production and dissemination.

Our study found that a comprehensive understanding of the context of target subgroup(s) increased the likelihood of finding appropriate KT methods.<sup>67,68</sup> The aim of both health promotion and KT is to use health topic knowledge to elicit an action from community stakeholders; therefore, examination of the literature on health promotion may help to enhance KT strategies to improve moving research results into practical action. The necessity to tailor KT strategies for individual Inuit communities and



subgroups within Inuit communities can be understood through the Health Belief Model. The Health Belief Model explains local health promotion is greatly affected by community and personal context, and are determined by personal perceptions about a disease and the strategies available to decrease its occurrence.<sup>69</sup> We can apply the Health Belief Model (or other health behavior models) to KT. For instance, subgroup and individual uptake of research results through KT may be explained by the perceived seriousness of disease, susceptibility to disease, and benefits and barriers to behavioural change.<sup>69</sup> Perceptions about a disease and the strategies available to decrease its occurrence can be very different between subgroups and can be modified by cues to action (e.g., events, people, or things that motivate behavioural change), motivating factors (e.g., culture, education level, past experiences), and self-efficacy (i.e., belief in one's own ability to do something).<sup>69</sup> Strategies for KT may be more effective if they incorporate understandings of local or target subgroup cues to action, motivating factors, and self-efficacy. To strengthen self-efficacy, the KT message must be relatable to the target audience.<sup>69</sup> Self-efficacy can be increased through social modeling, whereby an individual observes another similar to oneself successfully changing health behaviour, thereby strengthening the observer's belief that they too can master such a change.<sup>69</sup> Approaches for KT that are tailored to the community, and individual subgroups may improve self-efficacy. If KT messages are able to capture the particular Inuit community or subgroup's context, and elicit social modeling, KT may be more successful in influencing health behaviour within particular subgroups.

Literature outside this review on Indigenous and non-Indigenous populations found tailoring the research process to specific subgroups helped promote the development of

more nuanced and relevant research for the participants and community, and is enhanced by involving members of the subgroup in KT strategies.<sup>70,71</sup>

Conflicting messaging is a challenge in health-related KT in the Circumpolar North, and is also a common challenge in public health promotion globally.<sup>72,73</sup> Contradictory messaging can cause confusion among community stakeholders with what behavioural changes or actions are appropriate.<sup>34</sup> Health researchers working with Inuit communities must find ways to increase the cohesiveness and reconciliation of their messages involving contradictory findings across studies. Active involvement of community stakeholders as liaisons between research projects can encourage discussion across research groups helping researchers increase their own awareness of previous results that were communicated and may be outdated.<sup>72,73</sup> This increased coordination between research groups can improve cohesiveness of messages in the future.<sup>72,73</sup> Active communication between all affected parties could also help facilitate integrated KT,<sup>57</sup> improving the comprehension and cohesion of messages in results dissemination between researchers, communities, policy-makers, and practitioners.<sup>60</sup> Lack of time, resources, and personnel in the region, however, may be a barrier for community stakeholder involvement as research liaisons.<sup>34</sup> This may be a place where boundary organizations (e.g., Nunavut Research Institute, Inuit Research Advisors in each settled land claim region of Canada, Arctic Research Consortium of the United States, Greenland Center for Health Research) may be able to play a role in results dissemination of high impact and controversial issues.<sup>34</sup>

## **Limitations**

Limited capture of health studies that assess KT in Inuit communities in the Circumpolar North could be a result of an underreporting of KT assessments, a lack of quantity of KT assessments, and/or our search strategy. This review did not seek to capture assessments of KT from key organization websites or other grey literature publications, information from these sources may add to the discussion surrounding KT in Inuit communities.

## **Conclusion**

The small but burgeoning number of assessments of health-related KT in peer-reviewed publications suggests there is still much to be learned about KT in the Circumpolar North. To learn from past successes or failures in KT, it is strongly suggested that assessment of the KT process take place, and researchers disseminate the KT assessment results in a format that is accessible and available to future projects and researchers (e.g., peer-reviewed journal article). Given the often negative history of Indigenous health research, it is important that researcher promises of action are kept; therefore, assessments need to formally evaluate KT's success or failure to elicit its intended action. It may be necessary to rebuild the KT methodological framework for Inuit communities, such that it is grounded in Inuit oral histories and cultural practices, and based in actively attempting to deconstruct power dynamics in the KT process between researchers and researched (e.g., digital storytelling). Although community engagement was considered key to successful KT in the majority of the studies included in the review, discussion and discourse on the tensions, challenges, and

opportunities for improvement in community engagement is necessary. Similarly, assessments of KT should include a critical discussion on the role of community engagement and its effect on successful KT. Therefore, within the KT methodological framework, it is important to develop guidelines for the decision-making process around when, and how much, community involvement should occur, and by which community stakeholders providing useful direction around community engagement. Lastly, learning from health promotion literature and behavior models, if KT messages are able to capture the particular Inuit community or subgroup's context, and elicit social modeling, research may be more successful in eliciting action within particular subgroups. Overall, this scoping review was intended to inform future KT methods within Inuit communities, and improve future critical reflection and assessments of the KT process.

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## Tables

Table 3.1 Definitions of knowledge translation-related terms.

Term	Definition
“Knowledge translation”	<p>“a dynamic and iterative process that includes <u>synthesis, dissemination, exchange</u> and <u>ethically-sound application of knowledge</u> to improve the health of Canadians, provide more effective health services and products and strengthen the health care system. This process takes place within a complex system of interactions between researchers and knowledge users which may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user.”</p> <p>-Canadian Institutes of Health Research (CIHR), 2014 (<a href="http://www.cihr-irsc.gc.ca/e/39033.html#Definition">http://www.cihr-irsc.gc.ca/e/39033.html#Definition</a>)</p> <p>“the process of translating knowledge from one format to another so that the receiver can understand it; often from specialists to non-specialists. KT is sometimes represented as a one-way, and sometimes a two-way, process.” (p. 2)<sup>74</sup></p>
“Knowledge transfer”	<p>“a one-way process of sharing knowledge which can be construed as more of a teacher- student relationship than other knowledge-related activities and perhaps associated with mutual exploration of an issue.” (p. 2)<sup>74</sup></p>
“Knowledge exchange” or “Knowledge Transfer and Exchange”	<p>The exchange of knowledge refers to the interaction between the knowledge user and the researcher, resulting in mutual learning.” – CIHR, 2014 (<a href="http://www.cihr-irsc.gc.ca/e/39033.html#Definition">http://www.cihr-irsc.gc.ca/e/39033.html#Definition</a>)</p> <p>“KTE [knowledge transfer and exchange] is a process of exchange between researchers and stakeholders/knowledge-users designed to make relevant research information available and accessible to stakeholders for use in practice, planning and policy-making. Stakeholders are involved early in the research process to provide guidance to shape the research questions and information about the context in which research results are likely to be used.” – <i>Institute for Work &amp; Health, no date (n.d.)</i> (<a href="http://www.iwh.on.ca/kte-principles">http://www.iwh.on.ca/kte-principles</a>)</p>
“Dissemination”	<p>“Dissemination involves identifying the appropriate audience and tailoring the message and medium to the audience. Dissemination activities can include such things as summaries for / briefings to stakeholders, educational sessions with patients, practitioners and/or policy makers, engaging knowledge users in developing and executing dissemination/implementation plan, tools creation, and media engagement.” – CIHR, 2014 (<a href="http://www.cihr-irsc.gc.ca/e/39033.html#Definition">http://www.cihr-irsc.gc.ca/e/39033.html#Definition</a>)</p> <p>“an active approach of spreading evidence-based interventions to the target audience via determined channels using planned strategies.” (p. 118)<sup>75</sup></p>
“Results sharing” or “Knowledge sharing”	<p>“The exchange of knowledge between and among individuals, and within and among teams, organizational units, and organizations. This exchange may be focused or unfocused, but it usually does not have a clear a priori objective.”</p> <p>“An exchange of knowledge between two individuals: one who communicates knowledge and one who assimilates it. In knowledge sharing, the focus is on human capital and the interaction of individuals. Strictly speaking, knowledge can never be shared. Because it exists in a context; the receiver interprets it in the light of his or her own background” – <i>Encyclopedia of Knowledge Management, 2006</i><sup>76</sup></p>
“Implementation”	<p>“the use of strategies to adopt and integrate evidence-based health interventions and change practice patterns within specific settings.” – <i>Fogarty International Center, National Institutes of Health, 2013</i> (<a href="http://www.fic.nih.gov/News/Events/implementation-science/Pages/faqs.aspx">http://www.fic.nih.gov/News/Events/implementation-science/Pages/faqs.aspx</a>)</p> <p>“the process of putting to use or integrating evidence-based interventions within a setting.” (p. 118)<sup>75</sup></p>
“Diffusion”	<p>“the passive, untargeted, unplanned, and uncontrolled spread of new interventions. Diffusion is part of the diffusion-dissemination-implementation continuum, and it is the least-focused and intense approach.” (p. 118)<sup>75</sup></p>

Table 3.2 Search string used in EBSCOHost and ProQuest® aggregator databases including terms for population, knowledge translation, health, and location.

Category	Terms
Population	Inuit OR Inuk OR Inupiat OR Inupiat OR Inuvialuit OR Eskimos OR Tikigaq OR Inuvialuit OR Netsilik OR Eskimo OR Kalaallits OR Kalaallit OR Aleuts OR Aleut OR Yupik OR Yup'ik OR Alutiiq OR Chugach
KT	"knowledge translation" OR "knowledge transfer" OR "knowledge mobilization" OR "results sharing" OR "results dissemination"
Health	health OR wellbeing OR wellness OR aid OR disorder OR burden OR preventative OR chronic
Location	Circumpolar OR Arctic OR Canada OR Denmark OR Greenland OR Chukotka OR Russia OR Alaska

Table 3.3 Databases included in EBSCOHost and ProQuest® searches on March 12, 2015.

Aggregator database	Databases included	Results	Databases not included
ProQuest	Alt-PressWatch, Algology Mycology and Protozoology Abstracts (Microbiology C), Animal Behavior Abstracts, Aquatic Science & Fisheries Abstracts (ASFA) 1: Biological Sciences & Living Resources, Aquatic Science & Fisheries Abstracts (ASFA) Aquaculture Abstracts, Aquatic Science & Fisheries Abstracts (ASFA) Marine Biotechnology Abstracts, Bacteriology Abstracts (Microbiology B), Biochemistry Abstracts 1, Biochemistry Abstracts 3, Biotechnology Research Abstracts, Calcium & Calcified Tissue Abstracts, Chemoreception Abstracts, COS Conference Papers Index, Ecology Abstracts, Endocrinology Abstracts, Entomology Abstracts, Genetics Abstracts, Health & Safety Science Abstracts, Human Genome Abstracts, Immunology Abstracts, Industrial and Applied Microbiology Abstracts (Microbiology A), Neurosciences Abstracts, Nucleic Acids Abstracts, Oncogenes and Growth Factors Abstracts, ProQuest Deep Indexing: Biological Sciences, Toxicology Abstracts, TOXLINE, Virology and AIDS Abstracts, Canadian Newsstand Complete, Canadian Research Index, Dissertations & Theses @ University of Guelph, EconLit, Environmental Sciences and Pollution Management, Ethnic NewsWatch, GenderWatch, International Bibliography of the Social Sciences (IBSS), Linguistics and Language Behavior Abstracts (LLBA), PAIS International, Periodicals Archive Online, PILOTS: Published International Literature On Traumatic Stress, ProQuest Sociology Collection, Social Services Abstracts, Worldwide Political Science Abstracts	0	ABI/INFORM Global, ABI/INFORM Trade & Industry, AGRICOLA, ARTbibliographies Modern (ABM), Avery Index to Architectural Periodicals, Plant Science, CBCA Complete, ebrary® e-books, ebrary® e-books, ERIC, Hoover's Company Profiles, International Bibliography of Art (IBA), MLA International Bibliography, Philosopher's Index, PRISMA (Publicaciones y Revistas Sociales y Humanísticas), ProQuest Agriculture Journals, ProQuest Asian Business & Reference, ProQuest European Business, ProQuest Historical Newspapers: The Globe and Mail, ProQuest Historical Newspapers: The New York Times, ProQuest Historical Newspapers: The Scotsman, RILM Abstracts of Music Literature
	MEDLINE®, Canadian Newsstand Complete, Dissertations & Theses @ University of Guelph, Ethnic NewsWatch, GenderWatch, ProQuest Dissertations & Theses A&I, ProQuest Political Science, ProQuest Psychology Journals	124	
EBSCOHost	America: History & Life, Anthropology Plus, Communication Abstracts, Ergonomics Abstracts, Family & Society Studies Worldwide, GreenFILE, Library Literature & Information Science Full Text (H.W. Wilson), Library, Information Science & Technology Abstracts, Film & Television Literature Index with Full Text	0	Agricola, Art Abstracts (H.W. Wilson), Art Index Retrospective (H.W. Wilson), Business Source Complete, Criminal Justice Abstracts with Full Text, eBook Collection (EBSCOhost), Garden, Landscape & Horticulture Index, Historical Abstracts, Hospitality & Tourism Index, L'Année philologique, Mental Measurements Yearbook with Tests in Print, Music Index, Regional Business News, SPORTDiscus with Full Text, Index Islamicus, eBook Academic Collection (EBSCOhost), FRANCIS, Hospitality & Tourism Complete
	Academic Search Premier, Bibliography of Native North Americans, CINAHL Plus with Full Text, Communication & Mass Media Complete, Environment Index, Women's Studies International, CINAHL	589	

Table 3.4 Summary of information collected in data charting form during the data extraction step of this scoping review included knowledge translation (KT) methodology, article information, and overall recommendations given by the studies.

Charting categories	Information collected
Information on the article	author(s) year of publication year of study location within Circumpolar North type of document target group context of article written specific health subfield health outcome studied types of researchers/organizations involved
KT methodology	aim(s) of study study design KT method used validation of KT method of KT assessment outcome measures of KT success
Recommendations	important results

Table 3.5 Select findings from charting of 17 included articles including author(s), title, document type, year study was published, year study was conducted, field of health research, location, type of knowledge translation (KT) assessment, and funding source(s).

Authors	Title	Document type	Year published	Year conducted	Field of health research	Location	Type of KT assessment	Funding source(s)	Ref
Libby S. Dean	Environment and health risk communication pathways in Aboriginal communities: Learning from the case of foodweb contaminants and nutrition issues with young Inuit women in Nunatsiavut	Thesis	2009	2005	environmental health risk messages	Nain, Nunatsiavut, Newfoundland & Labrador, Canada	Qualitative evaluation	Canadian Institutes of Health Research (CIHR), Northern Contaminants Program (Indian and Northern Affairs)	<sup>34</sup>
Sennait Yohannes	Traditional food consumption, anthropometry, nutrient intake and the emerging relationship between Inuit youth and traditional knowledge in a Baffin Island community.	Thesis	2009	2008	food use, nutrient status, and anthropometry	Pangnirtung, Nunavut, Canada	Quantitative and qualitative evaluation	Nasivvik Centre (CIHR)	<sup>37</sup>
Megan Kot	Challenges and opportunities for small community drinking water systems – A knowledge translation perspective	Thesis	2009	N/A	drinking water	Anonymous community, Nunavut, Canada	Qualitative evaluation	NSERC	<sup>41</sup>
Erica L. Pufall <i>et al.</i>	Community-derived research dissemination strategies in an Inuit community	Journal Article	2010	2009	zoonotic parasites in wildlife meat	Nain, Nunatsiavut, Newfoundland & Labrador, Canada	Qualitative evaluation	Nasivvik Centre (CIHR), International Polar Year	<sup>35</sup>
Candyce Hamel	Determinants of Participation in an Online Community of Practice (OCOP)	Thesis	2010	2008	Epidemiology & community based research initiatives	Nunatsiavut in Newfoundland and Labrador, Nunavik in Quebec, Nunavut, the North West Territories, and Ottawa, Canada	Qualitative evaluation	N/A	<sup>42</sup>
Emilie Counil <i>et al.</i>	Translational research to reduce trans-fat intakes in Northern Quebec (Nunavik) Inuit communities: a success story?	Journal article	2012	2007-2009	dietary trans-fat	Kuujuuaq and Akulivik Nunavik, Canada	Reflection only	Nasivvik Centre (CIHR), International Polar Year	<sup>31</sup>

Nancy Poole <i>et al.</i>	Improving substance use treatment for First Nations, Métis and Inuit Women: Recommendations arising from a virtual inquiry project	Journal article	2013	2010-2011	substance use and fetal alcohol spectrum disorder (FASD)	Nunavut, and Northern Quebec, Canada	Reflection only	Health Canada	32
Cindy Jardine <i>et al.</i>	Knowledge translation with Northern Aboriginal communities: A case study	Journal article	2010	N/A	health risks: lifestyle behaviours, exposure to environmental contaminants	Nain and Hopedale, Nunatsiavut, Newfoundland & Labrador, Canada	Reflection only	Health Canada	36
Martina Tyrrell	Making sense of contaminants: A case study of Arviat, Nunavut	Journal article	2006	N/A	contaminants	Arviat, Nunavut, Canada	Reflection only	N/A	28
Heather Myers <i>et al.</i>	Long-Range Transport of Information: Are Arctic Residents Getting the Message about Contaminants?	Journal article	2005	2002-2003	contaminant knowledge	Clyde River, & Pond Inlet, Nunavut; Makkovik, & Nain, Labrador, Canada	Quantitative and qualitative evaluation	Northern Contaminants Program (Indian and Northern Affairs)	29
Dionne Gesink <i>et al.</i>	Developing a culturally competent and socially relevant sexual health survey with an urban Arctic community	Journal article	2009	N/A	sexual health	Nuuk, Greenland	Quantitative and qualitative evaluation	Greenlandic Medical Research Council, CIHR Team in Circumpolar Chronic Disease Prevention, Kommissionen for Videnskabelige Undersøgelser I Grønland	11
Sven O.E. Ebbesson <i>et al.</i>	Recruitment and community interactions in the GOCADAN Study	Journal article	2005	2000-2004	Heart and vascular disease	Norton Sound, Alaska, United States	Reflection only	The US National Institutes of Health (NIH)	33
Bert B. Boyer <i>et al.</i>	Building a community-based participatory research center to investigate obesity and diabetes in Alaska Natives	Journal article	2005	N/A	genetics, nutritional and behaviour risk	Southwest Alaska, United States	Reflection only	NIH	27
Bert B. Boyer <i>et al.</i>	Sharing results from complex disease genetics studies: A community	Journal article	2007	N/A	genetics	Southwest Alaska, United States	Reflection only	NIH	30

	based participatory research approach								
Darren Thomas	Development of Coastal climate change action plan, Arviat Nunavut	Thesis	2008	2003	environmental health	Arviat, Nunavut, Canada	Reflection only	Fisheries and Oceans Canada, Manitoba Hydro, Ocean Management Research Network, National Resource Institute	38
Cameron Bradshaw	Sailivik: A place of tranquility	Thesis	2009	2008	landscape architecture & mental health	Pangnirtung, Nunavut, Canada	Reflection only	N/A	39
Agata Durkalec	Understanding the role of environment for Indigenous health: A case study of sea ice as a place of health and risk in the Inuit community of Nain, Nunatsiavut	Thesis	2013	2010	environmental health	Nain, Nunatsiavut, Newfoundland & Labrador, Canada	Reflection only	ArcticNet, Nasivvik Centre for Inuit Health and Changing Environments (CIHR)	40

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## Figures

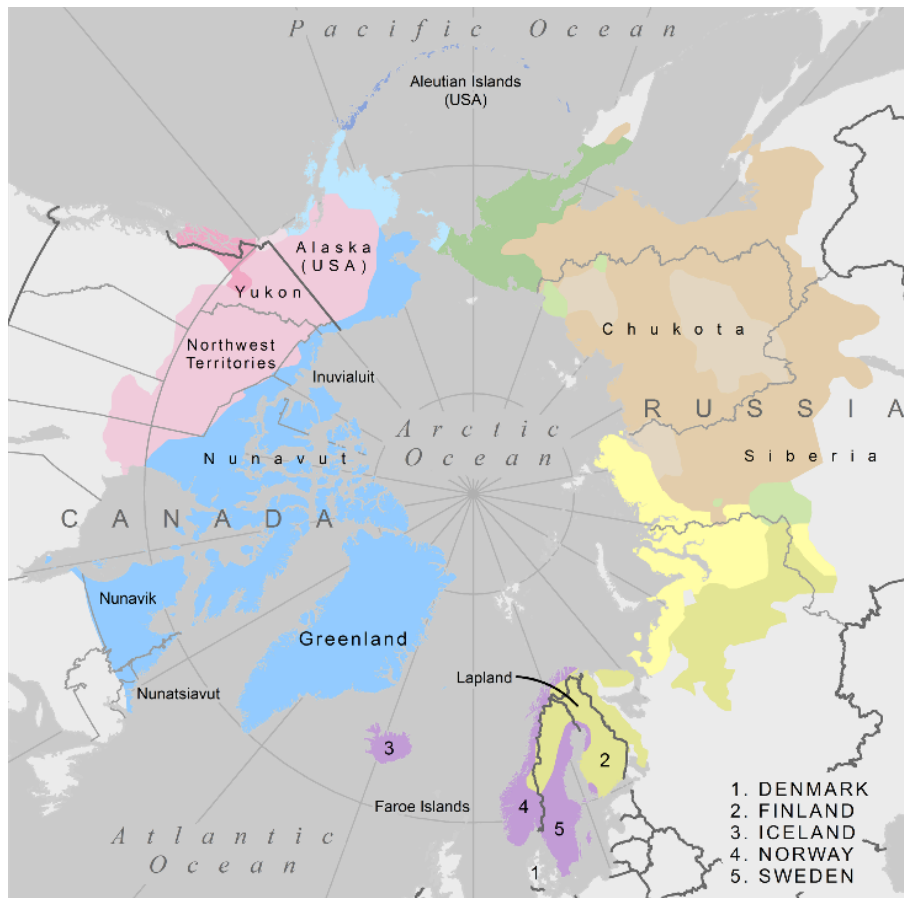


Figure 3.1 Map of the Circumpolar Northern region adapted from Cunsolo Willox *et al.* (2014).<sup>77</sup>

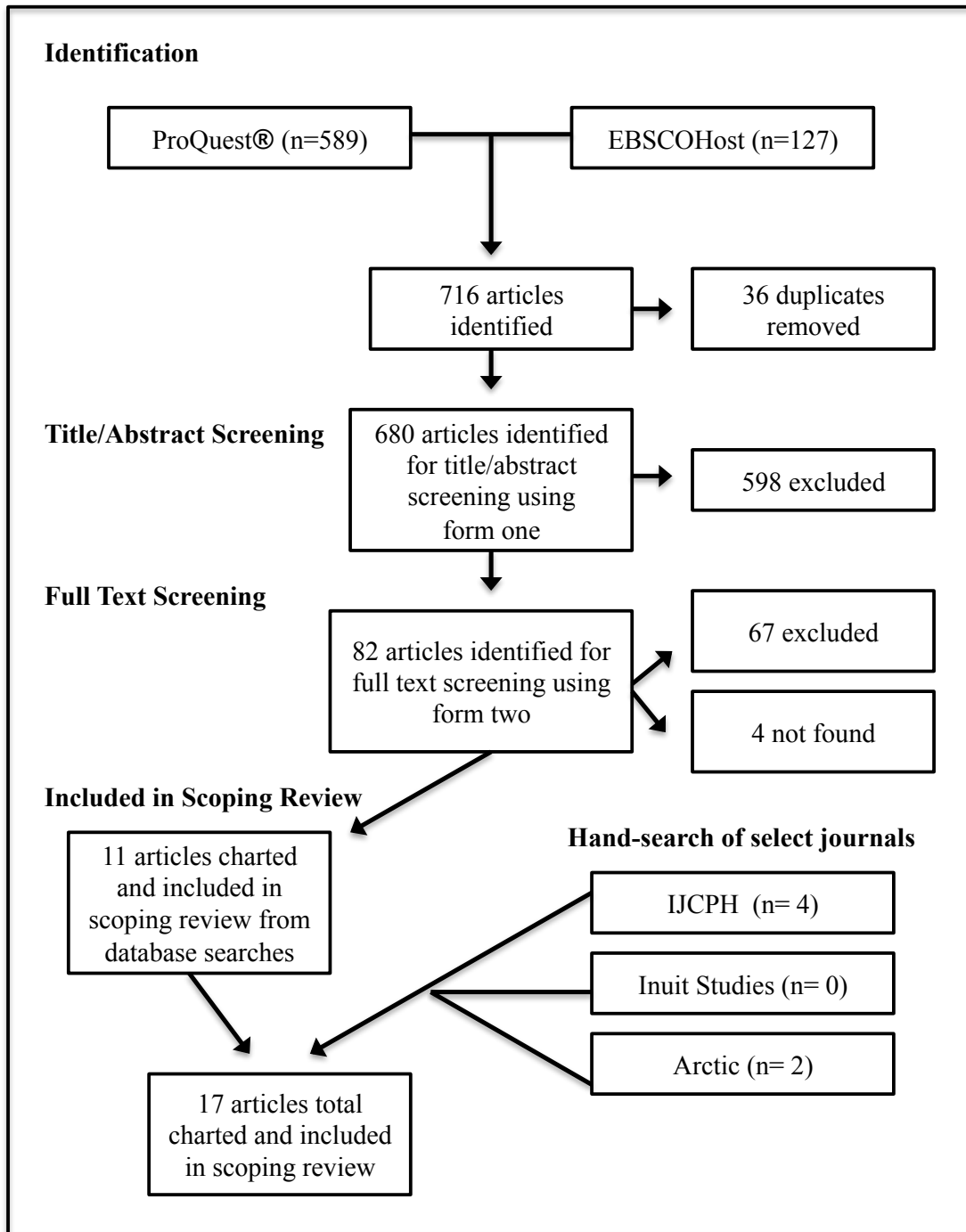


Figure 3.2 Search result numbers in the form of a flow diagram including identification, title/abstract screening, full article screening as well as included articles in the scoping review adapted from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram for reporting standards in systematic reviews.<sup>78</sup>

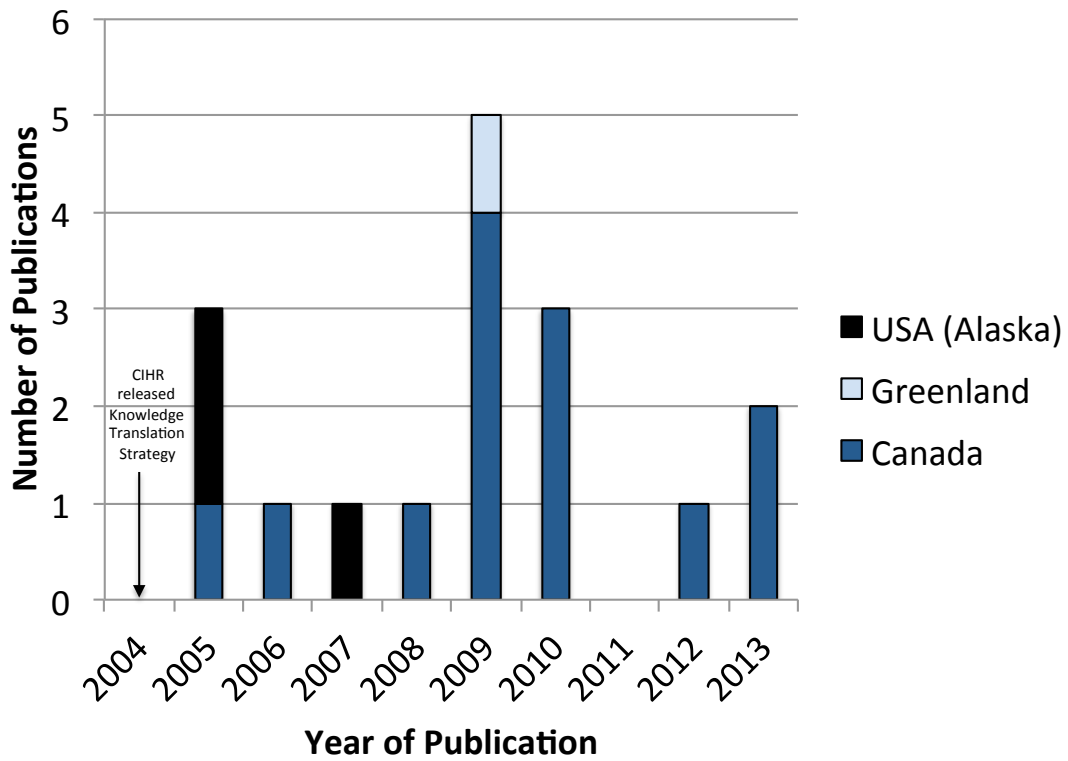


Figure 3.3 Thirteen (76.5%) of the articles included were conducted in Northern Canada,<sup>28,29,31,32,34-42</sup> three (17.6%) in Alaska, United States,<sup>27,30,33</sup> and one (5.9%) in Greenland.<sup>11</sup> All studies were published between 2005 and 2013, the arrow indicates the year Canadian Institutes of Health Research (CIHR) release its Knowledge Translation Strategy.<sup>53</sup>

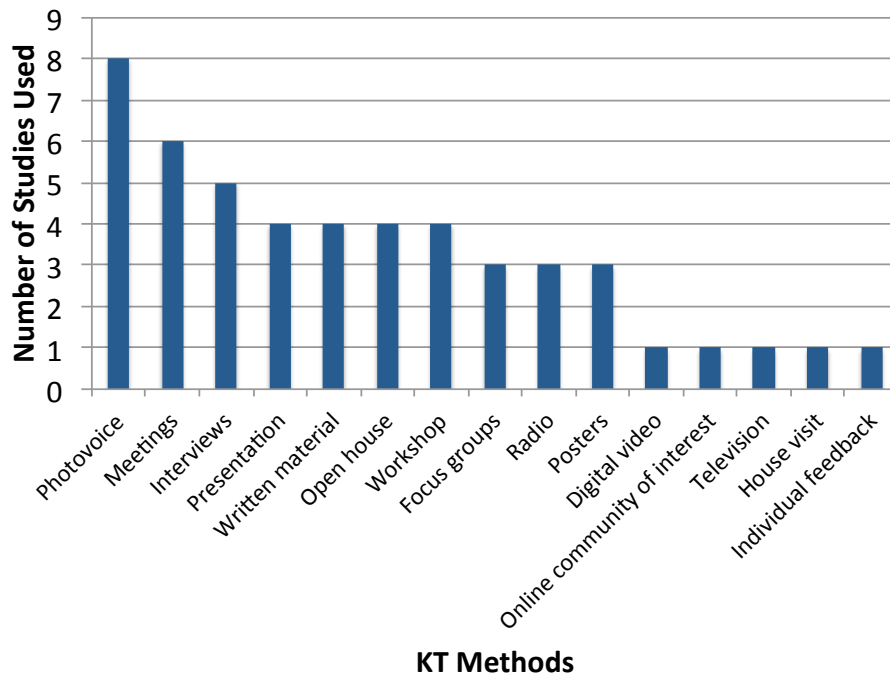


Figure 3.4 Bar graph indicating the number and methods of knowledge translation (KT) assessments used in the analysed studies. There were a wide variety of KT methods assessed: workshops;<sup>27-30</sup> stakeholder meetings;<sup>28,31-33</sup> written material;<sup>28,29,31,33</sup> presentations;<sup>27,31,33,40</sup> focus groups;<sup>34,35,40</sup> open houses;<sup>29,36,38,40</sup> radio broadcasts;<sup>28,31,40</sup> digital video;<sup>37</sup> community of interest groups;<sup>42</sup> PhotoVoice;<sup>36</sup> television broadcasts;<sup>28</sup> household visits;<sup>33</sup> and, immediate individual feedback (categories are not mutually exclusive).<sup>41</sup>

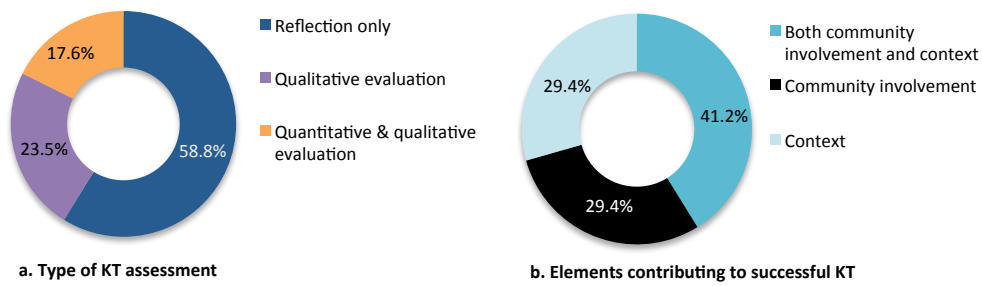


Figure 3.5 a. Doughnut graphs displaying: a. 58.8% of studies used reflection as their only method of assessment of knowledge translation (KT),<sup>27,28,30-33,36,38-40</sup> 23.5% used qualitative evaluation alone,<sup>34,35,41,42</sup> and 17.6% used both quantitative and qualitative methods to assess knowledge translation (KT);<sup>27,29,37</sup> b. 100% of studies included key themes indicating the necessity of community involvement (29.4%),<sup>27,31,37-39</sup> context (29.4%),<sup>28,29,34,41,42</sup> or both (41.2%).<sup>11,30,32,33,35,36,40</sup>

## **CHAPTER FOUR: SUMMARY, LIMITATIONS, RECOMMENDATIONS, NEXT STEPS, AND CONCLUSIONS**

### **Summary**

My thesis research examined the Inuit-specific burden of acute gastrointestinal illness (AGI) in Iqaluit (chapter two), as well as the extent, range, nature, and common themes in literature involving health-related knowledge translation (KT) assessment activities in Inuit communities in the Circumpolar North (chapter three). To examine the burden of AGI for Inuit in Iqaluit, Nunavut, data were obtained from a retrospective, cross-sectional, door-to-door survey conducted between September 15 – October 5, 2012 and May 18 – June 2, 2013 in Iqaluit, Nunavut. This survey collected data on self-reported AGI, demographic information, socio-economic information, food consumed, water consumed, exposure to animals, and results dissemination preferences. A subset of survey data was used to find the Inuit-specific annual incidence of AGI, and identify factors associated with self-reported AGI cases for Inuit in Iqaluit. The Inuit-specific annual incidence rate of AGI was similar to previous incidences in the Canadian North,<sup>1</sup> and higher than both national<sup>2-6</sup> and international<sup>7-15</sup> incidences. Independent variables that were associated with increased odds of AGI for Inuit in Iqaluit (e.g., consumption of raw meat, and gender) differed from results found in a previous study including both Inuit and non-Inuit in Iqaluit.<sup>1</sup> This difference suggests that there can be different exposure pathways and pathogens causing symptoms of AGI for different populations within the same geographical location. A focus on Inuit-specific factors in health research in this burden of illness study was intended to improve understandings

of Inuit specific AGI factors to help guide public health prioritization, inform disease prevention, and enhance health promotion program development.

Next, a scoping review was conducted to examine assessments of human health research KT in Inuit communities in the Circumpolar North. Specifically, the scoping review involved identifying the research question, developing a search query, identifying relevant studies, selecting studies, charting data, and collating, summarizing, thematically analyzing, and reporting results. The volume of literature on KT assessments in health research in Inuit communities in the Circumpolar North was small, but ranged across many health disciplines. Three primary themes were identified through thematic analysis of the literature stressing the importance of: (1) inclusion of stakeholders;<sup>18,20,21,24-29</sup> (2) local context (e.g., social, geographical, cultural);<sup>16-26</sup> and (3) cohesive messaging<sup>16,23,27</sup> in KT throughout the research process to better suit the needs of Inuit communities. The most common theme presented in the literature was to involve community stakeholders in the research process as early and as often as possible. Involving community stakeholders can position the research within a local context incorporating community values and knowledge,<sup>18,20,21,24-26,30</sup> enhance knowledge of communication pathways of the target audience,<sup>16,23,27</sup> and ultimately improve research strategies.<sup>18,20,21,24-32</sup> The results from this scoping review were intended to increase future understanding of health and local knowledge sharing networks, increase the relevancy of research, and improve local uptake of research in Inuit communities in the Circumpolar North.

In summary, this thesis presented the results from two separate but intertwined studies. The scoping review will inform dissemination of results for the AGI study, but it also validated active participation in KT methods used in the AGI study involving early and ongoing community stakeholders from study conception through to interpretation of results.

## **Limitations**

For the burden of AGI study for Inuit in Iqaluit, a retrospective cross-sectional survey was used, which did not allow for the determination of causal relationships between factors and AGI cases. This limitation is common with all cross-sectional survey studies.<sup>33</sup> The AGI study had a high response rate; however, males and individuals 0-19 years of age were under-represented. Additionally, the over- or underreporting of AGI due to self-reporting and recall bias may lead to the potential for misclassification bias.<sup>34,35</sup> When capturing self-reported cases of AGI, chronic illness cases of gastrointestinal illness were excluded; however, participants with undiagnosed chronic diseases may have been misclassified as a case. Finally, this study did not involve any laboratory testing for specific pathogens causing AGI symptoms. Therefore, the study was only able to hypothesize that Inuit have differing exposure pathways than non-Inuit, but was not able to identify which pathogens were responsible for AGI symptoms.

The limitations of the scoping review on health research KT in Inuit communities in the Circumpolar North included a language bias, as the search was limited to English-only



studies. Language bias is a common limitation to many scoping reviews.<sup>36-39</sup> Further, the review identified only a small number of studies from Russia, Alaska, USA, and Greenland which could simply be a result of our search strategy, and/or lack of peer-reviewed publishing of assessments of health research KT in those areas. Due to the limited representation of studies from Circumpolar Northern countries outside of Canada, themes presented are perhaps limited to voices from Canadian studies.

## **Recommendations from the Research**

Recommendations are made based on the work presented in this thesis and include:

- Consider potentially differing factors associated with AGI for subgroups:  
Results from the AGI chapter indicated that there can be differing factors for subpopulations, even if annual incidence rates between the sub-population and population are similar. It is important to understand these differing associations to improve targeted health promotion, prioritization, and programming within communities in the future.
- Involve community stakeholders in research KT: Results from this thesis research indicated participation from community stakeholders was essential in research KT for Inuit communities in the Circumpolar North.<sup>18,20,21,24-32</sup>  
Research KT in Inuit communities requires active and equitable participation from community stakeholders in order to ensure integration of community values, knowledge, and technical assessments into the entire study process.<sup>40</sup>  
Ultimately research can be conceived, led, and owned by the community in collaboration with researchers.

- Consider local context in all Inuit health research: Research (from conception through to dissemination of results) must consider context of the participants in the research, as well as target audiences. Many factors contribute to the understanding of context, including the political, cultural, social, economical, geographical, and colonial environment. Results from our research indicated increased understanding of context can result in research that is more accessible, relevant, and culturally appropriate, resulting in more uptake of research into practical action in Inuit communities.<sup>16–26,30</sup>
- Assess KT activities: Our research results suggested there is a limited quantity of publications on assessments of human health research KT in Inuit communities in the Circumpolar North. An increase in the frequency of assessments of health research KT activities could be helpful, and such assessments should be published and readily available to future researchers, policy makers, and practitioners. An increase in the distribution of knowledge gained from KT activities in Inuit communities is critical in order to learn from past experiences to inform future methods of engagement.

## **Next Steps**

Based on the research presented in this thesis, future research could include:

- Testing for pathogens: Our results suggest that the transmission pathways and pathogens causing AGI may differ for Inuit and non-Inuit living in the same city. This hypothesis could be tested by incorporating laboratory testing of samples from cases so as to identify pathogens that cause AGI symptoms in

Iqaluit, which may improve our understanding of causal pathways of AGI for Inuit in Iqaluit. Identifying the pathogens causing AGI in Iqaluit would better inform public health planning, prioritization, and programming. Pathogen testing may also limit misclassification bias by providing an incidence based on laboratory confirmed infectious AGI.

- Analyzing results dissemination preferences: The survey used for the AGI chapter also gathered data on preferred results dissemination methods for participants. An analysis of Inuit-specific results dissemination preferences will add valuable information to the study's dissemination strategies moving forward. Additionally, this analysis will enhance the KT chapter adding perspective from Inuit in Iqaluit specifically.
- Consulting with key informants to strengthen the scoping review: Collaboration with key informants (e.g., community members, researchers, practitioners, policy makers) could enhance the scoping review and increase the usefulness of results.<sup>37,38</sup> Consultation with key informants may provide valuable insights (e.g., effectiveness, cost-effectiveness) that may not have been captured in the scoping review alone.<sup>37,38</sup>
- Searching non-English databases to identify more KT studies: Searching databases that are non-English may capture assessments of health research KT in Greenland, Russia, and other parts of the Circumpolar North where languages other than English may be used. This additional search could add knowledge to the scoping review from these areas.

## **Conclusions**

The study on AGI found the Inuit-specific annual incidence of AGI to be similar to non-Inuit in Iqaluit, and identified unique factors associated with AGI in Inuit in Iqaluit. This finding highlights that factors associated with AGI can differ for sub-populations within the same community. The scoping review illustrated that inclusion of community stakeholders throughout the research process informs researchers of local context, and may provide a bridge between research groups improving cohesiveness of messaging and overall KT strategies. Understanding the Inuit-specific experience with AGI as well as optimizing human health research KT with continued Northern partners' collaboration, can advance important information for public health planning, prioritization, and programming for Inuit.

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## APPENDIX

### Appendix 1: Annual Incidence Rate and Proportion Equations

#### Eq. 1: Annual Incidence Rate<sup>38</sup>

$$= \frac{\# \text{ cases}}{\frac{1}{2} [(\text{total at risk}) + (\text{total at risk} - \text{cases})]} * \frac{365}{14 \text{ day recall period}}$$

**and**

$$= \frac{\# \text{ cases}}{\frac{1}{2} [(\text{total at risk}) + (\text{total at risk} - \text{cases})]} * \frac{365}{28 \text{ day recall period}}$$

Standard Error for Rate:  $\sqrt{(A/t^2)}$ , where A = number of cases; t = time at risk

Approximate CI: Estimated rate  $\pm Z_{\alpha} * SE$ , where SE is the standard error

#### Eq. 2: Annual Incidence Proportion<sup>38</sup>

$$= 1 - (1-x)^{365/14 \text{ day recall period}}, \text{ where } x = (\text{cases})/(\text{total at risk})$$

**and**

$$= 1 - (1-x)^{365/28 \text{ day recall period}}, \text{ where } x = (\text{cases})/(\text{total at risk})$$

Standard Error for Proportion:  $\sqrt{(p(1-p)/N)}$ , where p = estimate of proportion; N = sample size

Approximate CI: Estimated rate  $\pm Z_{\alpha} * SE$ , where SE is the standard error

## Appendix 2: Title and Abstract Relevance Screening Form Used in Distiller

[SUBMIT FORM](#) and go to  or [Skip to Next](#)

1. Is this a study<sup>1</sup> that discusses human health research<sup>2</sup> KT<sup>3</sup> activities ?

Yes  
 No  
 Unsure

[Clear Response](#)

2. Does this study involve<sup>4</sup> Inuit<sup>5</sup>?

Yes  
 No  
 Unsure

[Clear Response](#)

3. Does this study take place in the Circumpolar North<sup>6</sup>?

Yes  
 No  
 Unsure

[Clear Response](#)

<sup>1</sup>Study: a primary detailed investigation and analysis.  
<sup>2</sup>Human Health Research: an investigation of the direct physical, mental, or social well-being of humans. For instance, we are interested in the environment's affect on human health, but not in environmental health itself.  
<sup>3</sup>Knowledge Translation (KT): KT as an all-encompassing term for those knowledge-sharing activities involving research to action in some capacity (this includes all aspects of research from development of research design through research dissemination).  
<sup>4</sup>Study involvement: inclusion of Inuit Peoples in the KT activity itself (transferring, exchanging, or receiving knowledge).  
<sup>5</sup>Inuit: All such descendants of the Thule culture inhabiting the Circumpolar North are included in our definition of "Inuit".  
<sup>6</sup>Circumpolar North: Countries/regions in the Arctic in which Inuit populations live including some regions in Canada, Greenland, Russia, United States (Alaska).

[SUBMIT FORM](#) and go to  or [Skip to Next](#)

### Appendix 3: Full Text Relevance Screening Form Used in Distiller

and go to  or [Skip to Next](#)

1. Does this study<sup>1</sup> assess<sup>2</sup> human health research<sup>3</sup> KT<sup>4</sup> activities ?

Yes  
 No  
 Unsure

2. Does this study involve<sup>5</sup> Inuit<sup>6</sup>?

Yes  
 No  
 Unsure

3. Does this study take place in the Circumpolar North<sup>7</sup>?

Yes  
 No  
 Unsur

<sup>1</sup>Study: a primary detailed investigation and analysis.  
<sup>2</sup>Assess: By this we mean any kind of review of the success of KT activities. Included in "assessment" are both evaluations (quantitative and qualitative), and reflections.  
<sup>3</sup>Human Health Research: investigation of the direct physical, mental, or social well-being of humans. For instance, studies on the environmental affect on human health were included, but on the health of the environment were not included.  
<sup>4</sup>Knowledge Translation (KT): KT as an all-encompassing term for those knowledge-sharing activities involving research to action in some capacity (this includes all aspects of research from development of research design through research dissemination).  
<sup>5</sup>Study involvement: inclusion of Inuit Peoples in the KT activity itself (transferring, exchanging, or receiving knowledge).  
<sup>6</sup>Inuit: All such descendants of the Thule culture inhabiting the Circumpolar North are included in our definition of "Inuit".  
<sup>7</sup>Circumpolar North: Countries/regions in the Arctic in which Inuit populations live including some regions in Canada, Greenland, Russia, United States (Alaska).

and go to  or [Skip to Next](#)