

**CULTURALLY SAFE EPIDEMIOLOGY**  
**Methodology at the Interface of Indigenous and Scientific Knowledge**

by  
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## **Abstract**

Since the early 20th Century, epidemiological research has brought benefits and burdens to Aboriginal communities in Canada. Many First Nations, Métis, and Inuit continue to view Western research with distrust; quantitative study methods are perceived as especially inconsistent with indigenous ways of knowing. There is increasing recognition, however, that rigorous epidemiological research can produce evidence that draws attention, and potentially resources, to pressing health issues in Aboriginal communities. The thesis begins by introducing a framework for culturally safe epidemiology, from the identification of research priorities, through fieldwork and analysis, to communication and use of evidence. Drawing on a sexual health research initiative with Inuit in Ottawa as a case study, the thesis examines cognitive mapping as a promising culturally safe method to reviewing indigenous knowledge. Juxtaposing this approach with a systematic review of the literature, the standard protocol to reviewing Western scientific knowledge, the thesis demonstrates the potential for cognitive mapping to identify culturally safe spaces in epidemiological research where neither scientific validity nor cultural integrity is compromised. Modern epidemiology and indigenous knowledge are not inherently discordant; many public health opportunities arise at this interface and good science must begin here too.

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# **CHAPTER 1**

## **Introduction to Culturally Safe Epidemiology**

Epidemiologists and other Western scientists have studied health issues of Aboriginal communities in Canada for over a century. Sometimes well-intentioned and sometimes not, this research has brought both benefit and burden to First Nations, Métis, and Inuit communities; on balance many continue to view research with distrust and suspicion.

To restore confidence in, and local ownership of, the research process, some scholars have explored alternative approaches that can be more culturally appropriate, including cultural sensitivity frameworks and participatory methods. These call for researchers to increase their cultural awareness and to integrate community perspectives into the research process. These approaches, however, generally fail to call into question certain implicit assumptions about the superiority of the Western scientific paradigm.

Discussion around the adaptation of research methods to the cultural context of those being studied is prominent in the realm of qualitative research, but less so in quantitative research, which is therefore often perceived as unreceptive to alternative epistemologies. As a result, the development of culturally appropriate methodologies has largely excluded quantitative research, including epidemiology. Still, there is recognition that rigorous quantitative research can draw attention and resources to address pressing health issues in Aboriginal communities. Moreover, rigorous quantitative research addresses many of the questions communities pose about the health of their people.

Beginning with a brief overview of earlier approaches to Aboriginal health research and the emergence of concerns for cultural safety, this chapter outlines a framework for culturally safe epidemiological research, raising discussion points where indigenous and



scientific knowledge may intersect or diverge and areas of culturally safe methodology in need of further development. These points will be revisited throughout the thesis with examples from a case study on Inuit sexual health with CIETcanada (Community Information and Epidemiological Technologies), based at the University of Ottawa's Institute for Population Health.

## **1.1 Earlier Approaches to Research in Aboriginal Communities**

Health services and health research in Aboriginal communities in Canada have changed substantially over the last several decades. In the early 20<sup>th</sup> century, when the Canadian government began systematically collecting statistical data on indigenous mortality and morbidity, there were marked health disparities between Aboriginal peoples and the general population in Canada. At that time, efforts to resolve health disparities were minimal, as the federal and provincial governments disagreed over who was legally responsible for the health of indigenous peoples.<sup>1</sup> The responsibility for Aboriginal health was not clearly addressed in the treaties, the Indian Act, or the British North America Act, leaving action on the part of government to provide indigenous health services without a clear legal basis.<sup>1</sup>

After 1944, when the Indian Health Services became a part of the new Department of National Health and Welfare, the Canadian government began playing a much larger role in the health of Aboriginal peoples. This increased expenditures for health services as well as scientific surveys and other health research.<sup>2</sup>

The increase in Aboriginal health research, encouraged by the government after the Second World War, Young argues, was not altogether altruistic in intent. He claims that government action against the epidemics raging through indigenous communities in the early 20th century was largely to protect neighbouring white communities.<sup>3</sup> That the provision of health services and research was seen by the government as an integral component of the policy to assimilate Canada's indigenous population is evident from the report of an Indian Agent in 1921: "nothing has a more civilizing effect upon them [Aboriginal peoples] than a display of the white man's skill in healing."<sup>4</sup> Young<sup>3</sup> described early intervention to improve indigenous health as "benevolent paternalism."

Not surprisingly, much of the early research on Aboriginal health was led by non-Aboriginal academics or government agents; community input or participation was limited to providing information. This coincided with a lack of indigenous skills in epidemiological and other scientific methods. Several scholars have criticized the underlying paternalistic and colonizing attitudes, which permeated research relations at the time.<sup>5-9</sup>

Over time, epidemiological research has made some positive contributions towards improving the health of Canada's indigenous peoples. For example, epidemiological research was crucial in detecting and drawing attention to the soaring rates of infectious disease, such as tuberculosis, among Canada's Aboriginal population in the early 20th century; this recognition brought about extensive government intervention resulting in substantial declines in infectious disease.<sup>10, 11</sup>

The impact of epidemiological and other scientific research, however, has not always been positive. The Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans describes a sensitive balance between harm and benefit in research with Aboriginal communities:

[T]here are historical reasons why Indigenous or Aboriginal Peoples may legitimately feel apprehensive about the activities of researchers. In many cases, research has been conducted in respectful ways and has contributed to the well-being of Aboriginal communities. In others, Aboriginal Peoples have not been treated with a high degree of respect by researchers. Inaccurate or insensitive research has caused stigmatization. On occasion, the cultural property and human remains of Indigenous Peoples have been expropriated by researchers for permanent exhibition or storage in institutes, or offered for sale. Researchers have sometimes treated groups merely as sources of data, and have occasionally endangered dissident Indigenous Peoples by unwittingly acting as information-gatherers for repressive regimes. Such conduct has harmed the participant communities and spoiled future research opportunities.<sup>12</sup>

Much epidemiological research concerning First Nations, Métis, and Inuit remains firmly embedded in a rigid Western scientific paradigm, categorizing these populations collectively as a "high risk" group. This reinforces negative stereotypes and discrimination, often framing Aboriginal communities as "sick, disorganized and dependent."<sup>6, 13</sup>

"Cultural essentialist" is Narayan's term for depictions of heterogeneous people as

homogeneous and unvarying; in fact the communities' values, interests, ways of life, and moral and political commitments are internally plural and divergent.<sup>14</sup> The cultural essentialist view attributes complex health behaviours to summary "factors" such as ethnicity, minimizing the heterogeneity of such a category.<sup>15</sup>

According to Dyck and Kearns,<sup>16</sup> "recognition of the fluidity of culture and ethnicity, and the social construction of "race" as a category of difference challenges the continued use of such concepts as explanatory and static variables," which can perpetuate stereotypical depictions of "lifestyle" and culture-blaming in the analysis. Cultural essentialist perspectives in research also tend to mislead health program and policymakers to focus on interventions at the level of cultural practices while disregarding the role of political processes in the perpetuation of unequal access to health services and other resources.<sup>16</sup>

Stratifying results by ethnicity or culture can help to demonstrate some health disparities between Aboriginal communities and the general population in Canada. Analysis of this type has helped to draw attention and resources to the field of indigenous health.<sup>17</sup>

Even from a traditional quantitative research perspective, the stratification of heterogeneous groups can pose a dilemma with respect to sample size and statistical power. It is tempting, therefore, to abandon quantitative methods for a more anthropological approach that focuses on the peculiarities of small groups, providing important insights into human functioning.

There is increasing recognition that exclusionary research, in which outside "experts" conduct research on a community while excluding those whom the research is intended to benefit, fail to account for cultural contexts and epistemological differences and are therefore ethically flawed and unacceptable to Aboriginal communities. They are also unlikely to improve understanding of the health issues facing Aboriginal peoples in Canada. Some scholars reject the "epistemic authority of Western scientists,"<sup>17, 18, 19</sup> calling for culturally appropriate "decolonizing" research methodologies that recognize an "urgent need for the perspective of Indigenous peoples to be adopted and valorized in the research process."<sup>18</sup>

## 1.2 Some Contemporary Approaches

Recognition that research across cultures may cause more harm than good has inspired much scholarly discussion on the development of more appropriate theoretical and methodological approaches. “Cultural sensitivity” formed a transition phase in the evolution of approaches to research on Aboriginal peoples. Rogler defined culturally sensitive research as the “interweaving of cultural components and cultural awareness into all phases of the research process.”<sup>20</sup> The cultural sensitivity approach largely calls for visiting researchers to increase their knowledge of the host culture’s beliefs and practices.<sup>21</sup> While this is important, the National Aboriginal Health Organization (NAHO) of Canada recently emphasized that sensitivity is only the “first step towards learning about oneself within the context of one’s interaction or relationship with people of a different culture.”<sup>21</sup>

Some scholars are dissatisfied with the cultural sensitivity approach. Polaschek,<sup>22</sup> for example, argues that cultural sensitivity requires consideration of the “other” culture without challenging researchers to reflect upon how their own culture, social position, or biases may be influencing the research. For Polaschek, cultural sensitivity is superficial in its analysis because it does not require the researcher to acknowledge the social or political positioning of a cultural group within a society or the power imbalances that may exist between the researcher and the researched.

Visiting researchers may unintentionally reinforce a power differential between themselves and the community by assuming an authoritative “expert” status in the researcher-researched relationship. This inevitably reduces the researchers’ receptivity to local input and potentially increases cultural risk by hindering community control over the research agenda. Wilson and Neville<sup>23</sup> suggest that researchers can mitigate cultural risk by possessing a sense of humility; listening and observing before speaking; being willing to recognize the expertise of those being researched; and willing to include the community’s protocols, aspirations, and needs into the research design.

Cultural safety is a more recent alternative to the cultural sensitivity framework. Rooted in postcolonial theory, cultural safety analyzes power imbalances, institutional discrimination, colonization, and colonial relationships in the context of health services,

policy, and research.<sup>21</sup> Culturally safe practice involves recognizing the power differentials underlying intercultural interactions and the historical origins of health disparities, including the ways in which colonialism continues to influence the lives and opportunities of marginalized groups.

Cultural safety theory originated among the Maori in New Zealand, expanding to include indigenous groups worldwide as well as immigrants and other ethnic minority groups. Until recently, the incorporation of cultural safety had largely been limited to nursing as a means to improve the quality of care in intercultural contexts.<sup>16, 24-26</sup>

Proponents of a cultural safety approach to nursing believe that health professionals who hold cultural prejudices and other assumptions may place the health of their patients at risk and seriously impair the quality of care.<sup>24, 25, 27</sup> Culturally safe care, therefore, requires the nurse to reflect upon his or her own cultural identity and recognize how it might influence his or her nursing practice.<sup>27</sup> Cultural safety recognizes that actions and interactions may affirm (culturally safe) or diminish, demean, or disempower (culturally unsafe) the cultural identity and well-being of an individual.<sup>24</sup> Thus, in nursing practice, it is the recipient of care who judges whether it is culturally safe.<sup>25</sup>

The culturally safe nursing movement has influenced other health practitioners working across different cultures, such as policy makers and researchers, to adopt a cultural safety approach. The following section will focus on the application of cultural safety theory to health research.

### **1.3 Culturally Safe Research**

Cultural safety extends beyond cultural sensitivity to examine the role of age or generation; gender; sexual orientation; occupation and socioeconomic status; ethnic origin or migrant experience; religious or spiritual belief; and disability.<sup>24</sup> Thus, cultural safety in research recognizes that health status cannot be simply attributed to a cultural identity, which inappropriately classifies a set of characteristics or behaviours under a descriptor as complex as culture; an intricate network of intersecting factors influences health. For example, identifying “Aboriginality” as an independent risk factor or explanation for an

Inuk's HIV positive status provides little real information. Cultural safety encourages us to consider the multiple underlying factors that may increase Inuit HIV infection, such as gender, gender violence, power gradients in a market economy, and other inequities.

This broader view of causality is in line with the recent shift away from linear models towards a systems approach in which health determinants are viewed as interacting systems. Moving away from “black box” epidemiology associated with attributing disease to a single risk factor, McDowell<sup>28</sup> saw epidemiological analysis as needing to uncover interacting causal layers that contain separate pathways, including both harmful and protective mechanisms.

The concern for cultural safety attempts to dispel cultural stereotypes and discrimination. It shifts away from cultural essentialist approaches that incorrectly portray Canada's indigenous peoples as homogenous, when this population is made up of some 600 recognized First Nations, scores of Métis, and dozens of Inuit groups coming from quite distinct historical, cultural, and geographic situations.

An increasing number of researchers have referred to, if not used, the cultural safety lens to reflect on their own research practice.<sup>6, 15, 16, 23, 29</sup> Proponents of culturally safe research agree that researchers should reflect on their own cultural assumptions and analyze critically the impact their theoretical stance has on the knowledge they generate. This includes reexamining how we frame health and its determinants. Culturally safe researchers are cognizant of the historical relationship between research and Aboriginal communities and, throughout the research process, mindful that some indigenous communities may still associate research with a history of colonialism and suspicion.

The privileging of Western epistemologies and methods in research to the exclusion of other approaches may be ineffective in addressing the health issues facing Aboriginal communities. It can be damaging if researchers misinterpret findings and draw conclusions that portray those researched inaccurately.<sup>23</sup> To guard against this, concern for the target community's cultural safety should extend throughout the research process from the establishment of the research question to the dissemination of the findings.<sup>23</sup>

It is not the place of visiting researchers to judge what is culturally safe or unsafe; this can only be determined by the intended target or beneficiaries of the research. Wilson

and Neville<sup>23</sup> point out that in reality this is rarely the case and often it is the researcher who decides or determines whether the study has met the criteria for cultural safety. To ensure the community has the opportunity to evaluate the cultural safety of the research, scholars of the cultural safety school agree that researchers must enable and encourage community involvement throughout the entire research process.

Recognition of the importance of community participation in research is not new. For many years, researchers and Aboriginal peoples alike have identified increased community participation as a crucial component to culturally appropriate research, as demonstrated by widespread advocacy for the OCAP (ownership, control, access and possession) principles<sup>30</sup> and the ever-increasing number of studies adopting a “community-based participatory research” (CBPR) framework. CBPR, which encompasses participatory action research (PAR) and other participatory approaches, is

A collaborative process that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change.<sup>31</sup>

Proponents of these participatory approaches can overstate the advantages and conflate CBPR and PAR with culturally appropriate research. It is also possible to conduct culturally unsafe CBPR, using this as a front for research according to conventional exclusionary methods.<sup>32</sup> Consultation with a community leader or hiring a local research assistant may appear sufficient to satisfy the requirements of CBPR. Apart from the constraints of qualitative methods that currently dominate the practice of CBPR, the increasing use of a participatory lexicon in research with indigenous communities may, if not accompanied by changes in power relationships, further damage faith in the research process and reinforce suspicion toward outside researchers.

The cultural safety notion of community participation explicitly requires that local or indigenous knowledge, values, and epistemologies be valued equally alongside Western scientific epistemologies and methods, not simply “integrated” into a paradigm otherwise dominated by Western science.<sup>16</sup> Thus, culturally safe research attempts to dismantle the conventional power structure between the researchers and the researched, where the former act as information-gatherers and the latter are treated merely as sources of data.

## 1.4 A Place for Quantitative Methods

It is sometimes assumed that qualitative research is based on constructivism, that knowledge is constructed, not discovered, and the belief that there are multiple realities rather than a single truth.<sup>33</sup> For this reason, qualitative methods are often perceived to be flexible, open to alternative ways of knowing, easily adaptable to cultural contexts, and encouraging of a high level of community control over the research process.<sup>33-37</sup> Thus implemented, qualitative research may be culturally safe.

That almost all literature on cultural safety is qualitative in nature<sup>26</sup> reflects the common belief, explicitly stated by Kenny et al.<sup>37</sup> that

Qualitative research methods that include individual and group interviews, focus groups and participant observation are often more compatible [than quantitative methods] with Aboriginal culture.

But not all questions related to health can be answered convincingly by qualitative research.

Quantitative research, including epidemiology, is often associated with positivism and methods that follow rigid and structured protocols, recognize a single truth or reality, and are conducted in a controlled manner by “objective researchers” to minimize undue influence or bias.<sup>33-37</sup> Thus framed, epidemiology appears antithetical to cultural safety.

Kenny et al.<sup>37</sup> assert that although

Quantitative data help in the allocation of scarce resources ... the past has shown that research methods that focused solely on quantitative methodologies are not always conducive to ‘the way things are done’ in Aboriginal contexts.

Some authors question use of qualitative and quantitative methods in the same study. Sale<sup>33</sup> believes that the increasingly popular “mixed methods” approach, combining incommensurate qualitative and quantitative methods, is a flawed effort to harmonize opposing philosophies concerning the nature of truth and reality. She argues that mixing research methods across paradigms fails to meet the standards of either approach. For her, attempts to introduce rigidity and objectivity to qualitative methods runs against the qualitative principle that knowledge is subjective and merely reflects the interpretive lens of



the researcher. Meanwhile, accepting subjectivity into quantitative methods inevitably introduces bias, which epidemiologists so adamantly intend to minimize.<sup>33</sup>

These dilemmas can arise when researchers adopt what McDowell and McLean<sup>38</sup> termed a “hierarchical” approach to combining qualitative and quantitative methods in which one method is treated as primary and the other as adjunct, included to amplify the impression provided by the primary. McDowell and MacLean instead recommend the “partnership” approach in which qualitative and quantitative methods are treated as equal but contrasting partners and suggested that the optimal blend may vary at different stages of the research process, since different potential biases are encountered at each stage.

Others agree that the difference between qualitative and quantitative methods need not be described in such stark terms. Andersson and colleagues<sup>39</sup> described a fundamentally epidemiological research process that consists of several moments, some requiring quantitative methods and others qualitative. They proposed that the qualitative-quantitative question is best approached by parsing the research process into moments, some of which are qualitative and some quantitative.

Selection of study methods should be driven by the research question; drawing exclusively on qualitative or quantitative methods is inadequate to satisfy most research questions. Study of a single phenomenon using mixed methods requires clarity about when each method is in play; here, mixed method refers to the timing of high quality qualitative moments, followed by high quality quantitative moments. It is not a hybrid of qualitative and quantitative.

The challenge of culturally safe epidemiology adds complexity. Parallel to the quantitative-qualitative debate is the divide between indigenous and Western scientific knowledge, often believed to be associated with qualitative and quantitative characteristics, respectively. While some researchers believe indigenous and Western scientific knowledge are incompatible, Agrawal<sup>40</sup> argues that the distinction may be somewhat artificial.

Although there are striking differences between philosophies and several forms of knowledge commonly viewed as either indigenous or Western ... we may also discover that elements separated by this artificial divide share substantial similarities.<sup>40</sup>

That there are important distinctions between epistemological systems does not mean

that there is no place for the use of Western scientific methods in indigenous protocols, or vice versa.

A first principle of intercultural health research is that the epistemological systems are rarely mutually exclusive in all aspects. If the different systems meet on a plane of mutual respect, including noninterference with sacred knowledge and acknowledgement of intellectual property, it is possible to establish an interface in which neither indigenous nor Western scientific protocols are compromised. This might be called culturally safe space, akin to what others have called ethical space.<sup>41</sup> With a common goal to attain understanding and knowledge that is directly applicable to improving the health of the community, Western scientists can support indigenous communities with research methods and protocols that do not undermine cultural integrity.

There are several theoretical and practical reasons why quantitative scientific research, including epidemiology, should be culturally safe. Some research questions posed by communities require quantitative methods. Recent questions posed by communities in CIET's community support program include "Is local industry increasing our risk of cancers?" or "How common are sexually transmitted infections in our community?" or "Is what we're doing to prevent domestic violence in our community working?"

These requests for research support all involve quantifying occurrence and exploring cause and effect through quantitative measures of association. As these processes were initiated by a request from the communities, this information can be pivotal in improving health and in efforts to attract attention to the needs and health priorities of the community.

The supposed absolute incompatibility between indigenous and Western knowledge may also be unfounded because it "seeks to separate and fix in time and space (separate as independent and fix as stationary and unchanging) knowledge systems that can never be so separated or fixed".<sup>40</sup> There is no doubt that scientific knowledge is continuously advancing and evolving and there is little reason to assume that indigenous knowledge is any different. The belief that indigenous knowledge is fixed in time and space stems from an incomplete perspective on the ethnogenesis of indigenous peoples — the process by which indigenous groups have come to be understood by themselves and others as ethnically distinct.<sup>42, 43</sup>

Yancey and other scholars<sup>43-45</sup> denounce the assumption that ethnicity is influenced

and defined purely by a common heritage, tradition, or nationality that a group carries from one generation and place to another. These scholars alternatively propose that ethnic boundaries and features, including indigenous knowledge, can also be shaped, modified, and reconstructed by contemporary demographic, political, social, and economic processes and therefore cannot be considered fixed in time and place.

## **1.5 A Framework for Culturally Safe Epidemiology**

To understand the opportunities for conducting culturally safe epidemiology it helps to parse the research process, breaking it up into distinct methodological moments: framing the issue, ethical review, funding, study design, review of existing knowledge, questionnaire development, sampling and recruitment, data collection and management, data analysis, interpretation of results, communication and application of evidence.

Suppose a community is concerned about its high rates of diabetes and wish to better understand the determinants of diabetes and generate robust evidence to make a case for government funding to develop local health programs and services to prevent and treat diabetes in the community. With references to this example, the following sections outline the various moments in the research process, from identification of research priorities to the application of evidence, highlighting points where scientific and indigenous interests may interface or diverge and areas of culturally safe methodology in need of further development.

### **1.5.1 Framing the Issue**

Culturally safe research would usually begin with a request from a community or, where it is the outside agency that initiates the research, consultation with community members to understand how they frame the issue. Most published epidemiological research in Aboriginal communities has been initiated by an external academic institution or government agency with their own research agendas and their own framing of the issue. Among other things, this often involves researchers entering the community to understand a

“health problem among Aboriginal peoples.” This raises immediate issues of cultural safety and scientific validity.

Framing the issue in an essentialist way (“Aboriginal”) inappropriately generalizes First Nations, Métis, and Inuit. Culturally safe research responds to requests for research coming from and designed specifically for each particular group, be it a First Nation or group of First Nations, Métis, or Inuit, each with their unique experiences and priorities. This makes it much more likely that interventions based on the research findings will be meaningful and relevant to the community or communities that requested it. It also increases the scientific validity of the research, ensuring the results more accurately reflect the realities of the target population and diverse subpopulations.

Framing health issues as “problems” with “risk factors” can also reinforce unhelpful stereotypes of First Nations, Inuit, or Métis as a sick, troubled population that is dependent on external help. This does not resonate with communities working towards greater self-determination and control over their own affairs. A focus on resilience, defined as “the means by which people choose to use individual and community strengths to protect themselves against adverse outcomes and to build their future,”<sup>46</sup> is more acceptable to research participants who may feel more comfortable completing a questionnaire that emphasizes their strengths rather than risks. A strengths-based approach may simultaneously increase the cultural safety of the research and decrease selection bias by improving response rates.

A strengths-based approach does not mean focusing solely on resilience to the exclusion of risk. Acknowledging behavioural risk factors and social inequities, it sheds light on the positive behavioural and social factors occurring within communities that may be promoted through programs and policies. In line with health promotion theory, this approach points to the potential harm of framing groups of individuals as victims who are “at risk” or as “problems” to be solved; instead, it acknowledges and supports their sources of strength and resilience.

Framing the issue is a research moment preeminently suited to qualitative methods. That process of consultation should lack nothing in the thoroughness that can be achieved by the best-managed qualitative research. There is little agreement, however, on best practices

for community consultation.

In the scenario described earlier, local skills in epidemiology may allow the community to independently investigate the high level of diabetes and design and demonstrate the need for locally relevant prevention and treatment programs. Too often, however, research is initiated by outside researchers, sent in temporarily to study the “problem” and report back to a governmental or other external body. Even if the researchers recognize importance of community consultation to understand the local reality and framing of the issues around diabetes, the process will likely be more improvised than systematic. While some researchers will engage in discussions with community members or leaders to establish an appropriate framing of the health issue, this process is often *ad hoc* at best. Consultation with a community leader, for example, may not represent the interests of all segments of the community, which will likely vary by age, gender, status in the community, and other factors. To ensure the framing of the issue and the research objectives are founded on the interests of the broader community, culturally safe methods are needed to capture the diversity of perspectives and priorities within the community.

Chapter 3 of the thesis will look at one method for community consultation that can be applied to survey the viewpoints of various segments of the study population.

### **1.5.2 Ethical Review**

Another key issue in culturally safe research is the evaluation of the study by a research ethics board (REB) cognizant of cultural safety. Academic research involving humans and all research funded by the Canadian Treasury (for example via the Canadian Institutes for Health Research) must receive approval from a REB before the study can begin. Research ethics boards aim to protect the rights and welfare of the participants and focus primarily on free and informed consent, privacy and confidentiality, and a fair distribution of benefits and burdens.

Scientific validity is a critical factor in ethical review since research must first be scientifically sound before it can be considered ethically acceptable.<sup>47</sup> For instance, if the methods are unable to answer the research question, the results become meaningless and

certainly provide no benefit to the participants or their community.

For research involving Aboriginal peoples, many REBs have added special considerations and guidelines to which researchers are expected to adhere.<sup>12</sup> Increasingly, Aboriginal communities are forming their own review boards to approve the research proposal whether or not it is already approved by another board. This is analogous to the guidance given in the International Guidelines for Ethical Review of Epidemiological Studies developed by the Council for International Organizations of Medical Sciences, which recommends that studies sponsored in one country but conducted in another satisfy the ethical standards of the host community in addition to the standards of its sponsor.<sup>48</sup>

Local review committees often examine factors that the committee of an academic institution may or may not consider. This includes the relevance of the research question to local priorities, the potential burden on community resources, the cultural appropriateness of the methodology, and other considerations of cultural safety.

Balancing conflicting demands from institutional review boards and local Aboriginal committees can be difficult. While a university REB may expect the methods and instruments to be finalized and submitted along with the ethics application, an Aboriginal process may require a greater degree of flexibility and openness to input from local stakeholders and adaptation to cultural context throughout the research process.

In the diabetes example, the community may wish to participate throughout the questionnaire development process to ensure the language and terminology are locally relevant and the questionnaire appropriately addressed key issues that may be unique to their community. Changes based on this input will increase the cultural validity of the instrument while the effect on scientific validity may be either beneficial or detrimental. Maintaining an optimal balance may involve ongoing collaboration and discussion between community members and scientific researchers. It can be difficult, however, to persuade a university ethics committee that the community will take an active part in developing a questionnaire when they are used to seeing a fully developed questionnaire prior to their approval to initiate contact with the community. This usually requires a separate conditional approval for design consultations.

Without harmonization between the institutional and Aboriginal ethics review

processes, it can be a challenge to satisfy requirements of scientific validity and cultural safety. Notwithstanding recent changes to the Tri-Council Policy Statement reflecting the widespread concern about inappropriate research in Aboriginal communities, there is often little recognition among REBs of the complexity involved in conducting research that is at once ethically sound, scientifically rigorous, and culturally safe.<sup>49, 50</sup> The Tri-council guidelines are directed entirely at researchers “going in” to communities, rather than to researchers involved in their own communities.

### **1.5.3 Funding**

The conditions under which research is funded constitute an important factor in the balance of cultural safety and scientific validity. Decisions by scientific bodies that fund large grants are mostly based on the credibility of the key researcher, the importance of the research question, and whether the proposed methods are adequate to answer the research question. Funders of epidemiological research expect that researchers will follow the scientific protocol outlined in the original funding proposal, so concerns about cultural safety have to be handled up front, at the protocol stage.

In the diabetes example, if the community wishes to initiate and have ownership over their own research, it may be difficult to acquire research funding without a university appointment or existing credibility in the field of epidemiology or endocrinology. Thus, the community may need to partner with external researchers and universities to acquire funding, which could potentially threaten self-determination and the cultural validity of the research process. Consequently, the community may even decide to decline the research opportunity altogether.

To recognize the unique circumstances of research with Aboriginal communities, the Canadian Institutes for Health Research (CIHR) recently released its Guidelines for Health Research Involving Aboriginal People, recommending a participatory approach to Aboriginal health research.<sup>51</sup> To enable researchers to meet these guidelines, CIHR funding policies will need to allow for the additional resource requirements that often accompany research protocols designed to be both culturally safe and scientifically sound. A number of

researchers have cited a discrepancy between the time and financial resources required to conduct research in a culturally safe way and the amount of funding that is made available for such projects.<sup>5, 52-54</sup>

Although research grants often include funds to hire local research assistants or data collectors on a temporary or part-time basis, there is rarely enough to permit full-time participation, which may lead the community to feel disempowered and lose interest. Fortunately, there is some indication that the situation is improving as CIHR has begun investing in the research process through development grants that help to fund partnership building and research planning. The work of CIET in Canada illustrates how a series of projects supported by different funding envelopes can be aligned to the advantage of communities.<sup>46</sup> Still, much progress is to be made before researchers and communities have the resources needed to maintain cultural safety throughout the research process.

Another important consideration is the additional pressure that culturally safe research may place on the resources of the community. The equal distribution of power that is central to culturally safe research brings both opportunity and cost to the community as well as the researchers.<sup>26</sup> Greater control over the research process means greater responsibility, which can be burdensome to the community. This has to be offset by the advantages to the community, which are usually more tangible with community-initiated research than with externally-initiated research.

In the past, researchers have used this as an excuse to carry on without local input.<sup>32</sup> Instead, this should prompt researchers to consider whether extra resources can be secured, if activities should be postponed until the community is ready, or if the study is appropriate or even needed at all.

#### **1.5.4 Study Design**

The nature of the research question posed by the community should set the research design. This is a sufficient basis to question the idea that culturally safe research must apply qualitative methods or even that qualitative research is inherently culturally safe.

In the diabetes scenario, for example, the community is concerned about the high



level of diabetes in the community. If the interest is how health programs and services can affect the lives of individuals living with diabetes, a qualitative design using unstructured interviews is an obvious choice. If, however, the interest is to demonstrate to government and other decision makers that existing prevention programs have reduced the occurrence of diabetes, and that they require continued funding, a robust quantitative design would be in order.

Among quantitative designs, randomized controlled trials (RCTs) are considered to produce the highest quality of evidence in the hierarchy of research designs.<sup>55</sup> Ill-suited to the investigation of environmental health concerns, RCTs are especially useful in demonstrating the effectiveness of interventions to attract resources.<sup>56</sup> But the rigorous scientific study protocol in this design requires special consideration for issues of cultural safety. A systematic review of research in Aboriginal communities in Australia found very few studies had a randomized controlled trial design.<sup>57</sup> The author of the review suggests as possible explanations a lack of local expertise, inadequate resources and infrastructure, and insufficient sample sizes in rural and remote communities.

Andersson and colleagues,<sup>58</sup> describing a locally-driven randomized community controlled trial on domestic violence with 12 Aboriginal women's shelters across Canada, have illustrated that RCTs can be run by Aboriginal communities, investigating an issue they consider to be a high priority, in full cultural safety. The trial evaluates locally-developed interventions to reduce domestic violence in Aboriginal communities. In order to influence decision makers and to obtain the resources they need, communities recognized that hard quantitative evidence was required to demonstrate that the programs were effective and deserved financial support. Drawing random numbers from a hat, directors of women's shelters allocated themselves to two waves of intervention, the second wave serving as controls for the intervention in the first wave.

### **1.5.5 Review of Existing Knowledge**

Most high quality research entails a literature review of published material on the subject of interest. It seems reasonable to question the cultural safety of a review that is

limited to Western scientific knowledge. Most reviews of published work are by definition limited to Western scientific knowledge, when a great deal of valuable knowledge exists at the community level.

In the diabetes example, researchers will conduct a review the published literature to see what risk factors or health interventions epidemiologists and other researchers have already studied in other or similar communities through scientific methods. It is unlikely, however, that they will consider the existing body of knowledge and beliefs held within the community itself, where members have extensive firsthand experience with the local reality and context in which diabetes is occurring.

Just as one might follow a rigorous protocol to review scientific literature, a review of indigenous or local knowledge requires a rigorous protocol. Unfortunately, few methods are available to researchers and communities to ensure the acquisition of new knowledge through research is building upon existing knowledge held in the scientific community as well as in indigenous communities for whom the research is intended to benefit.

Chapter 3 of the thesis will look at a method to reviewing local knowledge and Chapter 4 will juxtapose this approach to conventional methods for reviewing Western scientific knowledge (systematic review) and discuss how the two approaches can together contribute to culturally safe epidemiology.

### **1.5.6 Questionnaire Development**

The development of a research questionnaire is often informed by previous research; the benefits include prior validation and comparability implicit in standards-based instruments. The resulting questionnaire may account for health determinants associated with the outcome of interest in previous epidemiological studies.

Often, however, participating communities have hypotheses of their own that have not been considered, let alone measured and tested. Members of the study population likely face the realities of the issue under investigation on a daily basis and, as a result, have a well-informed understanding of the associated and potentially contributing factors and contexts. For example, previous research may not have examined the role of westernization,

poverty, or hunting laws on local food security and diet, issues that the community may view as central to the rise in diabetes. Few researchers, however, consult with community members during questionnaire development.

When consultation does occur, participation is often limited to a local ethical review committee that assesses the final draft of the questionnaire to ensure it is culturally appropriate and ethically sound. By this time, however, the researchers have already finalized the objective and much of the content of the questionnaire and it may be too late for the researchers to address the more fundamental concerns of the community. If the community is engaged and working alongside the researchers from the onset, the objectives and development of the questionnaire can be both culturally safe and scientifically sound.

Parsing the questionnaire development into several steps allows community participation in setting the research question or the conceptual framework of the enquiry; with this in hand, existing standard questions can be applied for many of the community-led categories. Further consultation followed by translation and back-translation helps to verify the relevance of the standard question.

Chapter 3 of the thesis will look at how locally-held beliefs and suppositions can be built into a study questionnaire to ensure the community's research questions and hypotheses are adequately measured and tested.

### **1.5.7 Sampling and Recruitment**

Conventional Western scientific wisdom posits that a large, randomly selected sample will ordinarily be representative for purposes of an epidemiological study. In many Aboriginal communities, particularly in rural or remote regions, immediate logistical problems arise with this sampling strategy. The situation is still more complicated where “cultural access” is a major issue. People who are easy to reach, who are more likely to respond, and who are open to scientific research are seldom those most affected. Some members of a population are often hard to reach by conventional random sampling methods. In many cases, this hidden population is of utmost importance in understanding the health issue.

In the diabetes example, investigating the determinants and distribution of diabetes across the whole community would require sampling from all segments of the population. Some members of the community, such as youth, hunters, and the disabled, may not be readily available, or willing, to participate in the research. Likewise, in the case of the randomized controlled cluster trial on domestic violence,<sup>58</sup> it will be important to include hard-to-reach members of the community such as the disabled, temporary migrants, or violent offenders.<sup>57</sup> One reason is that reaching this “hidden” population may be crucial to understanding the causes and effects of domestic violence in the community. Another reason is that the inclusion of hard-to-reach populations in the study is important to capture the diversity of the community, achieving a more truly representative sample.

Undersampling of some subgroups means a representative sample may not always be achieved. The rationale for random sampling can be difficult to explain to a community, Aboriginal or otherwise. Scientifically rigorous, culturally safe researchers may need to draw on alternative methods — for example, universal coverage — to increase the size and representativeness of a sample and appreciate local expertise in the composition and distribution of the population to improve the scientific validity and cultural safety of the sampling and recruitment process.

### **1.5.8 Data Collection and Management**

With household surveys and interviews, the greatest interaction between the researchers and the participants occurs during data collection and management, rendering this step in the research process especially prone to threats to both internal validity and cultural safety. For example, an interviewer may unknowingly bias a participant’s answer by influencing how the question is posed or clarified. Similarly, during data entry, the recording of unclear responses may be subject to the researcher’s interpretation. Conventional research follows a standardized protocol that aims to capture the participants’ responses accurately without exerting undue influence or bias. Yet this protocol must also respect individual differences in comprehension, and respect community preferences.

One approach to achieving this balance is to train community-based researchers

(CBRs), who have insight into the local culture. This has advantages and disadvantages. Community members conducting research in their own community may feel more invested in the success of the research, and therefore be highly committed to following local protocols. However, CBRs may find it difficult to remain impartial in their own community and unknowingly introduce bias into the research process. In addition, when researching sensitive issues, such as domestic violence, the presence of local interviewers may reduce disclosure.

In the diabetes scenario, for example, CBRs may have a friend or family member in the community who is struggling with diabetes and therefore may be highly motivated to follow research protocols to ensure thorough and high quality data collection. At the same time, participants may not feel comfortable discussing their food security or disclosing their true nutritional and physical activity behaviours with someone they know. CIET works around this by exchanging CBRs between communities, allowing participants to be interviewed by someone like themselves, but from a distant if similar community.

A participatory approach is not appropriate for all stages of research. Certain steps must be closed to participatory input or opinion. In data entry, for example, the researcher must enter the data according to a rigid protocol developed with prior consultation, including double data entry and validation of key strokes, without interpretation.

### **1.5.9 Data Analysis**

Data analysis is one of the most important and most challenging steps in conducting scientifically rigorous, culturally safe research. Conventional statistical methods may not be appropriate or relevant in the community setting. One reason is that conventional (frequentist) statistics do not formally integrate existing indigenous or local knowledge into statistical analysis, which communities may perceive to be exclusionary and culturally unsafe.

The conventional approach that combines analysis and inference — rejecting a null hypothesis through significance testing — is not intuitive, participatory, or mindful of knowledge beyond the variables being tested. It can be difficult, for example, to effectively

communicate frequentist statistics to communities about their probability or odds of developing diabetes, especially with disclaimers around p-values or confidence intervals. What's more, individuals may find it unintuitive to base their health-related choices and behaviours on a single statistic rather than take into account the existing knowledge, beliefs and experiences that inevitably affect their decision-making.

Bayesian approaches formally incorporate pre-existing evidence and beliefs as a prior distribution of probabilities; this offers a useful strategy to bridge local and scientific knowledge formally into statistical analysis. Several efforts are under way to translate fuzzy cognitive maps into Bayesian belief networks, using local knowledge and weighting of concepts to generate locally informed prior distributions that researchers can integrate formally into data analysis. This would allow the analysis to be conditioned, in a very real sense of the term, by indigenous knowledge.

Even where this is not possible, it is almost always possible to separate the analysis, seen as the mechanical if skilled “crunching” of data into summary parameters, and interpretation, the giving of meaning to these summaries. This fits with a Bayesian approach to analysis — separate steps for analysis and interpretation — even if it does not apply Bayesian statistics.

Chapter 3 considers an approach to building locally-held evidence and hypotheses into the data analysis strategy.

### **1.5.10 Interpretation of Results**

When communities seek the expertise of epidemiologists, they often want to answer a question of causality. Yet determining the cause of health outcomes is difficult and in most cases impossible. Although detecting associations among variables is central to the science of epidemiology, there are no fixed criteria to determine whether an association is causal; even the “gold standard” randomized controlled trial can be insufficient. Epidemiologists have long recognized that no single set of criteria demonstrates causality, but most agree on a minimum set of measures that increase confidence in an association hypothesized to be causal. These include minimizing the possibility that the association is due to chance,

confounding, or biases — considerations of analysis more than of interpretation.

Culturally safe epidemiology implies a mature analysis where these issues have received due attention. From that point on, usually interacting with the supporting epidemiologist, communities and other stakeholders should be involved in the interpretation of research findings to inform locally relevant decision making. One advantage is that emerging recommendations are more likely to reflect the community's true needs, and what is feasible in the setting.

In the diabetes scenario, unusual results or statistical associations with diabetes that external researchers do not anticipate or understand may be easily explained by community members, but only if they have the opportunity to participate in the interpretation of results. For example, a study on fruit and vegetable intake in the community may find in a follow-up survey that daily intake decreased dramatically from the previous year and conclude that nutritional behaviours have deteriorated over time. If given the chance, however, community members may explain that fruit and vegetable supplies just happened to be low that week due to weather conditions that delayed shipments.

### **1.5.11 Communication and Application of Evidence**

Without community control over research, data and results may be misused, resulting in culturally unsafe communication and application of evidence, which may perpetuate the concern that research continually portrays communities in a negative light. Few community members and advocates would agree that research ends with academic conferences and publications in scientific journals. While they may see the merit in communicating the results to press for new programs or resources, a common concern is that negative results will stigmatize the community. It is not uncommon that First Nations, Inuit, and Métis prefer to restrict the application of evidence to within their own communities.

In the diabetes example, local leaders may not feel it would not benefit the community to widely release findings that show high levels of poverty or high substance use as it may only increase stigma and stereotyping. In this case, community leaders may decide to use the data strictly for local decision-making and planning. Meanwhile, the community

may wish to publicize evidence that demonstrates the success of a local health promotion program as it could attract much needed resources to continue offering the program.

CIET has called this stage of the research SEPA (socializing evidence for participatory action), a communication and planning process that enables the integration of different voices from the community into planning to support an increasingly informed engagement and mobilization around priority issues in the community.<sup>59</sup> SEPA differs from social marketing, social advocacy, and social mobilization. Certain social marketing tools may be used at the dissemination stage of SEPA, but they are not inherently part of the process. Some elements of social mobilization are present in SEPA — dialogue and action at the level of government, public services, and communities, and between these spheres — but this mobilization seeks to avoid the pitfalls of social manipulation. It is a way of raising collective awareness and interest around the issues and the evidence, contributing to an increasingly informed, self-sustained environment for participatory action and change.

No protocol for the communication of evidence can be defined a priori as culturally safe. Communities should have the opportunity to participate in the interpretation and discussion of the research products and, based on that, establish how the results should be communicated and integrated into decision making.

Chapter 3 of the thesis will discuss the cultural safety potential of a method to presenting epidemiological study findings for community-guided interpretation and communication of evidence.

## **Rationale**

This thesis is based on the premise that that modern epidemiology should play a role in addressing health issues facing Aboriginal communities and should be included in the movement towards culturally safe research. It maintains that scientific and indigenous knowledge are not mutually exclusive and that epidemiological research in Aboriginal communities can and should be both culturally safe and scientifically sound. A modern study's scientific validity can often depend on indigenous knowledge. The thesis proposes that rigour and methodological discipline are essential to cultural safety. While cultural



safety literature is typically preoccupied with the epistemological biases in the methods of nonindigenous researchers, indigenous researchers could find the same concerns relevant in their adaptation of Western scientific methods to their own priority concerns. It is at the interface in which neither indigenous nor Western scientific protocols are compromised that a culturally safe space can be achieved.

The challenge, of course, is to develop research methods and protocols that locate these culturally safe spaces. In a recent literature review on cultural safety and its applicability to the Canadian context, Brascoupe and Waters<sup>26</sup> concluded that “the practicalities of cultural safety as an outcome rather than a concept have yet to be realized.” Indeed, the literature on cultural safety has focused mainly on theory rather than practical applications. Researchers must now collaborate with communities to jointly develop scientifically and culturally safe methods and protocols. The introductory chapter outlined some of the challenges and opportunities for culturally safe research protocols while identifying areas in need of further investigation.

This methodological thesis will focus on the development of scientifically and culturally safe protocols in the research planning and design stage, specifically in the review of existing knowledge. The application of cognitive mapping to review local or indigenous knowledge will be juxtaposed with systematic reviews as the conventional approach to the review of existing scientific evidence prior to epidemiological research, highlighting ways in which the two review methods can be bridged to locate culturally safe spaces in research.

The thesis does not propose that systematic review and cognitive mapping produce alternative and mutually exclusive representations of Western scientific and Inuit knowledge, respectively. An epidemiological study should begin with a review of existing evidence; in most cases, however, this is limited to the Western scientific literature, either by a general or systematic review. A systematic review is supposed to represent an exhaustive summary of existing scientific evidence relevant to a research question. Thus, for the purposes of the Inuit ACRA project, the systematic review results represent the scientific evidence on Inuit sexual health determinants, despite that there is almost certainly additional scientific knowledge not captured in the literature. The aim was to carry out what most epidemiologists would consider a standard review protocol and examine the implications of a review process

that is limited to one source or perspective.

The cognitive mapping tried to be systematic by involving local organizations and community members as experts who have first-hand experience with Inuit sexual health issues in Ottawa. As with the systematic review, the cognitive mapping results represent local Inuit knowledge and beliefs, even though the sessions did not include all Inuit in Ottawa. What the opinions represent might be akin to a publication bias: these are the Inuit who spoke. Just as a systematic review carries a caveat about unpublished and non-indexed literature, these results should not be misinterpreted as representing the views of Inuit in general or as a sum total of traditional indigenous knowledge.

The thesis focuses on Inuit and indigenous knowledge in the context of the Inuit ACRA project but also hopes to demonstrate the potential contribution of cognitive mapping to research with other study populations, such as immigrants, youth, or the homeless, who may welcome the opportunity to inform research on issues that concern them.

## **Objectives**

1. To consider two approaches to research planning and design, one that draws on Western scientific knowledge (a systematic review of the literature) and the other on indigenous or local knowledge (cognitive mapping).
2. To examine the application of cognitive mapping in establishing culturally safe spaces in epidemiological research.

## **Case Study**

Working towards these objectives, the thesis draws on a case study known as the Aboriginal Community Resilience to AIDS (ACRA) project. ACRA investigates how HIV/AIDS and sexually transmitted infection (STI) risk reduction initiatives can build on the resilience of Aboriginal peoples to improve health outcomes in their communities. The

ACRA project is a long-term and deliberately parsed approach that is working towards locally-designed sexual health interventions evaluated through community randomized controlled trials.

This thesis examines the specific case of the Ottawa Inuit component of the ACRA project, which seeks to identify, through structured consultation and a cross-sectional survey, indicators of resilience that may serve as protective factors in the prevention of STIs among Inuit living in Ottawa. The Ottawa Inuit ACRA is a collaborative research project between Inuit living in Ottawa and CIET (Community Information and Epidemiological Technologies), based at the University of Ottawa's Institute of Population Health. A member of CIET and the Inuit ACRA team, I coordinated the planning and design stage of the project and provided technical support to the Inuit Action Research Team (ICART), a group of Inuit researchers developing epidemiological skills and advancing Inuit-specific research at CIET.

This thesis considers two different protocols used to review existing knowledge and beliefs for the purposes of the Ottawa Inuit ACRA. In this case, existing knowledge and beliefs include risk and resilience factors known or hypothesized to play a role in the transmission of sexually transmitted infections among Inuit living in Ottawa. The first approach to reviewing this knowledge focuses on Western scientific knowledge and draws on systematic review methods to gather existing knowledge from the scientific literature. The second approach focuses on local or indigenous knowledge and draws on cognitive mapping methods to review the knowledge of Inuit living in Ottawa (the intended beneficiaries of the Ottawa Inuit ACRA project).

## **CHAPTER 2**

### **Systematic Review of Western Scientific Knowledge on the Determinants of Inuit Sexual Health**

#### **2.1 Rationale**

The purpose of the systematic review was to review the existing scientific evidence on the determinants of Inuit sexual health. Prior to conducting new research, we expect that epidemiologists will review the scientific literature to uncover pending hypotheses and ensure the study will generate new knowledge that builds upon rather than duplicates evidence that is already available in the existing body of knowledge. Researchers and research-users recognize the systematic review as a less biased alternative to traditional review methods.<sup>60</sup> The systematic review described in this chapter aims to review the knowledge and hypotheses that most epidemiologists or researchers would consider “existing knowledge” for the purposes of research planning and design.

This thesis ultimately intends to challenge the assumption that Western scientific literature is the only important source of existing knowledge and will evaluate the relevance and adequacy of the systematic review approach for culturally safe epidemiology. In chapter 4, the results of the systematic review will be juxtaposed against the results of another method, cognitive mapping, applied to review the knowledge and beliefs among Inuit living in Ottawa, to examine whether scientific research to date on Inuit sexual health in Canada has reflected the hypotheses and priorities of its target population.

## **2.2 Objective**

The objective of the systematic review is to identify the risk and resilience factors for the transmission of sexually transmitted infections among Inuit in Canada according to the Western scientific literature. Here, resilience is defined as “the means by which people choose to use individual and community strengths to protect themselves against adverse outcomes and to build their future.”<sup>46</sup> Thus, resilience factors may include socioeconomic, psychosocial, behavioural or biological factors.

The current chapter aims to describe the characteristics and general approach of the existing scientific research on Inuit sexual health and chapter 4 will discuss the results of the systematic review in greater detail.

## **2.3 Methods**

### **2.3.1 Search Strategy**

The literature search aimed to capture all risk and resilience factors for sexually transmitted infections among Inuit in Canada identified in scientific research in the published peer-reviewed and grey literature. Generally, there is a scarcity of Inuit-specific research and so it was not possible to limit the review to studies conducted in Ottawa or other urban settings. Due to the rarity of Inuit-specific research, the search strategy was deliberately designed to be highly sensitive, albeit sufficiently specific. Although the current review focuses specifically on Inuit communities in Canada, I designed the search strategy to also include Inuit and related groups outside of Canada. I anticipated that Inuit-specific research within Canada would be relatively scarce and therefore included other similar populations in the search strategy to ensure an adequate number of studies for the review. Although I ultimately excluded studies conducted outside of Canada from this exploratory review, the records were kept on file for future reviews with narrower objectives, such as meta-analyses on a particular STI outcome.

### *Published Peer-Reviewed Literature*

I searched four databases from OVID, including Medline (1950-current), Embase (1947-current), PsycINFO (1806-current), and Healthstar (1966-current), and three databases from EBSCO, including Global Health (1973-current), Bibliography of Native North Americans (1950-current), and CINAHL (1981-current).

I tailored the search strategy for each database (see Appendix II) but searched the following keywords in all text for each database:

1. Inuit\* or Eskimo\* or esquimaux or aleut\* or yuit\* or inughuit\* or unanga\* or alutiiq\* or cup'ik\* or yup'ik\* or yupik\* or inup?ia\* or kalaallit\* or native\* adj3 Alaska\*

AND

2. risk\* or resilien\* or prevent\* or behav\* or sex\* or demograph\* or soci\* or health\* or cultur\*

AND

3. HIV or human immunodeficiency virus or STI or STD or sexually transmitted or venereal disease\* or Chlamydia or gonorrh?ea\* or syphilis or Treponema pallidum or herpes or HPV or human papillomavirus or chancroid or Haemophilus ducreyi or trichomon\* or LGV or lymphogranuloma vernerum or Granuloma inguinale or Calymmatobacterium granulomatis or Klebsiella granulomatis or Donovanosis or Bacterial vaginosis or hepatitis B or HBV or hepatitis C or HCV or hepatitis D or HDV or Human T-cell lymphotropic virus type 1 or HTLV-1 or Cytomegalovirus or pediculosis pubis or scabies

### *Grey Literature*

I reviewed grey literature from the following sources:

- Health Canada ([www.hc-sc.gc.ca](http://www.hc-sc.gc.ca))
- Public Health Agency of Canada ([www.publichealth.gc.ca](http://www.publichealth.gc.ca))
- Pauktuutit Inuit Women of Canada ([www.pauktuutit.ca](http://www.pauktuutit.ca))

- Inuit Tapiriit Kanatami ([www.itk.ca](http://www.itk.ca))
- National Aboriginal Health Organization ([www.naho.ca](http://www.naho.ca))
- Canadian Aboriginal AIDS Network ([www.caan.ca](http://www.caan.ca))
- Aboriginal Canada Portal ([www.aboriginalcanada.gc.ca](http://www.aboriginalcanada.gc.ca))
- Canadian HIV/AIDS Information Gateway ([www.hivinfovih.ca](http://www.hivinfovih.ca))
- HPV Info Portal ([www.hpvinfos.ca](http://www.hpvinfos.ca))
- US Centre for Disease Control and Prevention ([www.cdc.gov](http://www.cdc.gov))
- State of Alaska Department of Health and Social Services ([www.hss.state.ak.us](http://www.hss.state.ak.us))
- US Indian Health Service ([www.ihs.gov](http://www.ihs.gov))
- Alaska Native Health Board ([www.anhb.org](http://www.anhb.org))
- Alaska Native Tribal Health Consortium ([www.anthc.org](http://www.anthc.org))
- World Health Organization ([www.who.int](http://www.who.int))
- Master's or PhD theses and dissertations

### **2.3.2 Study Selection**

I exported all search results into reference management software (Refworks) and removed duplicate records of the same report by reviewing the titles and abstracts. Myself and a second reviewer (Neil Andersson) independently reviewed the list of titles and abstracts to exclude articles that were clearly ineligible, i.e. do not study at least one risk or resilience factor for a sexually transmitted infection among Inuit in Canada.

Myself and another second reviewer (Beverley Shea) then independently reviewed the full-text articles selected in the initial screening process, rigorously applying the inclusion and exclusion criteria. The reviewers (MC and BS) compared their respective selections and resolved discrepancies and disagreements through discussion and consensus.

The primary reviewer also scanned the bibliographies of included studies for additional articles.

### *Eligibility Criteria*

The review included studies that meet the following inclusion criteria:

- 1) Primary research (qualitative or quantitative) of any study design
- 2) Collection of primary data on at least one (individual- or community-level) risk or resilience factor, including known intermediates, modifiers, or confounders, for one or more sexually transmitted infections specifically among Inuit in Canada.
- 3) Studies that focus on broader target groups that include Inuit, i.e. Aboriginal peoples, were included in the review if the analysis stratified primary data on at least one risk or resilience factor by ethnicity (Inuit-specific).
- 4) Study samples that included 90% or more Inuit or were consistently described by the author(s) as “Inuit,” but contain a small minority of non-Inuit, were included in the review.

The review excluded studies with the following characteristics:

- 1) Studies that do not include Inuit in Canada. The review also excluded studies that strictly refer to Inuit as members of a broader Aboriginal group (including First Nations, Métis, etc.).
- 2) Studies with samples limited to special risk groups (injection drug users, sex workers, men who have sex with men).
- 3) No age or gender restrictions applied.
- 4) No language restrictions applied.

### **2.3.3 Quality Assessment**

Myself and a second reviewer (Crystal Huntly-Ball) independently appraised the quality of eligible studies, including quantitative and qualitative designs. The objective of the systematic review was to include all studies on Inuit sexual health in Canada, regardless of



quality or validity, to understand the scientific perspective on this issue; for this reason, the review did not exclude studies on the basis of quality.

The reviewers appraised quantitative studies using the ‘Quality Assessment Tool for Quantitative Studies,’ developed by the Effective Public Health Practice Project, affiliated with McMaster University.<sup>61</sup> Thomas<sup>62</sup> found the tool demonstrated good content and construct validity and the tool is recommended by the Cochrane Public Health Group in the Cochrane Handbook for Systematic Reviews of Health Promotion and Public Health Interventions.<sup>63</sup> Applying this tool, the reviewers graded the quality of quantitative studies as 1 (strong), 2 (moderate), or 3 (weak).

In the absence of a validated quality assessment tool for qualitative studies, the reviewers applied an existing and widely used tool developed by the Critical Appraisal Skills Programme (CASP)<sup>64</sup> and recommended by the Cochrane Public Health Group<sup>63</sup> to appraise the qualitative studies included in the review. CASP is a checklist-style tool comprised of a series of 10 yes/no questions. In the current systematic review, the reviewers graded the quality of qualitative studies on a scale from 1 to 10 where 10 signifies a perfect score. For consistency with the quantitative studies, the reviewers considered a score of 1-3 for the qualitative studies as “weak,” 4-7 was “moderate,” and 8-10 was “strong.”

#### **2.3.4 Data Abstraction and Analysis**

Myself and a second reviewer (CHB) independently extracted appropriate information from the included articles using a standardized data abstraction form developed specifically for this review. Information retrieved from the papers included the citation, setting, target population, outcome(s) of interest, and determinants of sexually transmitted infections identified. Data abstraction included qualitative and quantitative evidence on risk and resilience factors examined by the studies regardless of statistical significance. The two reviewers resolved discrepancies or disagreements through discussion and consensus.

I synthesized the identified determinants of sexually transmitted infection by thematic synthesis,<sup>65-67</sup> which involved the dissection, coding, and organizations of narrative results into descriptive themes and sub-themes to facilitate summary analysis. For example, if a

quantitative study stratified the prevalence of a particular sexually transmitted infection by age group and sex, I organized the two factors into the categories “age” and “sex.” These categories later became part of the sub-themes *Age & Generation* and *Sex & Gender*, respectively, to facilitate comparison with the review of Inuit knowledge (see Chapter 2). As the reviewer, I created the initial themes and sub-themes based on the review of Inuit knowledge (by cognitive mapping), which identified a broader range of concepts, and organized the results from the systematic review into the existing categories with modifications as necessary. If a concept from the literature was not suited to any of these categories, a new one was created. In most cases, I modified the category to suit both the Inuit and Western scientific concepts. For example, the sub-theme *Access to and Use of Programs, Services, & Other Resources* did not originally include “Use of;” this was added only after reviewing the scientific literature, which, unlike the Inuit, focused largely on the *use of* rather than *access to* programs, services, and other resources.

I grouped the list of sub-themes further into four broader themes, representing the four types of health determinants: (1) structural and demographic factors, (2) behavioural factors, (3) psychosocial factors, and (4) biological and genetic factors. Here, *Structural and Demographic Factors* include broader social and political factors, such as social and cultural environments, access to services, and socioeconomic status, as well as age, sex and other demographic factors. *Behaviour Factors* include personal health practices and behaviours, such as abstinence, condom use, and substance use. *Psychosocial Factors* include social variables that influence an individuals’ emotional and mental health, such as social support and counselling, self-esteem, trust, and respect. *Biological & Genetic Factors* include inherited or physical health determinants, such as disability and genetic endowment. The complete list of themes and sub-themes are presented in Table 1.

I then examined the distribution of themes and sub-themes around the determinants of Inuit sexual health within the reviewed literature by content analysis,<sup>65,68</sup> which involved qualitatively and quantitatively analyzing the distribution of themes to identify patterns and comparisons across the included studies and the study characteristics. In particular, the analysis aimed to determine whether the type and frequency of identified risk or resilience factors for sexually transmitted infections varied by publication date (prior to 1990s and 2000 or later) to identify possible trends or patterns.

For several reasons, it was not feasible to conduct a meta-analysis of the review results, i.e. to extract and pool quantitative data from two or more high quality studies on a common outcome of interest (such as HIV infection) to produce a summary result. Firstly, there is a scarcity of Inuit-specific research on any given sexually transmitted infection. Secondly, much of the quantitative evidence that is available is of poor quality. Finally, the review intended to include qualitative research, which is not suitable for meta-analysis. For this reason, I examined both qualitative and quantitative data by thematic synthesis and content analysis.

**Table 1 Complete List of Themes and Sub-themes**

<b>STRUCTURAL &amp; DEMOGRAPHIC FACTORS</b>	<b>BEHAVIOURAL FACTORS</b>
Access to & Use of Programs, Services, & Other Resources Age & Generation Community Connection & Cohesion Culturally Relevant Resources Geographic Location History and Legacy of Colonization Housing, Employment, & Other Socioeconomic Factors Inuit Culture, Traditions, & Way of Life Justice & Reconciliation Knowledge, Information, & Education Parenting, Family, & Relationships Popular Culture, Internet, & Other Media Research & Surveillance Social Norms, Attitudes, Role Models, & Peer Pressure Safe Place Sex & Gender Sexual Orientation Sexual Violence & Other Abuse Taboo, Stigma, & Discrimination	Abstinence Casual & Multiple Sexual Partners Communication, Disclosure, & Sharing Experiences Nutrition, Physical Activity, & Healthy Lifestyle Recreation, Arts, & Leisure Safe Sex Sex Trade Sharing Needles & Other Personal Items Substance Use Testing & Screening Vaccines & Pharmaceuticals
<b>PSYCHOSOCIAL FACTORS</b>	<b>BIOLOGICAL &amp; GENETIC FACTORS</b>
Adaptation to Urbanization, Westernization, & Other Changes Focus on Strength & Resilience Mental Health & Healing Self-Esteem, Assertiveness, & Responsibility Social Support, Counselling, & Mentorship Trust & Respect	Physical Health, Biology, & Genetics

## 2.4 Results

### 2.4.1 Study Selection and Characteristics

Figure 1 describes the search strategy results. The systematic search of the peer-reviewed literature yielded a total of 381 abstracts (876 before the removal of duplicates), of which myself and a second reviewer (Neil Andersson) identified 15 for further examination. From the grey literature, the reviewers identified 8 relevant articles for further review. Myself and a second reviewer (BS) independently reviewed the 23 full-text articles, of which 22 met the inclusion criteria. A review of the bibliographies of the included articles identified five additional studies. Five of the 27 documents that were separate publications from the same study; the review included these but did not count them as separate studies. Thus, the systematic review included a total of 22 studies. Table 2 lists the characteristics of the included studies<sup>69-95</sup> and table 3 indicates the themes and sub-themes identified in each study (see appendix).

#### *Source*

Of the 27 total studies, including duplicate analyses, the reviewers retrieved 17 from the database search, five from the grey literature search, and five from the bibliographic scan. Of the seven databases searched, Healthstar and Medline both detected the highest number of eligible studies (n=13), followed by Embase (n=9), Global Health (n=6) and CINAHL (n=2). The Bibliographies of Native North Americans database did not detect any eligible studies.

#### *Study Design*

The vast majority of the included studies used quantitative study designs (20 of 22); only two used a qualitative design. The 20 quantitative studies included 17 cross-sectional studies, 1 prospective cohort study, 1 randomized intervention trial, and 1 mathematical predictive model. The two qualitative studies applied in-depth interviews and

semi-structured interviews with focus groups, respectively.

### *Quality Assessment*

Through quality assessment, the reviewers classified all of the studies (quantitative and qualitative) as “weak.”

### *Setting*

The selected studies included Inuit from all four land claim regions. The greatest representation was from Nunavut with 16 studies including Inuit living in this region, followed by Nunavik (included in three studies), Inuvialuit (included in three studies), and Nunatsiavut (included in two studies). One study included Inuit living in southern urban centres and two studies did not specify the location of the participants.

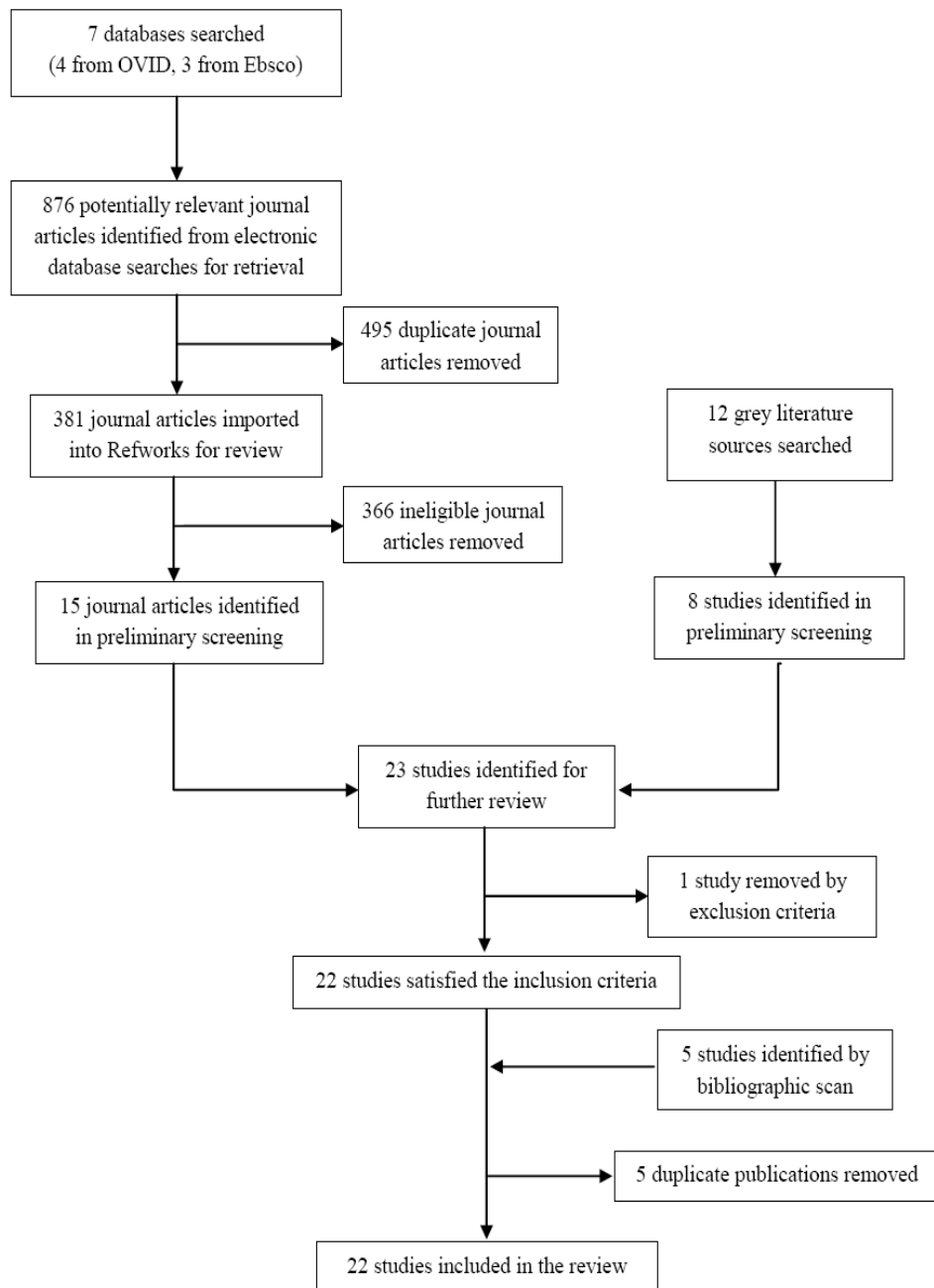
### *Primary Outcome*

The most commonly researched health outcome was hepatitis B virus (HBV) with nine studies focusing on HBV as an outcome. Three studies focused on HIV/AIDS, 3 on Chlamydia, 2 on human papillomavirus (HPV), 2 on herpes simplex virus, 2 on cytomegalovirus, and 1 on gonorrhoea. Two studies looked at sexually transmitted infections or sexual health more broadly.

Of the 22 studies included in the systematic review, 16 directly measured the occurrence of disease among study participants, while 5 studied knowledge, attitudes and behaviour, and 1 study constructed a mathematical predictive model of disease based on existing datasets.

### *Time of Publication*

The review included 12 studies published recently (since 2000) and the remaining 10 studies published prior to 1990 (nine in the 1980s and one in the 1950s). The review did not identify any eligible studies published in the 1990s.



**Figure 1 Systematic Review Search Strategy Results**

## 2.4.2 Time Trends

Of the 22 included studies, the review identified 10 published prior to 1990 and 12 published in 2000 or later. The systematic search did not identify any eligible studies published in the 1990s. Table 4 lists the sub-themes (by frequency of mention) identified in studies published prior to 1990 and in 2000 or later, respectively.

### *Distribution of Outcomes Researched*

The most commonly researched STI in both time periods was the hepatitis B virus (HBV) (n=six studies prior to 1990 and n=3 in 2000 or later).

The review found studies on hepatitis B and Chlamydia among Inuit published in both time periods. The review found studies on CMV and herpes simplex virus published only prior to 1990 and studies on HIV/AIDS, HPV, gonorrhea and STIs in general published only in 2000 or later.

All of the 10 studies published prior to 1990 directly measured the occurrence of disease in the study sample. Of the 12 studies published in 2000 or later, six directly measured the occurrence of disease in the study sample, five studied knowledge, attitudes and/or behaviour, and one constructed a mathematical predictive model based on existing datasets.

### *Distribution of Themes and Sub-themes*

The studies published prior to 1990 identified 25 (but only 5 unique) sub-themes, of which *Age & Generation* (n=9 studies) and *Sex & Gender* (n=8) were the most common. In this time period, nearly all of sub-themes fell under the category *Structural & Demographic Factors* (n=24).

The studies published in 2000 or later identified 113 (32 unique) sub-themes. *Age & Generation* (n=9) was the most commonly mentioned. In this time period, the highest

number of sub-themes (n=54) fell under the category *Structural & Demographic Factors*, followed by *Behavioural Factors* (n=40).

Five sub-themes appeared in both prior to 1990 and 2000 or later, including *Age & Generation*, *Sex & Gender*, and *Geographic Location*. None of the sub-themes identified prior to 1990 were unique to this time period. Twenty-seven sub-themes identified in 2000 or later were unique to this time period, the most common of which included *Knowledge, Information, & Education* (n=7) and *Testing & Screening* (n=7).

**Table 4 Concepts Identified by Publication Date (% of studies)**

<b>Pre-1990 (10 studies)</b>	<b>2000 or later (12 studies)</b>
Age (90%)	Age (75%)
Sex (80%)	Knowledge (58%)
Geographic Location (60%)	Testing (58%)
Culture (10%)	Communication (50%)
Sharing Personal Items (10%)	Sex (50%)
Abstinence (0%)	Use of Resources (50%)
Adaptation to Change (0%)	Abstinence (42%)
Biology (0%)	Biology (42%)
Colonization (0%)	Parenting (42%)
Communication (0%)	Self-Esteem (42%)
Community Cohesion (0%)	Substance Use (42%)
Culturally Relevant Resources (0%)	Culturally Relevant Resources (33%)
Discrimination (0%)	Healthy Lifestyle (33%)
Healthy Lifestyle (0%)	Safe Sex (33%)
Justice (0%)	Socioeconomic Factors (33%)
Knowledge (0%)	Mental Health (25%)
Mental Health (0%)	Multiple Partners (25%)
Multiple Partners (0%)	Pharmaceuticals (25%)
Parenting (0%)	Trust (25%)
Pharmaceuticals (0%)	Discrimination (17%)
Popular Culture (0%)	Geographic Location (17%)
Recreation (0%)	Popular Culture (17%)
Research (0%)	Sharing Personal Items (17%)
Resilience (0%)	Social Norms (17%)
Safe Place (0%)	Social Support (17%)
Safe Sex (0%)	Community Cohesion (8%)
Self-Esteem (0%)	Culture (8%)
Sex Trade (0%)	Resilience (8%)
Sexual Orientation (0%)	Safe Place (8%)
Sexual Violence (0%)	Sex Trade (8%)
Social Norms (0%)	Sexual Orientation (8%)
Social Support (0%)	Sexual Violence (8%)
Socioeconomic Factors (0%)	Adaptation to Change (0%)
Substance Use (0%)	Colonization (0%)
Testing (0%)	Justice (0%)
Trust (0%)	Recreation (0%)
Use of Resources (0%)	Research (0%)



## 2.5 Discussion

### 2.5.1 Study Selection and Characteristics

The review found most of the eligible studies through the databases rather than the grey literature. Of the seven databases searched, the review found the vast majority of eligible studies through OVID databases (Medline and Embase). The EBSCO databases were less productive, particularly the Bibliographies of Native North Americans (BNNA) database, which did not detect any eligible studies. Although the BNNA includes citations to literature on all indigenous peoples in North America, including Inuit, much of its content appears to be First Nations-focused.

A quick scan of the literature suggests that had the inclusion criteria been First Nations-specific, the review would have found a higher number of relevant studies. This may be partly due to fact that the First Nations population in Canada (N=698,025) is nearly 14 times higher than the Inuit population (N=50,485).<sup>96</sup> Also, Inuit communities are often more remote and difficult to access.

Nearly all of the included studies had a quantitative study design of “weak” quality because most adopted a cross-sectional study design, which ranks low in the hierarchy of evidence. The scarcity of robust, high-quality scientific research on Inuit sexual health should be of concern to decision-makers and service providers in Inuit communities who must to develop programs, services, and other resources based on weak or anecdotal evidence. This is particularly a concern for Inuit living in Inuvialuit, Nunavik, Nunatsiavut, and southern urban centres where few studies were found.

Almost half of the included studies focused on the hepatitis B virus (HBV), mostly from the 1980s when HBV in the north was receiving a lot of attention as researchers were newly developing and testing the HBV vaccine. The evidence on other sexually transmitted infections was sparse and overall the review found that relatively little is known about the status of Inuit sexual health in Canada.

The occurrence of sexually transmitted infections among Inuit in Canada is largely unknown. Not all provinces and territories collect ethnicity data for sexually transmitted

disease surveillance and those that do very often aggregate Inuit with First Nations and Métis into an “Aboriginal” category.<sup>96</sup> Although Inuit-specific surveillance data would be useful in the appropriate targeting of resources and development of relevant programs and services for Inuit, there are a number of limitations to the collection of ethnicity data in disease surveillance. These include inconsistency in ethnicity data collection or reporting across provinces and territories, potential misclassification of ethnicity at the time of diagnosis, and underrepresentation of those who may not wish to identify their ethnicity.<sup>96</sup> The stratification by ethnicity for some sexually transmitted infections, such as HIV, has already contributed to perceptions of Aboriginal peoples as a ‘high-risk’ group, fuelling stigmatization, which may further reduce the willingness among First Nations, Inuit, and Métis to disclose their ethnicity at the time of diagnosis.

### **2.5.2 Time Trends**

All of the studies published before 1990 focused on measuring the occurrence of disease in the study sample, stratifying for basic demographic characteristics. Meanwhile, later studies broadened their objective to consider the role of knowledge, attitudes, and behaviour and how health determinants interact to influence Inuit sexual health. This may suggest that, over time, the perception of sexual health in the scientific literature has expanded to recognize upstream determinants of disease and their interdependencies. Alternatively, this finding could indicate reluctance among Inuit to participate in more invasive research involving blood or other biological samples.

### **2.5.3 Strengths and Limitations**

This systematic review is, to my knowledge, unique in its focus on the Inuit-specific literature. Without previous reviews upon which the current review could build, I designed the protocol to be broad and exploratory. The original search strategy was therefore designed to be highly sensitive, including primary and secondary data on all sexually transmitted infections and all types of risk and resilience factors among Inuit and other indigenous

peoples in the circumpolar region. A scan of the titles and abstracts from the search, however, found the results were too heterogeneous and mostly irrelevant to Inuit in Ottawa. Therefore, I narrowed the selection criteria to include only primary data and exclude studies with other indigenous circumpolar peoples, such as the Alaska Natives in the United States and Inuit in Greenland. The inclusion of all types of risk and resilience factors, whether structural, behavioural, psychosocial, or biological, remained essential to ensure the review captured all facets of the Western scientific perspective on Inuit sexual health. Likewise, the review necessarily included primary evidence on sexual health determinants regardless of statistical significance or the qualitative or quantitative nature of the data.

With no previous review of the Inuit-specific literature to build on, the broad and exploratory nature of the search strategy was difficult to avoid. The results from this review can now provide a starting point for future systematic reviews with a narrower focus and a more rigid methodology. This review, however, found that there are an insufficient number of studies on any given sexual health outcome among Inuit populations and so a more specific and rigorous systematic review or meta-analysis may be difficult to conduct at this time.

For researchers and communities, this systematic review identifies important gaps in Inuit sexual health research and areas in need of further investigation. The review found that there is very little knowledge in the Western scientific literature for community leaders looking to engage in evidence-based decision-making. The challenge will be balancing the need for further evidence with a general mistrust and hesitation among Inuit communities to engage in research, particularly that which is initiated by outside researchers. Moreover, the evidence gaps and research needs identified in the systematic review are not necessarily in line with the needs and hypotheses held within Inuit communities.

Thus, a systematic review of the Western scientific literature, while valuable in identifying trends and gaps in existing epidemiological research, only provides one perspective. Indeed, there is little indication in the literature of the direction in which research beneficiaries would like epidemiological research to advance. To increase the relevance and value of research on Inuit health, researchers and communities require additional methods to review local or indigenous knowledge and perspectives.

## **2.6 Conclusion**

There is a paucity of Inuit-specific sexual health research in the Western scientific literature and little is known about the current status of Inuit sexual health in Canada, including the occurrence and distribution of sexually transmitted infections and their broader determinants of health. The number of studies on Inuit sexual health and the types of sexually transmitted infections researched does not appear to have increased since the 1980s, although the breadth and diversity of health determinants identified has expanded over time.

Although the systematic review of the literature suggests a lack of evidence on Inuit sexual health in Canada, it does not indicate whether there is desire among Inuit to pursue the research required to fill this evidence gap. New research is typically based on the existing evidence and gaps in evidence found in the literature; however, a review of the literature is generally limited to knowledge and hypotheses held within the Western scientific community and therefore only captures one perspective on any given health issue. In the case of the Inuit ACRA project, the systematic review was of limited value in identifying the current sexual health issues and true research needs among Inuit communities in Canada. The amount of research relevant to Inuit living in southern urban centres such as Ottawa is especially scarce. In addition to a systematic review of the literature, new methods are needed to identify local perspectives held outside of the Western scientific knowledge and belief system. Chapter 3 will propose cognitive mapping as one such method to reviewing local and indigenous interests and hypotheses to inform research and planning.

## **CHAPTER 3**

### **Review of Inuit Knowledge on the Determinants of Inuit Sexual Health**

#### **3.1 Rationale**

When formulating new hypotheses, researchers commonly conduct a review of the published scientific literature to identify the gaps in evidence and areas in need of further investigation to advance research forward and avoid duplication. Locally-held hypotheses and research questions, however, are not typically found in the published literature and are therefore rarely considered or empirically tested through scientific methods. Furthermore, as demonstrated in Chapter 2, there is often a scarcity of culturally-specific research in the Western scientific literature, particularly for smaller populations such as Inuit communities in Canada. When unavailable to researchers and decision-makers, local knowledge and priorities have minimal influence on the decisions that affect the lives of community members, often leading to culturally inappropriate interventions.

The Ottawa Inuit ACRA project aims to generate locally-relevant evidence on which decision makers can develop culturally appropriate interventions to promote healthy sexuality among Inuit living in Ottawa. To develop locally-driven research objectives, hypotheses, and instruments, the Inuit ACRA research team needed a method to rigorously review local knowledge and beliefs around Inuit sexual health, specifically on health determinants that promote resilience against STIs, just as one might review the scientific literature.

## **3.2 Objective**

The objective of this chapter is to review (by cognitive mapping) local knowledge and beliefs on the risk and resilience factors for sexually transmitted infections among Inuit living in Ottawa. Chapter 4 will juxtapose cognitive mapping with the systematic review approach to reviewing existing knowledge and assess its potential contribution to culturally safe epidemiology.

## **3.3 Methods: Cognitive Mapping**

The ACRA research team reviewed local knowledge and beliefs around Inuit sexual health in Ottawa using cognitive mapping in which community members used maps to graphically present their knowledge on the risk and resilience factors contributing to or preventing STIs in the community.

Cognitive mapping (CM) is a graphical representation of expert knowledge on the relationships between elements of a system or issue, comprised of concept nodes and causal links.<sup>97</sup> Typically, CMs take place in a focus group with a group of experts on the issue of interest and the session begins with a central concept or question. If we take the example of diabetes, the central question may be “What factors help to prevent diabetes in the community?” Conventionally, the experts participating in cognitive mapping are physicians and other health professionals. In the case of diabetes, this might include endocrinologists, family physicians, or nurses. In culturally safe epidemiology, however, experts can also include locals who are intimately familiar with the impact of diabetes in the community and the contributing factors. With the help of a facilitator, CM participants suggest the factors they believe to affect the central concept. In the case of diabetes, these factors might include physical activity, disability, genetics, healthy diet, access to healthy food, or community kitchen programs.

Cognitive maps use concept nodes to represent these influencing factors, which participants can join with arrows extending from the cause to the effect, indicating a causal relationship believed to exist between two concepts. For example, the concepts, such as healthy diet, access to healthy food, and community kitchen programs are represented by

*nodes* on the map. The participants may believe that community kitchen programs have an effect on access to healthy food, which in turn has an effect on healthy diet. The facilitator then connects these concepts or *nodes* with arrows, indicating the direction of the causal relationship. An advantage is that CM can present unstructured information in a graphical form to visualize the complexity and interconnectedness of concepts according to the experts' knowledge and belief system.

It is also possible to weight the causal links in the map according to relative importance to indicate the strength of association believed to exist between the two concepts by ranking the strength of the causal effect on a scale of 1 to 5 or “very weak” to “very strong.” Participants also indicate the positive or negative nature of the relationship. For example, participants may believe that community kitchen programs have a “very strong” positive influence on access to healthy food but access to healthy food only has a “moderate” positive effect on healthy diet. Thus, by expressing the causal influence levels in imprecise linguistic terms, the participants introduce a “fuzzy” aspect to generate a fuzzy cognitive map (FCM), which can be a useful representation of otherwise unstructured knowledge about causalities.<sup>97</sup>

Cognitive mapping and fuzzy cognitive mapping are commonly applied as group decision support tools to better understand the complexity of factors contributing to a particular outcome or decision. CMs and FCMs have helped to assess clinical decision-making tasks, such as medical diagnosis, in hospitals and other health care settings where the “experts” are physicians and other health professionals.<sup>98, 99</sup>

In culturally safe epidemiological research, CM and FCM may be an effective tool to review local knowledge and beliefs around a community health issue. For example, Giles and colleagues<sup>100</sup> applied FCM to understand the epidemiology of diabetes in a Mohawk community, contrasting the local perspective on diabetes to that of Western science. This expert knowledge, based on an intimate understanding of the local realities, can go on to inform various stages of the research process, including the formulation of hypotheses, questionnaire development, and even data analysis.

The application of concepts such as causality and strength of association, conventionally considered Western scientific notions, at first may appear unsuitable to

reviewing and presenting indigenous knowledge. This is only the case, however, if we believe that Western scientific and indigenous knowledge are mutually exclusive. Chapter 1 tried to dispel this belief, asserting that the distinction between Western scientific and indigenous knowledge may be somewhat artificial and that there can be substantial similarities between the two epistemological systems. In some cases, the advancement of one can depend on the other. Increasingly, indigenous communities are looking to scientific methods to answer their most pressing research questions while researchers are likewise consulting indigenous knowledge for scientific research.

The development of culturally safe epidemiology will depend on methods that can locate interfaces, or culturally safe spaces, in which neither indigenous nor Western scientific protocols are compromised. This thesis presents cognitive mapping as one such tool that may effectively locate culturally safe spaces in epidemiological research. This chapter 3 attempts to demonstrate how cognitive mapping can help render epidemiological concepts such as causality and strength of association more accessible to non-scientists by enabling them to communicate and translate their unstructured knowledge about the complexity and interconnectedness of concepts into a graphical form that is interpretable through scientific methods.

### **3.3.1 Participant Selection**

In the case of the Inuit ACRA project, Inuit living in Ottawa provided the expert knowledge to construct the cognitive maps. Initially, the aim was to conduct a single mapping session with members of the Inuit ACRA advisory group, consisting of representatives from Inuit organizations such as Tungasuvvingat Inuit (TI), Inuit Tapiriit Kanatami (ITK), Pauktuutit Inuit Women of Canada, Ottawa Inuit Children's Centre, Mamisarvik Healing Centre, and Inuit Non-Profit Housing Corporation. Incidentally, this group consisted almost entirely of adult women, which could bias the results of the mapping session. To generate a more representative sample of the knowledge and beliefs around Inuit sexual health in Ottawa, the research team decided to hold a series of additional mapping sessions with Inuit from other segments of the community including adult men, younger



youth (13-16 years), older youth (17-21), Elders, as well as Inuit health researchers. Table 5 presents the characteristics of the participating Inuit groups.

The research team recruited the Inuit men, youth and Elders through Tungasuvvingat Inuit (TI), an Inuit community and resource centre in Ottawa. I merged the results from the older youth map with the map from an additional mapping session held with older youth attending Nunavut Sivuniksavut, a post-secondary college program for Inuit youth from Nunavut. The research team held the mapping session with Inuit researchers during the Inuit Institute for Research and Planning, a training program for Inuit interested in developing skills in epidemiological methods and applications. Members of the Inuit Community Action Research Team (ICART), a group of Inuit health researchers at CIET, facilitated the mapping sessions with assistance from other CIET staff members. I was responsible for coordinating and supporting the ICART throughout the project, which included assisting with and attending all (except the Nunavut Sivuniksavut and men’s) mapping sessions.

**Table 5 Characteristics of Cognitive Mapping Participants**

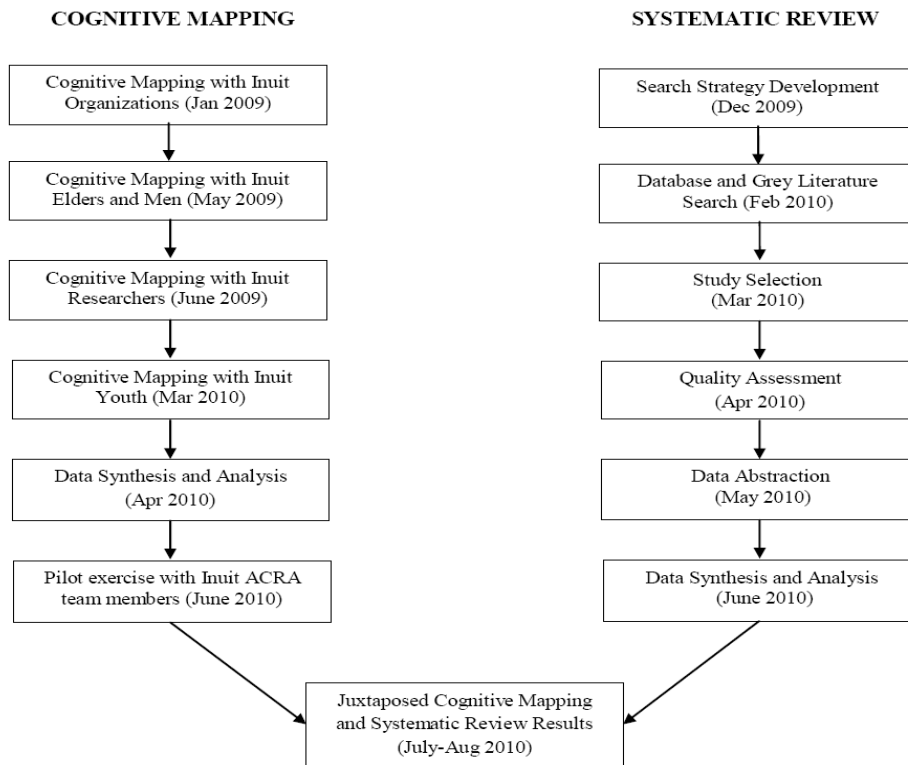
<b>Group</b>	<b>Number of Participants</b>	<b>Source</b>
Inuit Organizations	14	Representatives from Inuit service and advocacy organizations
Researchers	20	CIET Inuit Institute for Research and Planning participants
Elders	2	Tungasuvvingat Inuit community resource centre
Men	4	Tungasuvvingat Inuit community resource centre
Younger Youth	7	Tungasuvvingat Inuit youth camp
Older Youth	12	Tungasuvvingat Inuit youth camp and Nunavut Sivuniksavut college program

### **3.3.2 Data Collection**

At the beginning of each cognitive mapping session, the research team asked participants, “What factors help prevent HIV and other sexually transmitted infections among Inuit living in Ottawa?” The team posted this question on a large poster board in front of the group and a member from the ICART facilitated the discussion. Other members

of the research team wrote down the participants' responses on index cards, posted on the board around the central question and clustered roughly according to theme. A new card was added to the map each time a sexual health determinant was suggested by a participant. This exercise continued until the participants exhausted their collective set of concepts.

A true cognitive map should progress further to merge the collection of concepts into a set of common themes, which are then linked by arrows representing causal associations from the cause to the effect. In practice, however, many of the mapping sessions for the Inuit ACRA project did not complete this process, resulting in simply a collection of concepts contributing to the central question. A later section of this chapter describes a pilot exercise held with Inuit members of the ACRA research team to look at why most groups were unable to achieve the advanced stages of cognitive mapping and how the methods can be better adapted to community-based settings. Figure 2 presents a time chart of the thesis research, including the systematic review, cognitive mapping and pilot exercise.



**Figure 2 Time Chart of Thesis Research Process**

### 3.3.3 Data Synthesis and Analysis

Once the team completed all of the cognitive mapping sessions, I conducted a thematic synthesis of the maps, which involved dissecting and coding each concept into one or more topics. To facilitate analysis across the various maps (and comparison with the systematic review from Chapter 2), I categorized the complete list of topics into a set of 37 common sub-themes. For example, thematic analysis might dissect the concept *parents should talk openly with youth about sex* into the topics *parenting*, *communication*, and *youth*; *make sure your partner is clean* into the topics *partners* and *disclosure*; and *older generation sharing experiences with younger generation* into the topics *generation* and *sharing experiences*. I then grouped the topics into a smaller set of common sub-themes. So *parenting* and *partners* merged into the common sub-theme *Parenting, Family, & Relationships*; *communication*, *disclosure*, and *sharing experiences* merged into the common sub-theme *Communication, Disclosure & Sharing Experiences*; and *youth* and *generation* merged into the sub-theme *Age & Generation*.

While the facilitation and coordination of the individual cognitive mapping sessions was in collaboration with the Inuit Community Action Research Team (ICART), I synthesized and analyzed the maps independently. For each map, however, I asked a member from the ICART who had also attended that particular mapping session to review the interpretation of the concepts to verify that the method of categorization and list of sub-themes were an accurate reflection of the participants' responses and intended meaning.

Finally, I grouped the list of sub-themes further into four broader themes, representing four types of health determinants (defined in Chapter 2): (1) *Structural & Demographic Factors*, (2) *Behavioural Factors*, (3) *Psychosocial Factors*, and (4) *Biological Factors*. For example, sub-themes such as *Housing, Employment, & Other Socioeconomic Factors* and *Social Norms, Attitudes, Role Models, & Peer Pressure* fell under *Structural Factors*; *Safe Sex* and *Substance Use* under *Behavioural Factors*; *Mental Health & Healing* and *Social Support, Counselling, & Mentorship* under *Psychosocial Factors*; and *Physical Health, Biology & Genetics* under *Biological & Genetic Factors*.

I analyzed the themes and sub-themes emerging from the mapping sessions by

qualitative and quantitative content analysis, which involved examining the distribution of themes and sub-themes identified by the six participating groups of Inuit living in Ottawa (Inuit organizations, researchers, elders, men, younger youth, and older youth) to identify patterns both within and across the six maps. For quantitative analysis, I counted each concept's frequency of mention by the number of index cards on which it was raised.

### **3.4 Methods: Fuzzy Cognitive Mapping**

Another promising method explored in this thesis is the weighting of cognitive maps to generate a fuzzy cognitive map. By assigning directions (indicating a positive or negative association) and weights (or strengths) to the causal links between concepts in the map, according to their relative importance, participants can introduce a “fuzzy” element to the cognitive map, thus generating a “fuzzy” cognitive map (FCM). While binary cognitive mapping allows participants to indicate the presence or absence of a causal link between concepts, fuzzy cognitive mapping enables them to differentiate the relative effect of each connection in the map on the outcome of interest. Fuzzy cognitive mapping extends from cognitive mapping by introducing fuzzy logic, a mathematical approach to describing complex systems where only approximate information on concepts and relationships are available.<sup>101</sup>

Fuzzy cognitive maps are comprised of nodes representing variables or concepts (C) connected by arrows representing causal relationships. Each relationship is assigned a weight ( $e_{ij}$ ) which quantifies the association between concepts  $C_i$  and  $C_j$ . A positive weight ( $e_{ij} > 0$ ) indicates an excitatory relationship, i.e. as  $C_i$  increases  $C_j$  increases, while a negative weight ( $e_{ij} < 0$ ) indicates an inhibitory relationship, i.e. as  $C_i$  increases  $C_j$  decreases.<sup>100, 102-104</sup>

Fuzzy cognitive maps can also be presented as an  $n \times n$  adjacency table or matrix (shown below) containing the causal weights ( $e_{ij}$ ) for the associations between all possible pairs of concepts where the horizontal axis (row) represents causes and the vertical axis (column) represents effects to form a square matrix.

$$E = \begin{bmatrix} e_{11} & e_{12} & e_{13} & \dots & e_{1n} \\ e_{21} & e_{22} & e_{23} & \dots & e_{2n} \\ e_{31} & e_{32} & e_{33} & \dots & e_{3n} \\ \vdots & \vdots & \vdots & & \vdots \\ e_{n1} & e_{n2} & e_{n3} & \dots & e_{nn} \end{bmatrix} \quad i=1, \dots, n ; j=1, \dots, n$$

Weighting allows participants to identify key factors and community priorities around the central issue. Researchers and communities can apply this information to establish research objectives and priorities and to develop instruments that reflect and are relevant to the local reality. Typically, fuzzy cognitive mapping takes place in a hospital or other institutional setting with a small number of physicians or other health professionals participating as “experts.” In these cases, weighting is usually not a problem as the participants are often comfortable with statistical methods and the concept of quantifying strengths of association.

In the case of the Inuit ACRA project, however, many of the community members participating as “experts” in the cognitive mapping sessions were not accustomed to assigning weights or strengths of association to relationships they observe and experience in everyday life. Furthermore, while a small group of 2 or 3 participants does not usually have trouble arriving at a consensus, some of the Inuit ACRA sessions included as many as 20 participants, in which case consensus was logistically difficult to achieve. Thus, at the outset of the Inuit ACRA project, the transferability of weighting methods from a professional institution to a community setting was uncertain.

### 3.4.1 Community-based Fuzzy Cognitive Mapping

The use of fuzzy cognitive mapping outside a professional setting is still relatively new and thus, for the purposes of the Ottawa Inuit ACRA project, its application was exploratory and experimental with the objective to pilot the fuzzy cognitive mapping approach in a community setting. For each cognitive mapping session with the six groups of Inuit living in Ottawa, the facilitators aimed to achieve a final weighted (fuzzy) cognitive map; for some sessions, this was unproblematic, while for others it was not achievable.

Throughout the project, the research team noted and discussed successful and unsuccessful approaches to achieving a true fuzzy cognitive map to identify best practices. Still, these discussions were relatively informal and irregular and after all sessions were complete, it remained unclear whether and why fuzzy cognitive mapping was valuable or even possible in a community setting.

To further explore the feasibility and utility of fuzzy cognitive mapping in a community setting, I organized and facilitated a focus group session with the Inuit Action Research Team (ICART). The ICART consists of Inuit researchers who have facilitated and participated in cognitive mapping sessions and who are also Inuit living in Ottawa. Thus, the ICART researchers were in a unique position to provide valuable insight on the application of fuzzy cognitive mapping in a community-based research context. The pilot session was also an opportunity for the ICART to have further exposure to fuzzy cognitive mapping and discuss how the methods may be better adapted for community-based research purposes.

Because weighting was not achieved for every mapping session, I based the pilot fuzzy cognitive mapping session on what Özesmi and Özesmi<sup>103</sup> called a social cognitive map, a global map that includes all concepts from a collection of individual cognitive maps. In this case, I merged all of the variables from the individual cognitive mapping sessions with Inuit living in Ottawa, including Inuit organizations, researchers, Elders, men, younger youth, and older youth, to create a single common (or social) cognitive map.

Creating a social cognitive map of Inuit knowledge on sexual health first required organizing and translating the concepts generated from the individual cognitive maps into common themes around Inuit risk and resilience to sexually transmitted infections. I conducted the organization and translation of concepts and the ICART members then checked my interpretations to verify that the common themes were an accurate reflection of the original concepts proposed by the mapping participants.

The pilot FCM session started from a blank poster board with the central question (What factors help to prevent HIV and other sexually transmitted infections in the Ottawa Inuit community?) at the centre of the board. As for facilitator, I presented the participants with cue cards representing the common themes identified across the six cognitive mapping sessions with Inuit organizations, researchers, men, elders, younger youth, and older youth.

Under the direction of the participants, the facilitator arranged each theme on the map according to its causal link to the central outcome, beginning with the themes believed to be directly associated with STI transmission and working outward. The participants then instructed me to connect each pair of causally-associated themes with an arrow extending from the cause to the effect. This process continued until the participants identified all necessary connections to create the cognitive map.

Once the social cognitive map was complete, i.e. the participants were satisfied that the arrangement and connection of themes on the map accurately reflected their collective knowledge and beliefs about the risk and resilience factors for Inuit sexual health, the participants could begin to weight (rank) the associations between each causally-linked pair of themes. The group assigned a weight (or strength) from 1 to 5 where 1, 2, 3, 4, 5 signified very weak, weak, moderate, strong, very strong, respectively, to each link on the map (represented by an arrow). I also noted the direction of the associations (positive/excitatory or negative/inhibitory), according to the participants' perspective. The group resolved disputes among participants about the presence, direction, or causal strength of relationships through discussion and consensus. The exercise ended when the participants were satisfied the now 'fuzzy' cognitive map accurately reflected their collective view.

Finally, once the FCM was complete, I asked the participants to reflect on the experience and their impressions of the process with respect to the feasibility and utility of weighting in a community setting, particularly in the context of the current Inuit ACRA study and other similar projects.

### **3.4.2 Data Synthesis and Analysis**

For analysis purposes, I converted the causal strengths assigned to relationships in the fuzzy cognitive map from the categories (positive or negative) very weak to very strong (or 1 to 5) to values in the continuous interval [-1,1] as +/- 0.2, 0.4, 0.6, 0.8, 1.0, respectively. I analyzed the relative influence of concepts in the FCM (centrality), following methods similar to those suggested by Giles et al.<sup>100</sup>

## *Centrality*

The importance of a concept in the FCM was determined by its centrality ( $c$ ), the sum of the absolute value of its inputs ( $e_{ji}$ ) and outputs ( $e_{ij}$ ) calculated as;<sup>103</sup>

$$c_i = \sum_{j=1}^n |e_{ij}| + \sum_{j=1}^n |e_{ji}|$$

Concepts with a large centrality are involved in many strong causal relationships whereas concepts with a small centrality are involved in few weak relationships.

## **3.5 Results: Cognitive Maps**

The following sections describe the results of the cognitive mapping sessions with the six groups of participating Inuit (organizations, researchers, Elders, men, younger youth, and old youth). Table 6 lists some of the top sub-themes by frequency of mention identified by each group.

### **3.5.1 Inuit Organizations**

Fourteen members (13 female, 1 male) of the Inuit ACRA advisory committee, representing various Inuit organizations in Ottawa, contributed to the cognitive map. As many Inuit organizations do not only employ Inuit, a few of the participants attending this session were non-Inuit. It is unlikely, however, that these individuals biased the results of the map as they represented a small minority in the group and, as representatives of Inuit organizations, were familiar with Inuit culture and accustomed to advancing the interests of Inuit in Ottawa.

Five participants attended an in-person mapping session while the research team permitted other members of the advisory committee who wished to contribute but could not attend the session to submit concepts via email. The participants identified a total of 74 concepts (33 in-session, 41 emailed) around Inuit risk and resilience to sexually transmitted



infections, which I dissected and coded into 145 (27 unique) sub-themes. Table 7 lists some of the top sub-themes by frequency of mention identified by Inuit organizations.

The Inuit organizations' map included 27 different sub-themes. The most frequently mentioned sub-theme was *Knowledge, Information, & Education* (25 mentions), followed by *Culturally Relevant Resources* and *Communication, Disclosure, & Sharing Experiences* (each with 14 mentions). The majority of the sub-themes in this map were *Structural & Demographic Factors* (89 mentions).

### **3.5.2 Inuit Researchers**

Twenty participants (15 female, 5 male) contributed to the cognitive mapping session with Inuit researchers. The participants identified a total of 61 concepts around Inuit risk and resilience to STIs, which I dissected and coded into 104 (19 unique) sub-themes. Table 6 lists some of the top sub-themes by frequency of mention identified by Inuit researchers.

The Inuit researchers' map included 19 different sub-themes. The most frequently mentioned sub-themes were *Inuit Culture, Traditions, & Way of Life* and *Self-Esteem, Assertiveness, & Responsibility* (each with 13 mentions). The majority of the sub-themes in this map were *Structural & Demographic Factors* (63 mentions).

### **3.5.3 Inuit Elders**

Two Inuit elders (both female) participated in the cognitive mapping session. The participants identified a total of 41 concepts around Inuit risk and resilience to STIs, which I dissected and coded into 104 topics (26 unique) sub-themes. Table 6 lists some of the top sub-themes by frequency of mention identified by Inuit elders.

The Inuit elders' map included 26 different sub-themes. The most frequently mentioned sub-themes were *Knowledge, Information, & Education* (9 mentions) and *Sexual Violence & Other Abuse* (8 mentions). The majority of the sub-themes in this map were *Structural & Demographic Factors* (68 mentions).

### **3.5.4 Inuit Men**

Four Inuit male community members participated in the cognitive mapping session. The participants identified a total of 57 concepts around Inuit risk and resilience to STIs, which I dissected and coded into 99 (26 unique) sub-themes. Table 6 lists some of the top sub-themes by frequency of mention identified by Inuit men.

The Inuit men's map included 26 different sub-themes. The most frequently mentioned sub-theme was *Access to & Use of Programs, Services, & Other Resources* (19 mentions). The majority of the sub-themes in this map were *Structural & Demographic Factors* (53 mentions).

### **3.5.5 Younger Inuit Youth**

Seven Inuit youth community members aged 13-16 years (4 female, 3 male) participated in the cognitive mapping session. The participants identified a total of 24 concepts around Inuit risk and resilience to STIs, which I dissected and coded into 35 (17 unique) sub-themes. Table 6 lists some of the top sub-themes by frequency of mention identified by younger Inuit youth.

The younger Inuit youth's map included 17 different sub-themes. The most frequently mentioned sub-theme was *Social Norms, Attitudes, Role Models, & Peer Pressure* (6 mentions), followed by *Knowledge, Information, & Education* (5 mentions). The majority of the sub-themes in this map were *Behavioural Factors* (16 mentions).

### **3.5.6 Older Inuit Youth**

Twelve Inuit youth community members aged 17-21 years (8 female, 4 male) contributed to the cognitive map in two separate sessions with 7 and 5 youth, respectively. The participants identified a total of 45 concepts around Inuit risk and resilience to STIs, which I dissected and coded into 70 (23 unique) sub-themes. Table 6 lists some of the top sub-themes by frequency of mention identified by older Inuit youth.

The older Inuit youth's map included 23 different sub-themes. The most frequently mentioned sub-theme was *Knowledge, Information, & Education* (11 mentions), followed by *Substance Use* (8 mentions). The majority of the themes in this map were *Structural & Demographic Factors* (35 mentions).

### **3.5.7 All Inuit**

I combined concepts from the six cognitive mapping sessions, including a total of 59 participants, to understand the general view among all participants on the determinants of Inuit sexual health. The participants identified a total of 295 concepts around Inuit risk and resilience to STIs, which I dissected and coded into 557 (37 unique) sub-themes. Table 7 lists some of the top sub-themes by frequency of mention identified by all Inuit.

The Inuit participants identified 37 different sub-themes. The most frequently mentioned sub-theme was *Knowledge, Information, & Education* (67 mentions), followed by *Access to & Use of Programs, Services, & Other Resources* (38 mentions), *Communication, Disclosure, & Sharing Experiences* (37 mentions), and *Self-esteem, Assertiveness, & Responsibility* (32 mentions). The majority of the sub-themes identified by Inuit overall were *Structural & Demographic Factors* (323 mentions).

**Table 6 Rank-ordering of Concepts (% of total concepts in map): 6 Inuit groups**

<b>Organizations (N=145)</b>	<b>Researchers (N=104)</b>	<b>Elders (N=104)</b>	<b>Men (N=99)</b>	<b>Younger Youth (N=35)</b>	<b>Older Youth (N=70)</b>
Knowledge (17%)	Culture (13%)	Knowledge (9%)	Access to Resources (19%)	Social Norms (17%)	Knowledge (16)
Culturally Relevant Resources (10%)	Self-Esteem (13%)	Sexual Violence (8%)	Testing (9%)	Knowledge (14%)	Substance Use (11%)
Communication (10%)	Age (11%)	Safe Place (7%)	Knowledge (7%)	Abstinence (9%)	Access to Resources (9%)
Access to Resources (8%)	Parenting (11%)	Communication, (7%)	Culturally Relevant Resources (6%)	Communication (9%)	Sharing Personal Items (9%)
Parenting (7%)	Knowledge (10%)	Discrimination (6%)	Discrimination (6%)	Self-Esteem (9%)	Self-Esteem (9%)
Safe Sex (5%)	Adaptation to Change (9%)	Social Support (6%)	Substance Use (6%)	Recreation (6%)	Communication, (7%)
Trust (5%)	Gender (8%)	Trust (6%)	Adaptation to Change (5%)	Safe Sex (6%)	Culturally Relevant Resources (4%)
Culture (4%)	Communication (6%)	Justice (5%)	Parenting (4%)	Substance Use (6%)	Popular Culture (4%)
Adaptation to Change (4%)	Community Cohesion (4%)	Gender (5%)	Recreation (4%)	Age (3%)	Safe Sex (4%)
Self-Esteem (3%)	Resilience (4%)	Mental Health (5%)	Social Support (4%)	Parenting (3%)	Age (3%)
Social Support (3%)	Discrimination (3%)	Age (4%)	Research (3%)	Popular Culture (3%)	Safe Place (3%)
Community Cohesion (3%)	Social Support (3%)	Community Cohesion (4%)	Social Norms (3%)	Research (3%)	Sexual Violence (3%)
Sexual Violence (2%)	Recreation (2%)	Culturally Relevant Resources (4%)	Healthy Lifestyle (3%)	Healthy Lifestyle (3%)	Social Norms (3%)
Resilience (2%)	Trust (2%)	Culture (4%)	Safe Sex (3%)	Sex Trade (3%)	Abstinence (3%)

### 3.5.8 Inuit Adults versus Youth

I compared the maps from all adults and all youth to identify common and divergent perspectives across the generations on the risk and resilience factors for Inuit sexual health. Table 7 lists some of the top sub-themes by frequency of mention identified by Inuit youth and adults.

#### *Adults*

I combined the concepts contributed by all 40 adults (30 female, 10 male), including Inuit organizations, researchers, men, and elders, to represent the views of the Inuit adult

participants overall. The participants identified a total of 233 concepts around Inuit risk and resilience to STIs, which I dissected and coded into 452 (35 unique) sub-themes. Table 7 lists some of the top sub-themes by frequency of mention identified by Inuit adults.

The most frequently cited theme was *Knowledge, Information, & Education* (51 mentions), followed by *Access to & Use of Programs, Services, & Other Resources* (32 mentions). The majority of the themes identified by Inuit adults overall were *Structural & Demographic Factors* (273 mentions).

### *Youth*

I combined concepts contributed by all 19 youth aged 13-21 years (12 female, 7 male), to represent the views of the Inuit youth participants overall. The youth identified a total of 62 concepts around Inuit risk and resilience to STIs, which I dissected and coded into 105 (27 unique) sub-themes. Table 7 lists some of the top sub-themes by frequency of mention identified by Inuit youth.

The sub-theme most frequently mentioned by youth was *Knowledge, Information, & Education* (16 mentions), followed by *Substance Use* (10 mentions). The majority of the themes identified by Inuit youth overall were *Structural & Demographic Factors* (50 mentions).

### *Comparison of Adult and Youth Perspectives*

Of the 37 sub-themes identified across all the cognitive maps, 25 were common to the adult and youth perspectives. Sub-themes that were prominent in both the youth and adult systems included *Knowledge, Information, & Education, Communication, Disclosure, & Sharing Experiences, Access to & Use of Programs, Services, & Other Resources, and Self-esteem, Assertiveness, & Responsibility*.

Two sub-themes (*Sex Trade* and *Vaccines & Pharmaceuticals*) were unique to the youth maps. Ten sub-themes were unique to the adult maps, the most prominent of which

included *Adaptation to Urbanization, Westernization, & Other Changes* (20 mentions) and *Taboo, Stigma, & Discrimination* (17 mentions).

**Table 7 Rank-ordering of Concepts (% of total concepts in map): Youth, Adults, All Inuit**

<b>Youth (N=105 concepts)</b>	<b>Adults (N=452 concepts)</b>	<b>All Inuit (N=557 concept)</b>
Knowledge (15%)	Knowledge (11%)	Knowledge (12%)
Substance Use (10%)	Access to Resources (7%)	Access to Resources (7%)
Self-Esteem (9%)	Communication (6%)	Communication (7%)
Social Norms (8%)	Parenting (6%)	Self-Esteem (6%)
Communication (8%)	Culturally Relevant Resources (6%)	Culturally Relevant Resources (5%)
Access to Resources (6%)	Culture (5%)	Parenting (5%)
Sharing Personal Items (6%)	Self-Esteem (5%)	Culture (4%)
Abstinence (5%)	Adaptation to Change (4%)	Age (4%)
Safe Sex (5%)	Social Support (4%)	Adaptation to Change (4%)
Popular Culture (4%)	Age (4%)	Social Support (4%)
Age (3%)	Discrimination (4%)	Substance Use (3%)
Culturally Relevant Resources (3%)	Gender (3%)	Discrimination (3%)
Safe Place (2%)	Trust (3%)	Safe Sex (3%)
Sexual Violence (2%)	Community Cohesion (3%)	Gender (3%)
Healthy Lifestyle (2%)	Sexual Violence (3%)	Social Norms (3%)
Recreation (2%)	Safe Sex (3%)	Trust (3%)
Sex Trade (2%)	Safe Place (2%)	Community Cohesion (3%)
Testing (2%)	Testing (2%)	Sexual Violence (3%)
Social Support (2%)	Substance Use (2%)	Safe Place (2%)

### 3.6 Results: Fuzzy Cognitive Map

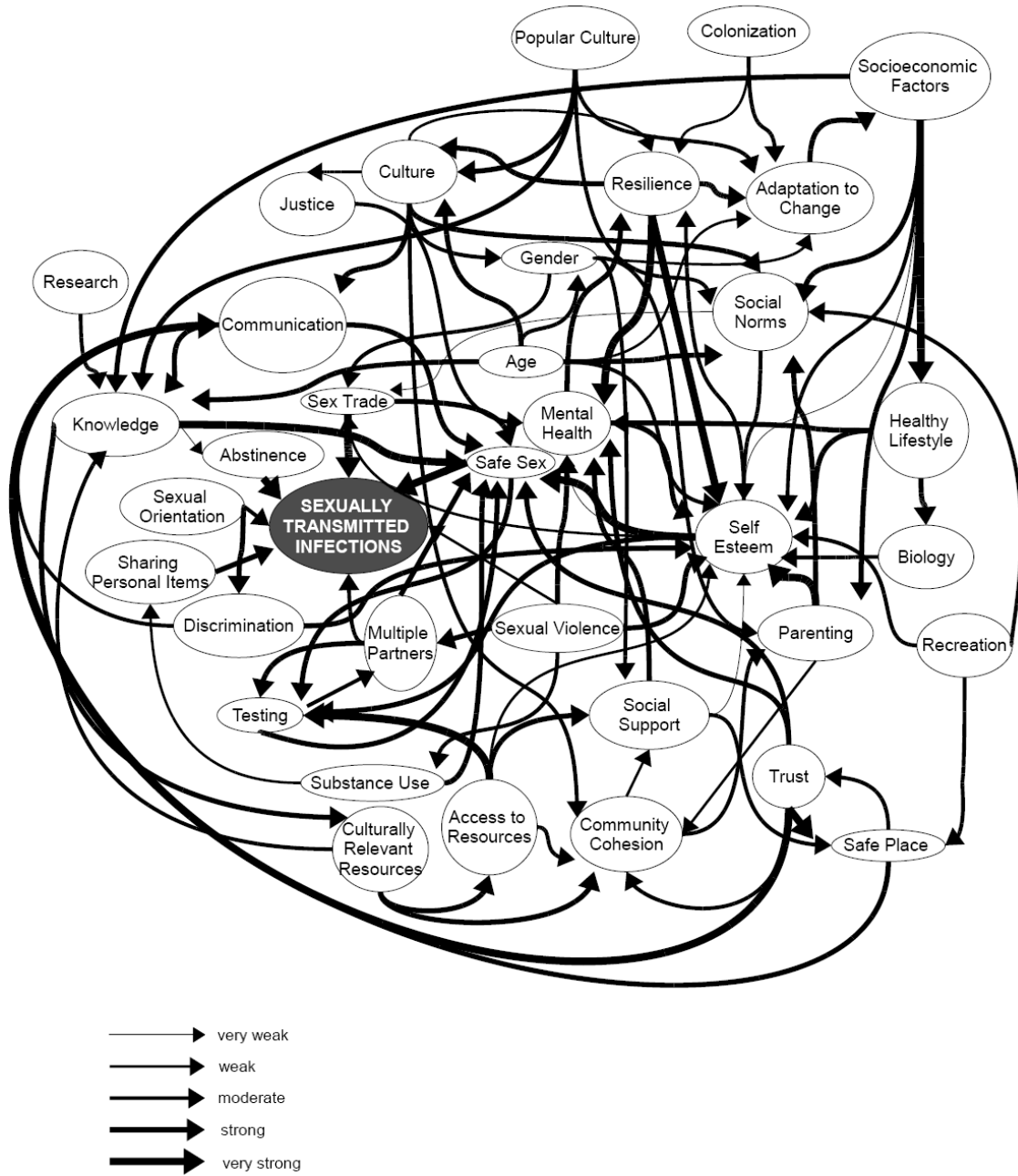
The following sections describe the results of the pilot fuzzy cognitive mapping pilot session with the Inuit Community Action Research Team. The final map is presented in Figure 3.

#### 3.6.1 Map Structure and Characteristics

Three members (2 female, 1 male) from the Inuit Community Action Research Team (ICART) participated in the fuzzy cognitive mapping session. The map consisted of the 36 concepts identified from the original 6 cognitive maps (including the central concept, STIs) and 97 connections.

The main direct effects on sexually transmitted infections were from *Abstinence* ( $e =$

-1.0), *Safe Sex* ( $e = -1.0$ ), *Sex trade* ( $e = +1.0$ ), and *Sharing Needles & Other Personal Items* ( $e = +0.8$ ). Other direct effects included *Casual & Multiple Sexual Partners* ( $e = +0.6$ ), *Sexual Orientation* ( $e = +0.6$  for homosexual versus heterosexual), and *Sexual Violence & Other Abuse* ( $e = +0.4$ ).



**Figure 3 Fuzzy Cognitive Map**

## Centrality

Table 8 lists the centrality for all concepts in the fuzzy cognitive map. Based on centrality, the main concepts included *Self-esteem, Assertiveness, & Responsibility* (c=11.4) and *Safe Sex* (c=8.6), followed by *Knowledge, Information, & Education* (c=6.4), *Mental Health and Healing* (c=6.4), and *Inuit Culture, Traditions, & Way of Life* (c=6.0). The high centrality of these variables indicates that they are involved in many strong causal relationships.

The concepts with the lowest centrality included *Research & Surveillance* (c=0.6) and *History and Legacy of Colonization* (c=1) and *Justice & Reconciliation* (c=1). The low centrality of these variables indicates that they are involved in a small number of weak causal relationships.

Figure 4 presents a variation of the fuzzy cognitive map where font size and proximity to the central concept indicates the level of priority (centrality) assigned to each concept in the map where larger font and closer proximity indicates higher priority (higher centrality).

**Table 8 Centrality of Concepts in Fuzzy Cognitive Map**

Concept	Centrality	Concept	Centrality
Self-Esteem	11.4	Adaptation to Change	3.6
Safe Sex	8.6	Gender	3.4
Knowledge	6.4	Healthy Lifestyle	3.4
Mental Health	6.4	Sexual Violence	3.4
Culture	6	Social Support	3.2
Resilience	5.8	Culturally Relevant Resources	3
STIs	5.4	Sex Trade	3
Social Norms	5.2	Popular Culture	2.8
Communication	4.8	Discrimination	2.2
Socioeconomic Factors	4.8	Recreation	1.8
Testing	4.8	Substance Use	1.8
Trust	4.8	Physical Health	1.4
Parenting	4.2	Sexual Orientation	1.4
Age	4	Sharing Personal Items	1.2
Community Cohesion	4	Abstinence	1.2
Multiple Partners	3.6	Colonization	1
Safe Place	3.6	Justice	1
Access to Resources	3.6	Research	0.6





**Figure 4 Fuzzy Cognitive Map by Centrality**

### 3.6.2 Process and Participant Feedback

The pilot fuzzy cognitive mapping session encountered similar obstacles to those experienced in the cognitive mapping sessions conducted with the six groups of Inuit living in Ottawa.

Despite the small number of participants, agreement on how the concepts should connect took more time than anticipated and often the participants required a lengthy discussion to arrive at a consensus. As one participant pointed out, “[t]he small group size made it easier to reach consensus for each relationship, though many required much discussion, and a larger and more diverse group probably would have taken much longer to finish the map.”

The map’s high number of concepts and interconnections presented another obstacle to the mapping process. The map eventually became so complex that the participants had difficulty following the map to see what connections were missing and which concepts were most important. This was one of the main concerns of the participants, one of whom expressed that “[i]t took a long time to find and map the relationships between the concepts, and because there were so many it resulted in a map that was complicated, difficult to read, and even a little hard to look at.”

Due to the cumbersome nature of the map (shown in Figure 3) and the length of time required to complete the cognitive mapping process, the group decided that the facilitator would translate the cognitive map from a paper to electronic format prior to weighting the map so the participants could view the relationships more clearly. In a following session, the facilitator displayed the electronic map on a projector at which point the participants began weighting the causal connections between concepts.

The ICART members found that even the electronic format was difficult to follow and preferred to enter the weights directly into an adjacency table, also displayed on a projector. An adjacency table displays the relationship between all possible pairs of causal factors with the causes presented vertically and the effects horizontally, much like a correlation table.<sup>100</sup> One participant noted that the adjacency table “made it easier, and also gave us a chance to look at the relationships from a different perspective which helped us

find relationships that we had missed previously.” Weighting from the adjacency table rather than the graphical map enabled the participants to view the complete set of possible connections between variables, to identify previously missed connections, and to focus on and rank each connection individually. Through exposure to the results in both a graphical and tabular form, the participants were also able to better understand unfamiliar concepts such as confounding, effect modification, and direct versus indirect relationships, while also visualizing the bigger picture to appreciate the complexity and interdependency of the system.

Once the participants established all connections and weighted the associations, the facilitator updated the electronic fuzzy cognitive map and presented it to the ICART participants to verify that the map was an accurate reflection of their knowledge and beliefs. During this third stage, the participants had the opportunity to reflect on the experience, to provide feedback on the method and process, and to comment on the feasibility of fuzzy cognitive mapping in a community setting.

Overall, the participants felt that fuzzy cognitive mapping was valuable in the identification of key health determinants, enabling communities and researchers to develop research hypotheses and priorities that the research team can then build into locally-relevant questionnaires and other instruments. One participant noted that the exercise was especially useful in clarifying indirect relationships and found fuzzy cognitive mapping to be a “very effective and powerful tool in showing how seemingly unrelated factors could affect the central concept.” The participants did note, however, that fuzzy cognitive mapping would be most effective with a smaller number of concepts and participants. A simpler map makes it easier to identify key determinants contributing to the central concept and having fewer participants accelerates the discussion and consensus process.

## **3.7 Discussion: Cognitive Maps**

### **3.7.1 Cognitive Maps by Group**

The results from each cognitive mapping session demonstrated considerable heterogeneity with each of the six participating groups providing a unique perspective on the determinants of Inuit sexual health. By holding cognitive mapping sessions with various segments of the Inuit population in Ottawa, it was possible to capture a more representative picture of the perspectives held within the community and to see how the priorities and interests of each group converge and diverge.

The following sections discuss the results from the cognitive maps according to the six groups of participating Inuit: organizations, researchers, Elders, men, younger youth, and older youth. Note that, although I draws some comparisons between the six maps, this is for exploratory purposes only. The findings from the cognitive maps allowed the research team to develop a general picture of the participating Inuit's views around sexual health and comparing the six maps helped the team to generate hypotheses to be further explored through the quantitative Inuit ACRA survey.

#### *Inuit Organizations*

For Inuit organizations, the prevention of sexually transmitted infections and promotion of Inuit sexual health largely requires parental involvement; having a trustworthy person you can turn to; discussing and having the right information about sex and safe sex; and having access to services, particularly those targeted towards Inuit.

The strong emphasis on culturally relevant resources was a distinctive feature of this map. Also identifying access to resources as a top priority, participating Inuit organizations provided important insight on the current gaps in sexual health programs and services for Inuit in Ottawa. A key message was that more Inuit-specific programs and services are necessary to increase Inuit use of and access to sexual health resources. Studies with other Aboriginal communities in Canada have found similar responses where participants expressed feeling intimidated, disempowered or discriminated against in their encounters

with mainstream health services.<sup>105-108</sup> They found that the negative experiences associated with a lack of culturally relevant care may ultimately restrict use of or access to services.

Inuit organizations were the only participants that raised the issue of colonization and also highlighted adaptation to change as a key determinant. Many of the participants in this session grew up in a northern Inuit community before moving to Ottawa and the map suggests that urbanization represented a significant adjustment in the participants' lives. Cross-cultural psychologists have studied the effect of cultural adaptation on health behaviour for some time and have found that because culture is such a powerful determinant of behaviour, the pattern of change and continuity in how people behave in a new society is often very complex.<sup>109-112</sup> Berry<sup>111</sup> explains that this process of adaptation or acculturation can depend on voluntariness (whether they enter the acculturation process voluntarily), mobility (whether they approach the new culture or if it was brought to them), and permanence (whether they settle in the new culture permanently or temporarily).

Indeed, Inuit participating in the mapping sessions described a highly complex adaptation process. Euro-Canadian culture was introduced involuntarily to Inuit communities at the time of colonization and the influence of this culture has increased greatly over time. The pressure to adapt becomes much stronger for Inuit who migrate to southern urban centres such as Ottawa and while some choose to remain there permanently, many others are more transient, travelling to the city intermittently for medical or other purposes. Some participants pointed to the difficulty in adapting to urban life with the increased anonymity and higher exposure to drugs, alcohol, and risky sexual behaviour. For the most part, however, participants focused on Inuit resilience, indicating positive strategies to adapt to life in a southern urban centre, such as creating a cohesive Inuit community in the city and regular communication between urban and northern Inuit.

### *Inuit Researchers*

According to Inuit researchers, the key to improving Inuit sexual health is self-confidence and a sense of responsibility; attention to youth and gender issues; more parental involvement and intergenerational sharing of knowledge; engagement in Inuit culture; and

adaptability to change.

The strong emphasis on Inuit culture, family and intergenerational communication was a distinctive feature of this map. Inuit researchers stressed the importance of passing down Inuit traditions, knowledge, and values from generation to generation in which intergenerational teaching between Elders, parents, and youth is an important source of resilience. The value of intergenerational teaching and communication for the promotion of youth, family and community health and well-being is well recognized in Aboriginal<sup>113-115</sup> and non-Aboriginal<sup>116-118</sup> communities alike. While research in non-Aboriginal populations points to the role of parental monitoring and communication on youth sexual behaviour, Aboriginal research has highlighted the holistic benefits of intergeneration teaching of cultural knowledge and tradition as it influences physical, mental, emotional, and spiritual well-being.

### *Inuit Elders*

Inuit Elders believed that efforts to promote Inuit sexual health should be directed at providing support and safe places for women and children who have experienced sexual violence; appropriate treatment for sexual offenders; reducing stigma and discrimination against homosexuals or people living with HIV/AIDS; talking openly and raising awareness about sex, especially among youth and Elders; and having a trustworthy person or place to turn to for support.

The strong emphasis on sexual violence and safe places was a distinctive feature of this map. Inuit Elders were also the only group to mention justice and reconciliation. The Elders discussed at length the issues around sexual violence, including the need for safe places to heal and seek support for victims as well as appropriate treatment for offenders. The increased occurrence of sexually transmitted infection, risky health behaviours and mental health issues among victims of sexual violence, particularly Aboriginal women, is well documented in the literature.<sup>119-122</sup> Interestingly, the relationship between sexual violence and sexually transmitted infections did not emerge as an important issue in the other sessions, although it is difficult to interpret the significance of this finding. As the Inuit

Elders' group was the smallest of the six maps (including only two participants), the views of one participant could easily bias the map towards that individual's perspective. Although not necessarily referring directly to sexual violence, the youth did stress the importance of avoiding dangerous situations through responsible partying and internet use. The youth identified unwanted sex and the associated risks for STIs as an important sexual health concern for their peers.

Interestingly, the Inuit Elders and youth were the only groups that did not raise the issue of adaptation to urbanization, westernization or other changes, which was relatively prominent in the other sessions. It could be that the Elders had adapted to these changes years earlier and no longer recognize the need to adapt as a current issue. Regardless, it is evident that Inuit of various generations will identify with different challenges and sources of resilience. Seeking out these various perspectives allowed the ACRA research team to capture a broader, more representative picture of Inuit knowledge and beliefs around sexual health.

### *Inuit Men*

According to Inuit men, the promotion of Inuit sexual health should focus on increasing access to resources, decreasing stigma and raising awareness.

The strong emphasis on access to resources was a distinctive feature of this map. Inuit men stressed the need for programs, services and other resources such as health clinics, food banks, counsellors, harm reduction programs, STI testing, condoms, community events, and sport and recreation programs. The men emphasized that, in order to increase use and access, resources should be culturally relevant and free of cost. Inuit men also saw the availability of recreation programs, such as community and sporting activities, as a means to keep people busy and away from unhealthy behaviours, such as drug and alcohol use, noting that "people need things to do." There is evidence supporting a relationship between participation in sport or recreation and risky health behaviours among females; however, research on this relationship among males is less clear.<sup>123-126</sup> Quantitative data from the ACRA survey will allow the research team to further explore the potential association

between recreation and health behaviours, stratifying by gender.

According to Inuit men, testing is an especially important resource for Inuit in Ottawa. The men believed that Inuit should seek testing and encourage their sexual partners to do the same for “peace of mind.” At the same time, they described getting tested as “intimidating,” noting that someone seeking testing for the first time “doesn’t know what to expect.” In a recent survey of First Nations, Métis, and Inuit youth across Canada, Worthington et al.<sup>127</sup> found participants had similar experiences of discrimination and fear around STI testing and recommended that “testing services and counselling must be respectful, compassionate, non-judgmental, and culturally responsive in order to provide emotional support and HIV information that is meaningful and memorable.” In studies with other Aboriginal communities, common determinants of STI testing have included self-perception of risk, confidentiality concerns, rural residency, accessibility, cultural relevance, socioeconomic status and gender.<sup>108, 128, 129</sup> Interestingly, the issue of testing was of low priority for the other five Inuit groups participating in the cognitive mapping sessions. The quantitative ACRA survey hopes to provide further insight into the facilitators and barriers to STI testing for urban Inuit.

### *Younger Inuit Youth*

Younger Inuit youth, aged 13-16 years, stressed that Inuit youth should talk openly about sex, learn about the consequences, wait until they are ready to initiate sexual activity, and have the self-confidence and responsibility to resist peer pressure.

Like the other Inuit participants, having the right information about sex and STIs was a primary concern for the Inuit youth. For them, a key issue was learning about sex and the potential health effects of unprotected sex before initiating sexual activity. The participants urged Inuit youth to “get all the information about it before you do it,” “make sure you know what you’re doing,” and to “see all the effects before you would want to have unprotected sex.”

One of the most interesting concepts on the younger Inuit youth map was “Google It!” This emphasis on the internet as a key source of information about sex and STIs is



consistent with the scientific literature, which shows the use of the internet for health information is rapidly increasing among youth.<sup>130</sup> The internet offers anonymity, online community support, the personalization of information through online feedback and refined searches, and access to information typically denied to them by parents and school teachers.<sup>130</sup> The credibility of online expertise and the risk of unwanted sexual solicitation and harassment, however, remains a serious concern.<sup>131</sup>

The strong emphasis on social norms and peer pressure was also a distinctive feature of the younger Inuit youth map and highlighted the varying perspectives on sex education across the generations. While Inuit adults emphasized parents and family as key resources, the youth indicated friends, popular culture, and the internet have a much stronger influence over sexual knowledge, attitudes, and behaviour. The scientific literature affirms that friends and popular media are highly influential and act as key sources of sexual health information for youth.<sup>130, 132-135</sup> Powell et al.<sup>135</sup> found youth often approach trusted friends before parents and authority figures because of a commonality of experience and mutual understanding—“you’re going through the same thing together at the same time.” These studies also discovered that youth tend to favour passive information sources such as TV, movies, magazines and the internet over active sources such as parents or health professionals.

As this session was held with youth attending an Inuit-specific camp that focused on Inuit culture and tradition, one might expect the participants to have a stronger connection with their culture than other Inuit youth in Ottawa. Interestingly, however, concepts around culture, culturally relevant resources, and adaptation to change did not appear on this cognitive map. It is likely that many of the participating youth grew up in the city and therefore may feel more accustomed to a southern way of life than the adult participants or perhaps the youth did not identify the connection between Inuit culture and sexual health simply by virtue of their age. In general, the younger youth focused more on downstream behavioural factors such as talking and learning about sex, acting responsibly, and delaying sexual initiation. These are the sorts of messages typically taught in a school-based sexual education class, where many of the youth have likely acquired much of their knowledge about sex and sexually transmitted infections.

### *Older Inuit Youth*

For the older Inuit youth, aged 17-21 years, the key to promoting sexual health and preventing the spread of STIs involves learning about STIs, safe sex and how to access services; acting responsibly, especially when drinking or using drugs; and being open and honest with your sexual partner.

The strong emphasis on substance use and harm reduction was a distinctive feature of this map. These youth recognized the importance of drinking responsibly (e.g. “know your limits”) and having reliable friends and safe places to stay when under the influence (e.g. “stay with friends”), indicating a positive relationship between substance use and unsafe sexual behaviour. The youth used the term “drunk buddy” to describe friends who look out for one another during a night of partying. Studies with both Aboriginal<sup>136-139</sup> and non-Aboriginal<sup>140-143</sup> populations have affirmed a positive relationship between substance use and the occurrence of risky sexual behaviour, HIV and other infections.

Unlike the younger youth, older youth did mention Inuit culture as a determinant of sexual health; nevertheless, it was a minor factor in the cognitive map. Older youth noted the importance of “learning about your culture” and “talking to Elders.” It is worth mentioning that when the issue of culture arose during the session, a participant noted that the group had identified the issue earlier in the session but that the facilitator had neglected to write it down. Thus, it is important not to overstate slight differences across maps as variation may be due to biases or oversight on the part of the facilitators.

### *All Inuit*

Overall, Inuit participants believed that sexual health promotion should focus on increasing awareness and discussion about sex and STIs; encouraging parents and Elders to support and talk to youth and children; promoting self-esteem and determination; engaging in Inuit culture and traditions; and improving access to resources, particularly those that are Inuit-specific.

Identifying the general priorities for all participating Inuit was useful in the

development of research objectives, hypotheses and the questionnaire for the Inuit ACRA project. By focusing on the key issues across all six cognitive maps, the research team was able to ensure that the research tools were relevant to the study population. Following cognitive mapping, the quantitative survey can serve to measure and test the priority issues and hypotheses identified by the community. The findings from the individual cognitive mapping sessions, however, demonstrate that, while there are important commonalities in the knowledge and beliefs of all participating groups, each segment of the Inuit population in Ottawa held a unique perspective on the issue of sexual health and sexually transmitted infections. The stratification of results by generation or gender uncovered important variations in the participants' knowledge and belief systems that the research team may not have detected had they aggregated and analyzed the various perspectives as one.

#### *Comparison of Adult and Youth Perspectives*

Overall, the adult participants identified a slightly wider variety of sub-themes than the youth; however, the youth had a surprising amount of insight to share and identified a wide variety of sub-themes, considering there were substantially fewer youth participants than adults contributing to the cognitive maps.

Inuit adults (including Inuit organizations, researchers, Elders, and men) believed that the key to promoting good sexual health is to have access to the resources and education needed to obtain adequate knowledge and information about sex and STIs. This may be through formal sexual education at school, health promotion resources in the community, or open discussion with a trustworthy friend, parent or other family member. Adults also stressed the importance of access to health care, testing, harm reduction programs, recreation, counselling, and support services. The participants emphasized that the most effective education and health services are those that are culturally relevant, integrating Inuit tradition and way of life. Discussions with Inuit adults suggest that threats to cultural identity can negatively influence one's self-esteem and confidence to take responsibility for themselves and others. This concern over the loss of cultural continuity as it impacts self-determination and mental health echoes those expressed by other Aboriginal peoples and

scholars in Canada.<sup>111, 144, 145</sup>

The Inuit youth aged 13-21 years agreed with the adults on the importance of access to health information, services and other resources. Youth and adults also shared an opinion on the value of open communication about sex and self-confidence to act responsibly. The session with youth suggested that friends and peers, rather than parents, have a substantial influence on youth sexual health knowledge and behaviour. The youth identified self-esteem and confidence as crucial to resisting this peer pressure. They also recommended acting responsibly when under the influence drugs and alcohol or abstaining from substance use altogether.

I observed some noteworthy differences between the Inuit adult and youth cognitive maps in the priority assigned to certain sexual health determinants, particularly those around Inuit culture; adaptability to change; stigma and discrimination; and parental involvement in the promotion of youth sexual health.

The topic of Inuit culture and tradition was very prominent in the adult cognitive map but rare in the youth map. Recall that the youth participating in the cognitive mapping sessions included those attending an Inuit youth camp run by a local Inuit community resource centre, involving traditional Inuit activities and games, as well as Nunavut students attending an Inuit-specific college program based in Ottawa. One might expect these youth to be more connected with their culture than other Inuit youth in Ottawa; however, the significance of such a finding from a series of focus groups, involving small convenience samples, should not be overstated and this finding could very easily have occurred by chance.

To further examine the relationship between age or generation and engagement with Inuit culture as it relates to sexual health, the research team included a number of questions around Inuit culture, traditions, and way of life in the quantitative Inuit ACRA survey. The research team can explore the potential association between age and culture in the analysis of the survey data, including stratification by potential confounders, such as level of involvement in cultural activities and events in the community, or length of time living in the city versus a Northern Inuit community.

The issue of parental involvement in promoting youth sexual health was also very

prominent in the adult maps but almost never mentioned by the youth. While adults often identified parents and family as positive or negative role models and an important source of sexual health information and support, youth often identified their friends and other peers as having a substantial influence on their sexual health knowledge, beliefs, and behaviour. One possible explanation for this finding is that there were almost certainly more parents in the adult sessions than in the youth sessions and research indicates parents tend to evaluate themselves as sex educators more positively than their adolescent children evaluate them. Still, there is substantial evidence that both parents<sup>146-148</sup> and peers<sup>149-151</sup> play an important role in influencing youth sexual behaviour.

Inuit adults frequently talked about adaptability to change. Focusing largely on urbanization, Inuit adults described the move from the north to a southern city and the associated changes or experiences as “overwhelming” and “intimidating.” Nevertheless, the participants asserted that Inuit are “quick to adapt to changes.” While a key factor from the adult perspective, the Inuit youth never mentioned this sub-theme. It could be that many of the youth participating in the cognitive mapping sessions grew up in Ottawa or another southern centre and therefore have not experienced the challenges of adapting to an urban or “Western” environment. Alternatively, youth may simply be more adaptable than adults. Again, the research team can explore these relationships and the role of potential confounders further through the quantitative ACRA survey.

The issue of stigmas and discrimination was frequently identified by Inuit adults but never by the Inuit youth. The youth, particularly those aged 17-21, appeared to be more comfortable and assertive than the adult participants when talking about HIV/AIDS, STIs and other sexual issues during the cognitive mapping sessions. A possible explanation may be that the younger generation has had more exposure to sexual health promotion and education and therefore may not consider sex to be a taboo subject. In fact, adults and Elders participating in the mapping sessions shared stories about the taboo surrounding sexual issues when they were young, expressing regret that their own parents were not more open about sex and sexuality. Accordingly, these adult participants also strongly emphasized the importance of being open with children and educating them about sex (e.g. “be more open with children” and “giving information to younger generation”). These findings are similar to those of other studies in which parents aim to provide the sexual health education to their

children that they wished they had received from their own parents.<sup>152, 153</sup>

Although the data from the cognitive mapping sessions is inadequate to estimate the relationship between age and attitude towards sexuality in this population, it would be reasonable to anticipate that such a relationship exists. Studies in other populations suggest that youth sexual health has largely improved over previous generations,<sup>154</sup> which could be partly due to an increased presence of school-based sex education and parent-child communication about sexuality. Indeed, research indicates that supportive relationships at school and at home are associated with positive sexual health outcomes in youth;<sup>155</sup> however, barriers such as parental discomfort and opposition to comprehensive school-based sex education remain.<sup>153, 154, 156</sup> Again, the research team can explore these hypotheses further when analyzing the data from the quantitative Inuit ACRA survey.

When compared to the adults, Inuit youth appeared to place greater importance on issues around abstinence, peer pressure, popular culture, sex trade, substance use and harm reduction.

The higher emphasis on abstinence among the youth was not surprising. Presumably, many of the participants had not yet engaged in sexual activity and the choice of when to initiate sexual activity is an important decision for youth. Still, there is concern among health professionals and scholars over the increase in abstinence-only sex education coincident with a decrease in safe sex instruction.<sup>157-159</sup> The debate over abstinence-only sex education versus comprehensive (also called abstinence-plus) sexual education, which promote safer sex practices in addition to abstinence, is ongoing, albeit more active in the United States than in Canada. Recent reviews of the literature have found most abstinence-only programs do not delay initiation of sex among youth and have no significant positive effects on any sexual behaviour while most comprehensive programs positively affect sexual behaviour, including delayed sexual initiation and increased condom use.<sup>158, 159</sup>

Discussions during the cognitive mapping sessions with adults suggest participating Inuit parents oppose abstinence-only sex education. With respect to teaching youth about sexual health, the adults placed a strong emphasis on speaking openly with youth about sex and the risks of STIs but never suggested that youth should abstain. In fact, some adults recalled their parents warning them to remain abstinent with no further explanation, which

they believe left them ill-equipped to face the realities of sex, STIs, and pregnancy. These adults stressed the need to be honest with youth about sex by acknowledging that youth may be sexually active and giving them the information and resources they need to be safe.

Youth placed a stronger emphasis on social norms and peer pressure than adults, but also viewed this issue in a different way. Adults identified parents as role models and family and home life as primary determinants of sexual health attitudes and norms (e.g. “healthy homes mean healthier Inuit” and “role model to your children”). Youth, however, did not identify parents or family as role models, and perceived friends and popular culture to be key influences (e.g. “find a good friend” and “sex on TV desensitizes sex”). Indeed, while peer pressure was a key issue for youth (e.g. “don’t give in to peer pressure” and “do your own thing”), it was not mentioned by any of the adult participants.

Substance use was the second most frequently identified sub-theme in the youth maps, mostly from the older youth. With the exception of the men’s group, however, this issue was infrequently raised in the adult maps. When discussing the risk of STIs associated with substance use, adults focused on the implementation of formal harm reduction initiatives, such as needle exchange or safe injection programs for drug users. Youth, however, focused more on an informal social support system of friends (e.g. “drunk buddy”) to stay safe and out of danger when under the influence of drugs or alcohol. Scholars and health professionals have advocated for harm reduction and peer support programs to decrease the harmful effects of youth drug and alcohol abuse; however, debate over the effectiveness and appropriateness of these programs has hindered funding, implementation and public acceptance.<sup>160-163</sup>

Concepts related to sharing personal items were also more central in the youth maps than in the adult maps. While adults only referred to the sharing of needles or crack pipes, youth also identified the risks of sharing other personal items such as razors, sex toys, and toothbrushes. This finding could be due to chance or it may result from a newer generation of sex education. The participating youth appeared knowledgeable about the facts of STI transmission and open to talking about sex and STIs, suggesting that these Inuit youth in Ottawa are informed and are accessing current sexual health information. One question that the youth version of the ACRA survey intends to answer is “Where youth are accessing this

sexual health information: at home, at school, on the internet, from a health professional or elsewhere?” Inuit organizations and service providers in Ottawa expressed strong interest in this information to identify the gaps in sexual health knowledge and services, particularly for youth.

### **3.7.2 Cognitive Maps by Theme**

The following sections discuss the results from the cognitive maps according to the four types of health determinants: structural, behavioural, psychosocial, biological and genetic.

#### *Structural & Demographic Factors*

Structural and demographic factors included broader social and political factors, such as social and cultural environments, access to services, and socioeconomic status, as well as sex, age and other demographic characteristics

Overall, structural and demographic factors were those most commonly identified of the four themes. The prominence of structural factors is partly due to the importance placed on knowledge, which ranked among the five most important determinants for all 6 groups. Inuit participants strongly emphasized the importance of awareness-raising and access to STI information, such as modes of transmission and places to seek treatment and support. Suggestions included structured school-based sexual education programs as well as Elders, parents, and other trusted persons as sources of sexual health information. Some groups highlighted the need to communicate sexual health information in a more culturally appropriate way, incorporating elements of Inuit culture and tradition, incorporating Elders, traditional knowledge, and Inuktitut language, into educational resources.

Despite the strong emphasis on knowledge as a necessary component of sexual health promotion, participants recognized that it is far from sufficient. The importance of education and teaching appeared to be about more than just information. What matters is the source of



information, the media through which it is communicated, the environment where teaching takes place, and the cultural relevancy of the education material or teaching style.

Specifically, for education to be effective and eventually lead to positive health outcomes, participants believed teaching should occur in a safe environment with someone you trust, draw on Inuit values and knowledge, and be age and gender-appropriate.

The low significance assigned to socioeconomic factors was unexpected as socioeconomic status, economic opportunity, and related factors are increasingly recognized in health promotion as key social determinants of health, simultaneously influencing several other health determinants.<sup>164-167</sup> The quantitative ACRA survey includes several questions around income, education, employment and housing, which will help to shed light on the relationship between socioeconomic status and sexual health within the Inuit population in Ottawa.

The mention of colonization by Inuit participants was minor; however, its presence in the maps is noteworthy. Some participants insisted that the historical and continuing effects of colonialism and “dominance of whites” have, through various intermediate factors, hindered Inuit health. The presence of this sub-theme in the cognitive maps indicates that some Inuit view the determinants of sexual health to be broad-reaching, possibly originating from the experiences of ancestors and past generations. The legacy of colonization as it relates to the health of indigenous peoples is well-recognized by scholars as demonstrated by the expansive discourse on post-colonial theory, which acknowledges, responds to, and analyzes the cultural legacy of colonialism.<sup>7, 106, 168-174</sup> Colonial legacy as a determinant of health is often dismissed or neglected by health professionals who may not see it as an actionable item that can be targeted through intervention; however, proponents of cultural safety and other post-colonial theories disagree. They have argued physicians, nurses and other health professionals can improve the cultural safety of their daily practice by understanding the many ways in which colonialism continues to affect the lives of indigenous and other colonized peoples.

### *Behavioural Factors*

Behavioural Factors included personal health practices and behaviours, such as abstinence, condom use, and substance use.

Overall, behavioural factors were the second most frequently mentioned theme after structural and demographic factors but across the maps participants assigned these factors a varying level of priority. Behavioural factors were considered to be of low importance by Inuit organizations, researchers and Elders, but were a high priority for Inuit men and youth, who frequently raised the issues of abstinence, substance use, sharing needles, STI testing, safe sex, recreation, and other factors that were generally minor in the other sessions.

Of the behavioural factors, issues around communication were the most prominent overall. Specifically, participants recommended open communication across generations, including open discussion about sex on the part of Elders and parents with youth and children, and between intimate partners, including safe sex negotiation and open disclosure of sexual health status.

Across the six maps, the issues of sex trade and pharmaceuticals were the least prominent behavioural factors and the youth were the only participants to mention these sub-themes. The low importance assigned to vaccines and pharmaceuticals could be due to a lack of awareness around the availability of vaccines, such as the hepatitis B vaccine, and treatment for some infections, such as Chlamydia and gonorrhoea. An alternative explanation may be that the participating Inuit believe sexual health promotion should focus on upstream primary prevention or community-based initiatives. The research team can explore these perspectives further in the quantitative Inuit ACRA survey.

### *Psychosocial Factors*

Psychosocial Factors included social variables that influence an individuals' emotional and mental health, such as social support, counselling, self-esteem, and respect.

Although the third most frequently mentioned theme overall, the priority assigned to psychosocial factors varied between the participating groups. Specifically, Inuit

organizations, researchers and Elders believed psychosocial factors such as trust, respect, and mental health play an important role in sexual health promotion. Comparatively, Inuit men and youth tended to favour behavioural factors, with the exception of adaptability to change (prominent on the men's map) and self-esteem and social support (prominent on the youth maps).

Of the psychosocial factors, concepts around self-esteem, assertiveness and responsibility were the most prominent overall. Inuit participants talked about acknowledging one's risk for STIs, taking responsibility to reduce risky behaviour, asserting oneself with their sexual partner to negotiate safe sex and encourage STI testing, and increasing self-esteem and confidence, especially for youth. There is substantial evidence in the scientific literature affirming the relationship between low self-esteem or assertiveness and risky sexual behaviour, suggested by the Inuit participants.<sup>175-179</sup> The research team will further explore the importance of this relationship in the Ottawa Inuit population through the ACRA survey.

Although concepts around resilience were the least prominent of the psychosocial factors, in many ways resilience permeated all of the cognitive maps. Participating Inuit tended to focus on strength and resilience rather than on risk and adversity. Indeed, the classic STI 'risk' factors such as sex trade, casual or multiple sexual partners and sexual orientation were among the least prominent sexual health determinants identified across the six cognitive maps. The ACRA (Aboriginal Community Resilience to AIDS) project intends to respond to communities' preference for a strengths-based approach to health promotion by emphasizing resilience rather than risk.

### *Biological & Genetic Factors*

Biological and genetic factors included inherited or physical health determinants, such as disability and genetic endowment.

Overall, concepts around biological and genetic factors were assigned the least priority of the four themes. This suggests that participating Inuit may recognize the determinants of sexual health, including the transmission of HIV and other sexually

transmitted infections, as a broad causal network of upstream factors, including structural, behavioural, and psychosocial influences. This perspective would be in line with a population health approach, which considers not only the biomedical determinants such as medical care and treatment but also the broader factors that can influence health outcomes in a population, such as education, income, social support and culture.<sup>180-182</sup>

### **3.7.3 Strengths and Limitations**

Although few of the sessions achieved true cognitive maps, the concepts collected from each group nonetheless provided a rich source of information and insight that guided the Inuit ACRA research process.

Holding separate mapping sessions presented important benefits beyond generalizability. For one, it permitted the stratification of results to compare knowledge and beliefs across the various segments of the Inuit population in Ottawa. Although comparisons were imprecise and strictly exploratory, observed differences and similarities helped to generate hypotheses that the research team can explore further through the quantitative Inuit ACRA survey. The separation of adult and youth perspectives also allowed the team to tailor the adult and youth versions of the questionnaire more appropriately to the target population. Finally, participants expressed feeling more comfortable discussing a sensitive issue such as sex and sexually transmitted infections with others of a similar age or gender. Thus, it is likely that separating the sessions generated cognitive maps that more accurately reflect the knowledge and beliefs of the community.

The cognitive maps may have provided a more in-depth representation of the Inuit perspective in Ottawa had all six groups achieved a true cognitive map, including the creation of concept themes and causal links. Particularly in the sessions with a higher number of participants, however, the length of time required to simply gather the concepts (i.e. determinants of Inuit sexual health) often involved the full length of the session. Thus, many of the groups did not proceed beyond a list of concepts and comparison across the different maps could not take into account the more intricate aspects of a true cognitive map, such as the direction of causation, intermediate factors, and direct versus indirect causal links. For

this reason, comparison of the various perspectives held by participating Inuit (organizations, researchers, Elders, men, younger youth, and older youth) was based on the frequency of mention method to identify priority concepts for the respective mapping sessions. Section 3.9 will consider the advantages of proceeding to a more advanced level of cognitive mapping and discuss the results of the fuzzy cognitive mapping exercise with the Inuit community action research team (ICART).

In some cases, the frequency of mention measure was an adequate estimate of importance. For example, Inuit organizations strongly emphasized the need for culturally relevant resources, raising 14 concepts around the sub-theme while the younger youth did not refer to this issue at all, clearly suggesting that the participants aged 13-16 years did not identify this as a key determinant of sexual health.

Clear contrasts in the frequency of mention, however, were not always evident. For example, Inuit organizations mentioned the issue of safe sex seven times (out of 145 total sub-themes) while older Inuit youth aged 17-12 years identified this sub-theme three times (out of 70 total sub-themes). In this case, it becomes very difficult to compare the relative importance of safe sex from the two perspectives based on the frequency of mention. Without statistical testing, it is of little value to compare the absolute and proportionate frequency of mention, which takes into consideration the total number of sub-themes identified in the map. Due to the potential for bias, however, the application of statistical testing to detect significant differences in the frequency of mention would be futile and potentially misleading.

Interpreting the frequency of mention can also be difficult as the number of times a concept is raised can easily be influenced by chance fluxes in the group's discussion and the number of participants in the session. For example, Inuit Elders frequently raised the issues of sexual violence and justice while these sub-themes were absent or infrequent in the other maps. Yet, it is unlikely that this finding is representative of the knowledge and beliefs of other Inuit Elders in Ottawa as there were only two individuals in the session who, perhaps by chance, engaged in a discussion around sexual violence and justice. The facilitator recorded each time an issue was mentioned in the discussion as indicated by the number of cue cards on which it was raised. Thus, the limitations to using frequency of mention to

measure a concept's importance and level of priority are evident and should be acknowledged. Nevertheless, in the absence of an alternative unit of measure, the frequency of mention approach was a useful proxy indicator of importance and a guiding tool in research planning. A key purpose of the cognitive mapping was exploratory, to generate hypotheses (not conclusions) that can be further explored in a baseline survey.

The use of the frequency of mention method to identify priority determinants from the maps was due to time and other logistical constraints in the sessions, most of which did not achieve true cognitive maps. Often, the participants required the entire length of the session to identify all relevant concepts and interruption of the participants by the facilitator to proceed to the next stage may have introduced a bias into the mapping process. Time constraints arose most often during sessions including a large number of participants, some involving up to 20 participants. Although it depends on the participants, the research team found that groups of 3 to 5 were ideal to acquire a sufficiently diverse perspective without encountering logistical constraints. With a group of this size, the team found that approximately 3 hours with a short break was usually an appropriate length of time to complete a fuzzy cognitive mapping session from beginning to end without losing the interest of the participants. Larger groups can result in an excessive number of concepts, which can become cumbersome to organize, group into themes, connect with causal links, and assign weights in a single session.

Another potential limitation to the analysis of the cognitive maps is the method of thematic analysis used to create common themes and sub-themes. In order to capture the nuances of the concepts raised in the sessions, I kept the sub-themes sufficiently specific; yet, this also led to a high number of sub-themes with a small number of mentions, making it more difficult to detect notable differences between sub-themes and across maps. Over-aggregation, however, may have obscured the meaning of the sub-themes. Well-defined sub-themes proved to be useful when formulating relevant questions for the Inuit ACRA survey. For summary analysis purposes, I categorized the sub-themes further into broader themes (structural, behavioural, psychosocial, and biological and genetic factors); this allowed for the detection of general patterns across maps while maintaining the integrity of the individual sub-themes.

To reduce bias and misinterpretation in the creation of the sub-themes from the concepts identified in the mapping sessions, members of the Inuit Community Action Research Team (ICART), who had also attended the sessions, verified and corrected my interpretations.

### **3.8 Discussion: Fuzzy Cognitive Map**

As most of the six mapping sessions held with the Inuit in Ottawa did not achieve true cognitive maps, frequency of mention was the only measure available to analyze these maps.

Fuzzy cognitive mapping (FCM) offers an additional dimension to cognitive mapping in which participants can express not only the presence and direction of a causal link but also the positive/negative nature and strength of association. In the fuzzy cognitive mapping exercise, the Inuit Community Action Research Team (ICART) members completed all components of the FCM process, including the presence, direction, positive/negative nature, and strength of each causal link, allowing for a more in-depth analysis than was possible for the six cognitive maps. The information from the FCM was valuable in the planning and design of the Inuit ACRA project.

The fuzzy cognitive mapping session with the ICART allowed the team to communicate detailed information on how they believe the sub-themes to be causally linked. For one, the graphical representation of their beliefs enabled participants to indicate the presence of and differentiate between direct and indirect relationships. The fuzzy cognitive map indicates that the direct effects on STI transmission included *Abstinence, Safe Sex, Sex Trade, Sharing Needles & Other Personal Items, Casual & Multiple Sexual Partners, Sexual Orientation, and Sexual Violence & Other Abuse*. Moving outward from the central concept, the participants indicated many more factors believed to have an indirect influence on STIs.

The weights assigned to each causal link enabled the team to identify the relative strength of the relationships while the centrality measure identified concepts believed to play a prominent role overall in determining Inuit sexual health. For example, concepts with the strongest direct influence on STI transmission included abstinence, safe sex, and sex trade,

which the participants ranked as having a “very strong” direct effect, while self-esteem, safe sex, and knowledge were central to the map as a whole. This information can be extremely valuable to community planners and health promoters who must identify local priorities so programs and services, which are invariably working within a limited budget, can have the highest possible impact on the community’s health.

The purpose of the fuzzy cognitive mapping exercise was largely exploratory to test and develop the methods and process for a community-based setting. Overall, the findings from the pilot fuzzy cognitive mapping session with the Inuit Community Action Research Team were very useful. Through general observation and participant feedback, I noted best practices as well as areas in need of development through the piloting process.

The pilot session with the ICART indicates that the fuzzy cognitive mapping process is best suited to a limited number of participants and concepts. Indeed, of the six maps, the sessions that reached the fuzzy cognitive map stage were those that included a smaller number of participants and concepts. For example, one of the mapping sessions with older Inuit youth aged 17-21 years included seven participants who identified a total of 38 concepts, which I grouped further into eight themes with 14 total connections prior to weighting the relationships. This group of Inuit youth was able to identify the relevant concepts (determinants of Inuit sexual health), group the concepts into common themes, connect the themes to indicate causal relationships, and rank these relationships by importance within a single 3-hour session. Meanwhile, the session with Inuit researchers included 20 participants, identified 61 concepts and ran out of time even before the participants could group the concepts into broader themes. Likewise, the fuzzy cognitive map with the ICART consisted of 551 concepts, already grouped into 37 themes, and required three separate sessions and a total of nearly seven hours to complete.

### **3.8.1 Strengths and Limitations**

Despite the challenges, the ICART members were optimistic about the application of fuzzy cognitive mapping to uncover local knowledge, priorities, and hypotheses to inform research planning and design. Thinking about causal relationships in a more structured way



also enabled the participants to gain a deeper, more practical understanding of epidemiological concepts such as confounding and effect modification.

The exercise led participants to change the way they perceived certain concepts and their role in determining Inuit sexual health. Some concepts previously believed to have a minor impact on the central outcome turned out to be much more central in the map than expected. For example, *Housing, Employment, & Other Socioeconomic Factors*, identified only twice across all six cognitive maps, were much more prominent in the fuzzy cognitive map with a centrality ( $c= 4.8$ ) as high as *Communication, Disclosure, & Sharing Experiences*, the third most frequent sub-theme identified across the six cognitive mapping sessions.

As with the six cognitive mapping sessions, time constraint was also an issue for the fuzzy cognitive mapping session with the Inuit Community Action Research Team. Although there were only three individuals participating in the session, the high number of concepts (36) rendered the map busy, complex, and hard to follow. Due to the cumbersome nature of the map, the participants found it difficult to ensure they had appropriately connected and weighted all of the concepts on the map. For this reason, the participants decided to complete the links and weights on the adjacency table instead of the map. Feedback from the participants confirmed that the small number of participants “made it easier to reach consensus for each relationship” in a reasonable amount of time; however, it was difficult to map and weight the relationships “because there were so many” concepts.

The high number of concepts was largely because the participants were working with a “social” fuzzy cognitive map comprised of all concepts from the six maps created with Inuit organizations, researchers, Elders, men, younger youth, and older youth. Pooling concepts from several different maps with by diverse segments of the Inuit population in Ottawa to create the social fuzzy cognitive map may not have been appropriate. Just as in the meta-analysis of scientific literature, a review of local or indigenous knowledge through fuzzy cognitive mapping should recognize the disadvantages of pooling heterogeneous data.

### **3.9 Conclusion**

The cognitive maps (CM) created by the six participating groups of Ottawa Inuit demonstrated that the local knowledge and beliefs around Inuit sexual health varied by the participants' age, gender, and level of engagement in community health issues. The results indicate that cognitive mapping is an effective approach to reviewing and presenting unstructured community knowledge not found in the scientific literature.

The fuzzy cognitive mapping (FCM) exercise with the Inuit Community Action Research Team (ICART) added an another dimension to the information collected in the cognitive mapping sessions, providing further insight into the current issues and priorities in Inuit sexual health.

Elsewhere, scholars have found the application of fuzzy cognitive mapping (FCM) to be a useful group decision-making tool in professional settings such as hospitals.<sup>98,99</sup> The FCM exercise with the ICART demonstrated that, when conducted appropriately with a reasonable number of participants and concepts, fuzzy cognitive mapping may also be a powerful tool in community-based settings to facilitate priority identification by community stakeholders and to systematically build local knowledge and hypotheses into research.

In the case of the Inuit ACRA project, the results of the cognitive maps and fuzzy cognitive maps helped to guide several stages of the research process, including framing the issue, setting research priorities and objectives, questionnaire development, data analysis, and will likely influence the interpretation and communication of evidence as well. The application of cognitive mapping to research planning is discussed further in chapter 4.

## CHAPTER 4

### Juxtaposition of Western Scientific and Inuit Knowledge

#### 4.1 Rationale

Researchers commonly review existing knowledge in the planning and design stages of an epidemiological study to inform research objectives, hypotheses and instruments. Epidemiologists generally limit this review to Western scientific knowledge found in the published literature which is unlikely to include the knowledge and hypotheses of community members or other persons, such as local decision makers, for whom the research is intended. It is uncertain how a lack of community consultation influences the direction of research or whether the perspective of research beneficiaries might provide new insights to improve the cultural safety of an epidemiological study.

Drawing on the Inuit ACRA project, this chapter of the thesis juxtaposes the two methods (systematic review and cognitive mapping) to review existing knowledge and beliefs on Inuit risk and resilience to sexually transmitted infection. The Western scientific knowledge was reviewed by systematic review, a widely accepted approach to review scientific knowledge, while local Inuit knowledge was reviewed by cognitive mapping, a promising approach to review knowledge not typically found in the scientific literature. While differences in the two reviews' findings may result from real divergences in Western scientific and Inuit knowledge or epistemologies, this thesis is primarily concerned with the *methods* and how systematic review and cognitive mapping each contribute to the review of existing knowledge. The chapter goes on to discuss cognitive mapping's potential role in the advancement of culturally safe epidemiological research with Inuit and other communities disillusioned by a history of culturally unsafe research.

## 4.2 Objective

The primary objective of this chapter is to juxtapose the results of two methods to reviewing existing knowledge and hypotheses on Inuit sexual health: systematic review and cognitive mapping, reviewing Western scientific and local Inuit views, respectively, and to discuss the implications for culturally safe epidemiology

## 4.3. Methods

The methods applied to review the Western scientific and Inuit knowledge around Inuit sexual health were purposely and necessarily incongruent. To facilitate comparison across the two methods, however, I reorganized the results from the cognitive mapping sessions in a way that was more analogous to the results from the systematic review. For instance, while it was possible to count the frequency of mention for each sub-theme or theme within each cognitive map, it was not appropriate to do so for each study included in the systematic review. Thus, I resummarized the concepts from the cognitive maps to demonstrate the identification and frequency of mention *across* rather than *within* the six cognitive maps.

For comparison purposes, I considered the 22 studies included in the systematic review equivalent to the six cognitive maps created with Inuit living in Ottawa, counting an identified sub-theme a maximum of once per cognitive map and once per study. I conducted a qualitative and quantitative content analysis to juxtapose the results of the two review methods in which the studies from the systematic review and individual cognitive maps served as the units of analysis for the Western scientific and Inuit knowledge, respectively. Qualitative content analysis involved identifying common and divergent themes and sub-themes uncovered through the systematic review and cognitive mapping while quantitative analysis involved contrasting the most and least prominent themes and sub-themes.

## 4.4 Results

### 4.4.1 Quantitative Analysis

Table 9 summarizes the sexual health determinants identified across the 6 cognitive maps and 22 studies from in the systematic review by frequency of mention (as a percentage of the maps and studies, respectively).

**Table 9 Rank-ordering of Concepts: Cognitive Maps and Systematic (mention in % of maps/studies)**

<b>Cognitive Maps (6 maps)</b>	<b>Systematic Review (22 studies)</b>
Knowledge (100%)	Age (82%)
Social Norms (100%)	Gender (64%)
Communication (100%)	Geographic Location (36%)
Safe Sex (100%)	Knowledge (32%)
Self-Esteem (100%)	Testing (32%)
Social Support (100%)	Access to & Use of Resources (27%)
Age (83%)	Communication (27%)
Community Cohesion (83%)	Parenting (23%)
Culturally Relevant Resources (83%)	Abstinence (23%)
Parenting (83%)	Substance Use (23%)
Substance Use (83%)	Self-Esteem (23%)
Access to & Use of Resources (67%)	Biology (23%)
Culture (67%)	Socioeconomic Factors (18%)
Safe Place (67%)	Healthy Lifestyle (18%)
Gender (67%)	Safe Sex (18%)
Sexual Violence (67%)	Culturally Relevant Resources (14%)
Discrimination (67%)	Culture (14%)
Healthy Lifestyle (67%)	Multiple Partners (14%)
Recreation (67%)	Sharing Personal Items (14%)
Testing (67%)	Pharmaceuticals (14%)
Popular Culture (50%)	Mental Health (14%)
Research (50%)	Trust (14%)
Abstinence (50%)	Popular Culture (9%)
Multiple Partners (50%)	Social Norms (9%)
Sharing Personal Items (50%)	Discrimination (9%)
Adaptation to Change (50%)	Social Support (9%)
Resilience (50%)	Community Cohesion (5%)
Mental Health (50%)	Safe Place (5%)
Trust (50%)	Sexual Orientation (5%)
Geographic Location (33%)	Sexual Violence (5%)
Socioeconomic Factors (33%)	Sex Trade (5%)
Sexual Orientation (33%)	Resilience (5%)
Sex Trade (33%)	Colonization (0%)
Biology (33%)	Justice (0%)
Colonization (17%)	Research (0%)
Justice (17%)	Recreation (0%)
Pharmaceuticals (17%)	Adaptation to Change (0%)

Figures 5 and 6 present the results of the Western Scientific and Inuit reviews in map form. Font size and proximity to the central concept indicates the level of priority assigned to each concept in the map where larger font and closer proximity indicates higher priority.

### *Sub-themes*

From the systematic review, the sub-theme identified by the most studies was *Age & Generation* (identified by 18 of the 22 included studies), followed by *Sex & Gender* (identified by 13 of 22 studies).

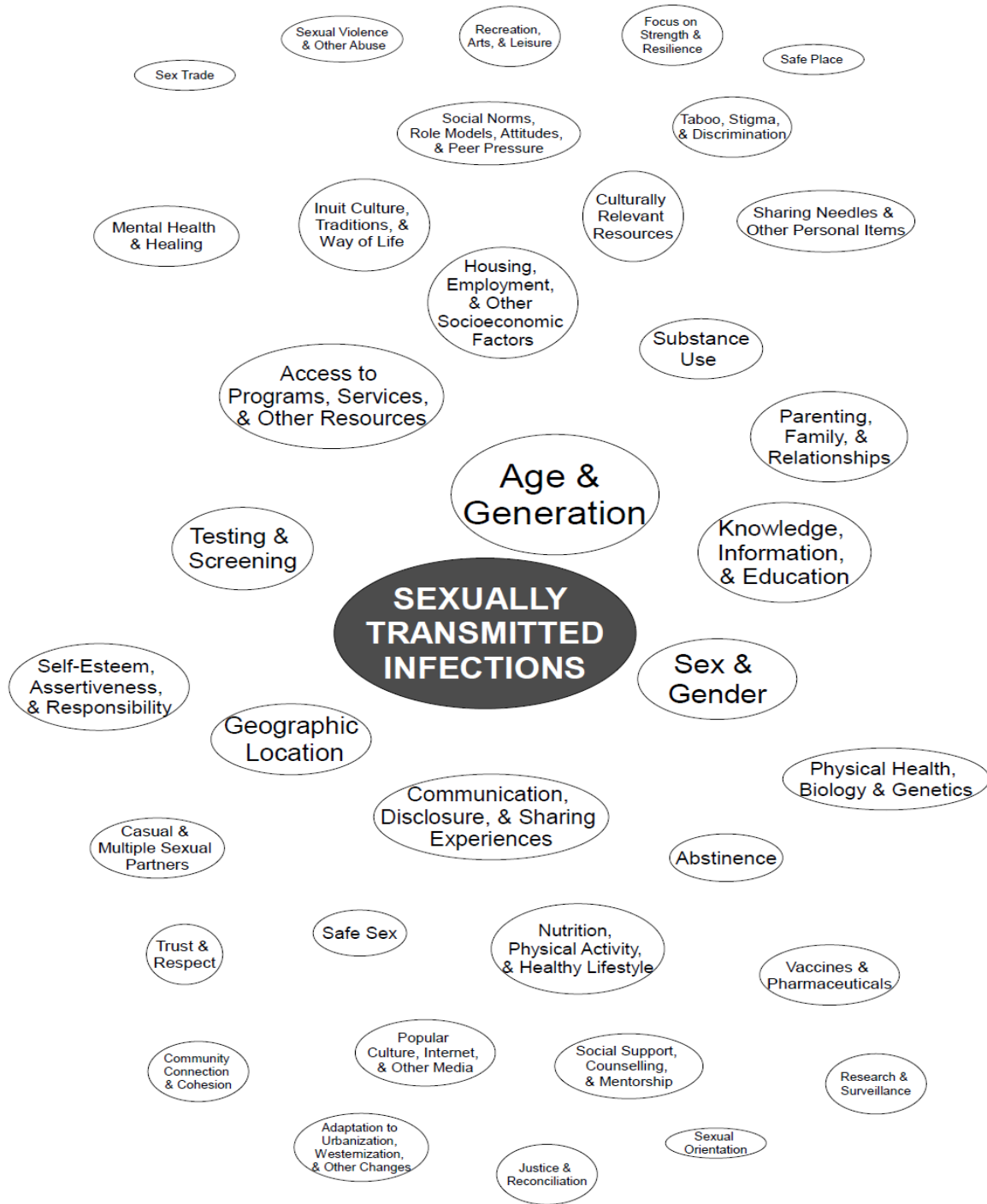
From the cognitive mapping sessions with Inuit, the sub-themes identified by the most cognitive mapping sessions (6 of 6 maps) include *Communication, Disclosure, & Sharing Experiences, Knowledge, Information, & Education, Social Norms, Attitudes, Role Models, & Peer Pressure, Safe Sex, Self-esteem, Assertiveness, & Responsibility, Social Support, Counselling, & Mentorship*.

Thirty-two of the 37 sub-themes were common to both the Western scientific and Inuit perspectives, of which *Age & Generation, Knowledge, Information, & Education*, and *Communication, Disclosure, & Sharing Experiences* were among the most prominent.

The sub-themes unique to the Inuit perspective included *History & Legacy of Colonization, Justice & Reconciliation, Adaptation to Urbanization, Westernization, & Other Changes, Recreation, Arts, & Leisure*, and *Research & Surveillance*. All of the sub-themes identified in the Western scientific literature were also identified by the Inuit participating in the cognitive mapping.

### *Themes*

Overall, structural and demographic factors were the most frequently identified determinants of Inuit sexual health in the both systematic review (n=78 mentions) and the cognitive maps (n=70 mentions). The relative prominence of the four themes was similar in the Western scientific and Inuit knowledge systems.



**Figure 5 Map of Western Scientific Knowledge**



**Figure 6 Map of Local Inuit Knowledge**



#### 4.4.2 Qualitative Analysis

I categorized the concepts identified through the systematic review and cognitive mapping into common sub-themes to facilitate comparison across the Western scientific and Inuit knowledge systems. A quantitative analysis, i.e. comparing the frequency of mention for each sub-theme, however, was not sufficient. While some sub-themes translated well across the two knowledge systems, for others there were marked differences in the intended meaning of the concepts organized into to the “common” sub-themes. Thus, a qualitative analysis was required to identify the more subtle similarities and differences between the two knowledge sets.

Based on the quantitative analysis, 32 of the 37 sub-themes around Inuit sexual health determinants were identified by both the systematic review and cognitive mapping; however, this tells us little about the information uncovered by each review method and may mislead us to overestimate the level of similarity between their respective findings. In fact, for the most part, the qualitative analysis found the systematic review and cognitive maps revealed very different perspectives on the same sub-theme. The results show commonalities but also important divergences in the findings of the systematic review and cognitive mapping. Appendix IV describes the qualitative analysis in greater detail.

Table 10 displays the level of agreement between the two sets of findings before and after consideration of the qualitative analyses. Of the 32 sub-themes commonly identified by both methods, it appears the scientific and Inuit review found a common perspective on 12 sexual health determinants. These include abstinence, casual sex, communication, culturally relevant resources, socioeconomic factors, mental health, parenting, biology, safe sex, sex trade, substance use, and trust.

**Table 10 Agreement across Inuit and Western Scientific Reviews**

<b>Themes</b>	<b>Agree by mention only</b>	<b>Agree by mention and definition</b>
Access to & Use of Programs, Services, & Other Resources	✓	
Age & Generation	✓	
Community Connection & Cohesion	✓	
Culturally Relevant Resources	✓	✓
Geographic Location	✓	
History and Legacy of Colonization		
Housing, Employment, & Other Socioeconomic Factors	✓	✓
Inuit Culture, Traditions, & Way of Life	✓	
Justice & Reconciliation		
Knowledge, Information, & Education	✓	
Parenting, Family, & Relationships	✓	✓
Popular Culture, Internet, & Other Media	✓	
Research & Surveillance		
Social Norms, Attitudes, Role Models, & Peer Pressure	✓	
Safe Place	✓	
Sex & Gender	✓	
Sexual Orientation	✓	
Sexual Violence & Other Abuse	✓	
Taboo, Stigma, & Discrimination	✓	
Abstinence	✓	✓
Casual & Multiple Sexual Partners	✓	✓
Communication, Disclosure, & Sharing Experiences	✓	✓
Nutrition, Physical Activity, & Healthy Lifestyle	✓	
Recreation, Arts, & Leisure		
Safe Sex	✓	✓
Sex Trade	✓	✓
Sharing Needles & Other Personal Items	✓	
Substance Use	✓	✓
Testing & Screening	✓	
Vaccines & Pharmaceuticals	✓	
Adaptation to Urbanization, Westernization, & Other Changes		
Focus on Strength & Resilience	✓	
Mental Health & Healing	✓	✓
Self-Esteem, Assertiveness, & Responsibility	✓	
Social Support, Counselling, & Mentorship	✓	
Trust & Respect	✓	✓
Physical Health, Biology, & Genetics	✓	✓

#### **4.4.3 Implications for Research Planning and Design**

The results of the cognitive mapping and fuzzy cognitive mapping provided valuable insight into community-held perspectives, hypotheses and priorities around Inuit sexual health in Ottawa. Alongside the systematic review, this information informed many stages of the Inuit ACRA research process, including framing the issue, the development of research hypotheses and objectives, data analysis plan, and culturally safe research instruments.

### *Framing the Issue*

The way in which an issue is framed or presented at the onset of study can determine how the target community receives a project, inevitably affecting nearly all subsequent stages of the research process. Epidemiologists often frame health issues as “problems” and communities as “at risk.” Indeed, I found this to be the case in the systematic review on Inuit sexual health conducted here. This approach, however, does not always resonate with communities, Aboriginal or otherwise. Through previous experience with outside researchers, some believe that research has brought little benefit to Aboriginal communities and only perpetuated negative stereotypes about First Nations, Métis, and Inuit.

Through cognitive mapping with Inuit organizations and other stakeholders during the planning stages of the Inuit ACRA project, the research team discovered some resistance against the usual “risk factor” approach to epidemiological research. Many believed the focus on “risk” portrayed Inuit as an unhealthy, troubled population and preferred to emphasize “resilience” and strength among Inuit to overcome adversity. Cognitive mapping allowed community members to express their perspectives and frame the issue on their own terms by mapping out concepts and causal links contributing to the outcome of interest. In response to this feedback, the Inuit ACRA research team was cognizant of the strengths-based approach throughout the research process, which influenced how the team presented the project to the community, posed questions in the questionnaire, and analyzed, interpreted and communicated the results.

In line with health promotion theory, this approach recognizes the potential harm of framing groups of individuals as victims who are “at risk” or as “problems” that need to be solved and instead acknowledges and supports the sources of strength and resilience within communities.

### *Development of Research Hypotheses and Objectives*

The widely-supported OCAP principles encourage local self-determination through ownership, control, access, and possession over research in Aboriginal communities. This

includes the determination of research goals and objectives to ensure local needs and priorities are driving the research and not simply the interests of outside researchers, academic institutions, and funding agencies.

The research team developed some of the research objectives based on existing knowledge from the Western scientific literature, taking into account the factors known to increase one's risk for HIV/AIDS and other sexually transmitted infections. The scientific literature, however, was unable to account for other locally- or culturally-specific factors that may also play a role in Inuit sexual health in Ottawa.

Cognitive mapping played an important role in ensuring local needs and priorities were driving the Inuit ACRA project. Based on the prominence of concepts in the cognitive mapping sessions and their centrality in the fuzzy cognitive map, the ACRA research team was able to identify key priorities and hypotheses held among Inuit community members and other stakeholders in Ottawa. For instance, while virtually absent in the scientific literature on Inuit sexual health, cultural factors such as one's relationship with Elders and engagement in traditional activities featured prominently in many of the mapping sessions. This encouraged the research team to include the influence of culture on Inuit sexual health as a key research objective. Focusing on the issues that are important to the community increased the relevance of the project to the local reality and needs, likely enhancing the cultural safety of the research and encouraging community participation.

#### *Development of Data Analysis Plan*

Prior to designing the data collection instruments for the Inuit ACRA project, the ICART team created a data analysis plan to ensure the instruments collected data on the primary outcomes, predictors, as well as potential confounders or effect modifiers. Primary outcomes included sexually transmitted infections and other sexual health outcomes, such as sexual health knowledge, attitudes, and behaviours. Predictors included potential risk and resilience factors, such social and cultural factors. Potential confounders and effect modifiers included demographic characteristics such as age and gender. The data analysis plan ensured the research instruments only collected data on variables that would be ultimately used in

data analysis. This aided the team in designing instruments that were as concise and specific as possible. Collecting information that the research team would ultimately not consider in data analysis could simultaneously decrease cultural safety and scientific validity by misusing the respondents' time and increasing the occurrence of missing data.

The results from the cognitive mapping sessions and systematic literature review were instrumental in identifying the primary outcomes and predictors of interest as well as potential confounders and effect modifiers. The analysis plan and research instruments excluded concepts that were not relevant to the Inuit population in Ottawa or that the ACRA questionnaire could not adequately measure.

In general, although the breadth of knowledge was limited, the scientific literature provided a set of baseline factors for the Inuit ACRA study to take into account. Meanwhile, the knowledge from the cognitive maps, albeit unstructured and anecdotal, was more vast and diverse and allowed the team to identify local priorities and hypotheses requiring further investigation through the ACRA project. Thus, the two review methods each identified important considerations overlooked by the other and applied together, helping the research team to address key issues of scientific validity and cultural safety early on.

### *Development of Research Instruments*

To increase internal validity, development of the Inuit ACRA research instruments began with existing sexual health questionnaires applied in other communities. Although not formally validated, the research team selected questionnaires that CIET has repeatedly piloted in similar projects. These questionnaires provided a reliable starting point on which the ACRA research team could build and adapt for the urban Inuit setting. The local knowledge identified through cognitive mapping was instrumental in this process.

The cognitive map also aided in the development of age-appropriate questionnaires. Holding separate cognitive mapping sessions with Inuit youth and adults helped to create a comfortable environment in which participants could speak openly about sexual health among their peers. It was also valuable in tailoring the instruments to develop adult- and youth-specific versions of the Inuit ACRA questionnaire.

As much as possible, the research team attempted to keep many of the survey questions identical for both adult and youth questionnaires to allow for direct comparison between adult and youth responses. These included questions on issues identified as priorities in both the youth and adult cognitive maps, such as knowledge, communication, access and self-esteem.

For other items, such as those pertaining to issues on which adult and youth perspectives diverged, the research team added, removed, or modified the question to render the questionnaire more relevant or appropriate for the participants' age group. Through consultation with Inuit youth, the research team was encouraged to minimize the length of the questionnaire as much as possible to maximize participation in and completion of the survey, thus improving the quality of the data collected. For this reason, the team could only include the most relevant questions for inclusion in the youth questionnaire and the results from the youth-specific cognitive mapping sessions were especially useful for this purpose. For example, based on the priority issues identified in the youth maps, the research team modified the survey to focus more on questions about peer pressure and assertiveness, choice ability in sexual encounters when under the influence of drugs or alcohol, and the internet and popular culture as sources of sexual health information. Meanwhile, the research team assigned lower priority to questions on Inuit culture, culturally relevant resources, and adaptation to urbanization and other changes, which featured prominently in the adult but not the youth maps.

The quantitative survey data will provide further insight on the commonalities and differences, suggested by the cognitive maps, between adult and youth perspectives on Inuit sexual health.

### *Interpretation and Communication of Evidence*

It is important to recognize the distinction between data analysis and interpretation, particularly in culturally safe research. Epidemiologists and communities will likely interpret the same statistic in very different ways, perhaps placing it in different contexts with different explanations for the finding. Divergent interpretations of epidemiological findings

have contributed to distrust and suspicion towards research within Aboriginal communities. It is not uncommon for outside researchers to misinterpret or miscommunicate findings, leading to an unjustified negative portrayal of a community as irresponsible, incompetent, or “at risk.” In culturally safe research, the interpretation and communication of evidence should be a collaborative process with local knowledge valued equally alongside scientific knowledge. For this process to be truly inclusive, evidence must be presented in a way that is accessible and comprehensible to community members who may not be familiar with statistics such as an odds ratio or relative risk.

Fuzzy cognitive mapping is one method that may be valuable in presenting epidemiological evidence to community members. To aid the interpretation and communication of epidemiological findings, researchers and communities may display statistical associations in a fuzzy cognitive map that presents variables as nodes, causal or associated links as arrows, and measures of association as weights assigned to each link in the map. Thus, through fuzzy cognitive mapping, epidemiological evidence can translate from technical formats such as regression models and complicated tables of odds ratios and 95% confidence intervals to a more pragmatic representation of the findings that more closely resembles the reality with which community members are familiar.

## **4.5 Discussion**

### **4.5.1 Juxtaposition of Systematic Review and Cognitive Mapping**

In the context of the Inuit ACRA project, juxtaposing the results of the systematic review and cognitive mapping helped to identify knowledge gaps and areas in need of further research. It also encouraged the team to reflect on whether research is responding to or in line with local priorities. While there was some overlap between the results of the two reviews, the cognitive mapping and systematic review uncovered notably divergent perspectives on Inuit sexual health.

In general, the results of Western scientific literature seemed to portray health determinants as simple or isolated factors while the cognitive maps showed how these factors

intersect with other determinants. Whether this resulted from a more intricate or multi-dimensional worldview among Inuit cannot be answered by this thesis, which is concerned with how cognitive mapping can complement the systematic review method to achieve a more complete and inclusive review of existing knowledge. It is likely that the complexity of the Inuit review reflects the more open and flexible method of knowledge-gathering inherent in cognitive mapping, which can accommodate unstructured information and knowledge more easily. Conventional Western scientific methods for collecting data prefer to study well-defined, measurable variables using validated instruments; this rigidity is part of what makes “good science.” Cognitive mapping, on the other hand, does not require data or knowledge to be structured in any particular form. Thus, Western scientific perspectives do not necessarily view health and its determinants in a simple, structured way but the characteristics that define scientific methods may not adequately capture the complexity or nuances of the true perspectives held within the scientific community.

The value of cognitive mapping extends beyond its ability to accommodate various forms of knowledge about causality. Through standardized and structured protocols, a series of cognitive maps or fuzzy cognitive maps assembled with various segments of a population may serve as a systematic review of community knowledge. Alongside a systematic review of the scientific literature, this approach is a promising method for culturally safe knowledge review in epidemiological research.

#### **4.5.2 Implications for Research Planning and Design**

In the planning of the Inuit ACRA project, the research team aimed to review existing knowledge to help frame the issue, formulate the research objectives, and to develop culturally safe, scientifically valid instruments, based on existing Inuit and scientific knowledge. Good epidemiology should account for potential confounders, including factors *known* to play a role, while advancing research by expanding on what is already known, including factors *hypothesized* to be play a role.

Most researchers review the relevant literature and take into consideration existing scientific knowledge when designing their study. For the Inuit ACRA project, an initial scan



of the literature indicated that the existing knowledge on Inuit sexual health was extremely limited with a lack of diversity and breadth on the sexual health issues studied. With such a wide gap in evidence in the Western scientific literature, there is very little indication of the direction in which new research, such as the Inuit ACRA project, should advance. The systematic review of the literature, described here, confirmed this limitation, but provided a valuable starting point on which the ACRA project could build.

The cognitive mapping provided the research team with a detailed picture of Inuit sexual health, including the risk and resilience that Inuit experience in everyday life. This knowledge strongly influenced the direction of the ACRA project, particularly in setting research objectives, hypotheses, and identifying key issues to fill the knowledge gaps found in the scientific literature. Meanwhile, the systematic review of the literature identified important baseline factors, typically demographic characteristics that participants may have overlooked in the cognitive maps, to measure and consider as potential confounders or effect modifiers.

In culturally safe research, systematic review of the scientific literature may not provide a sufficient review of existing evidence. Through cognitive mapping, the Inuit ACRA project discovered a wealth of community knowledge that helped to guide a research process that was locally relevant as well as scientifically rigorous. These methods are equally relevant to non-Aboriginal populations that may feel marginalized or excluded from research on issues that concern them. Likewise, researcher can apply cognitive mapping to review unpublished scientific knowledge and other sources of knowledge not found in the scientific literature. Cognitive mapping accommodates various forms and sources of knowledge, providing a common medium through which researchers and communities can share and discuss ideas.

#### **4.5.3 Strengths and Limitations**

This thesis proposes a new application of cognitive mapping as a method to systematically review local perspectives and other unpublished knowledge sources alongside the standard protocol (systematic review). Juxtaposing the results of the systematic review

and cognitive mapping, the thesis demonstrates how the two methods, when applied together, can generate a more complete and inclusive review of existing knowledge. This practice may simultaneously increase the scientific validity and cultural safety of research.

Because the reviews included qualitative, quantitative and unstructured forms of knowledge, selecting the method to compare the two sets of results was not obvious. Here, I compared the relative number of cognitive mapping sessions (out of six) and studies (out of 22) that identified a given sub-theme to determine the key issues and priorities by each review method. This ‘frequency of mention’ approach is not ideal; however, due to the incongruities in the nature of the data between the cognitive maps and the literature, few alternatives were available.

If the literature review was limited to quantitative data, it may have been possible to compare the strengths of association for each concept between the fuzzy cognitive map (using centrality) and the systematic review (using odds ratios). This approach has been attempted elsewhere by Giles et al.<sup>100</sup> in comparing indigenous and Western scientific knowledge systems around the determinants of diabetes among Aboriginal peoples. In the present systematic review, however, very few of the included studies attempted to measure strengths of association and limiting the review to those that did would have dramatically decreased the number of included studies. The purpose of this analysis was to explore and juxtapose the knowledge (evidence) and beliefs (hypotheses) uncovered through systematic review and cognitive mapping. Thus, limiting the systematic review to studies quantitatively measuring strength of association may have unnecessarily restricted the scope of the review, excluding important hypotheses held within the scientific literature. Comparing the strengths of association between fuzzy cognitive maps (representing local or indigenous knowledge) and systematic reviews (representing Western scientific knowledge) is nonetheless a promising approach to ensuring that research is equally informed by each knowledge system, opening opportunities for culturally safe epidemiology.

## 4.6 Conclusion

Decision makers in Canada are increasingly encouraging a shift towards evidence-based practice (EBP). This model would expect sexually transmitted infection prevention programs and policies founded on high-quality evidence on the determinants of sexual health to be more effective than those that are not evidence-based. That Inuit groups continue to insist that current STI prevention efforts are ineffective and inappropriate to their communities begs the question, “From whom and where is this evidence derived?” To date, the hypotheses and research questions posed by Western epidemiologists and other scientists who are unaware of the local reality have instigated the vast majority of the evidence collected on STIs among Inuit.

This chapter considered some of the consequences of excluding local knowledge and hypotheses in the planning and design of epidemiological research, drawing on the Inuit ACRA project as a case study. Juxtaposing a review of local knowledge by cognitive mapping with the standard protocol for review of Western scientific knowledge (systematic review), the chapter discussed the contributions and added benefit that may result from research that is equally informed by both viewpoints. The systematic review and cognitive mapping provided complementary perspectives that allowed the Inuit ACRA research team to formulate a more complete view of Inuit sexual health while simultaneously increasing the cultural safety and scientific validity of the research.

## CONCLUSION

Following the distrusting historical relationship between Aboriginal communities and scientific research, the application of cultural safety theory to research may help to restore trust and increase the stake that Aboriginal communities have in their own research. Scientific methods of knowledge-gathering, including epidemiology, are often perceived to be inconsistent with indigenous epistemologies and protocols and antithetical to cultural safety. This thesis has argued that epidemiology can and should have a place in the movement towards culturally safe research. In many cases, the cultural safety of research can directly depend on scientific methods and validity and vice versa.

To date, developments in culturally safe research have failed to proceed beyond theoretical discussion. For culturally safe epidemiology to be accepted by both communities and epidemiologists, proponents of this approach need to develop and promote practical applications and protocols that are at once methodologically sound and culturally appropriate and accessible. Culturally safe spaces can be found at the interface of Western scientific and indigenous knowledge where neither scientific validity nor cultural integrity is compromised. Thus, methods are needed to bridge scientific and indigenous knowledge as equal partners to locate these culturally safe spaces in epidemiology.

This thesis has presented cognitive mapping as one promising method for culturally safe epidemiology. Prior to conducting new research, epidemiologists commonly conduct a review of the scientific literature to survey the existing knowledge related to the research question. This protocol, however, may not be culturally safe as it does not consider the wealth of existing knowledge that may exist locally within the study population, i.e. the intended beneficiaries of the research. Currently, there are no established culturally safe protocols for the review of local or indigenous knowledge.

Drawing on the Inuit ACRA project as a case study, the thesis proposed cognitive mapping as a valuable method to reviewing local or indigenous knowledge. Valued alongside Western scientific knowledge, local or indigenous knowledge may be systematically built into research, locating culturally safe spaces throughout the research process from the identification of research objectives and hypotheses to the communication and application of evidence.

In the context of the Inuit ACRA project, the thesis juxtaposed the cognitive mapping approach to review local or indigenous knowledge around Inuit sexual health with the conventional approach to reviewing Western scientific knowledge (systematic review). Specifically, the thesis considered the implications of excluding alternative, i.e. local or indigenous, sources of knowledge from the research process with respect to the scientific validity and cultural safety of the Inuit ACRA project and other epidemiological studies.

The thesis found notable commonalities and differences between the results of the two reviews. The systematic review and cognitive maps identified many of the same concepts but with very divergent views on the definition and influence of these determinants on Inuit sexual health.

Studies in the systematic review often framed sexual health determinants as unidimensional, independent risk factors and focused largely on basic demographic characteristics, such as age and sex. Due to the small number of Inuit-specific studies, many of which were published over 20 years ago, the systematic review provided limited insight into the current reality of Inuit sexual health in Ottawa. The findings ensured the Inuit ACRA data analysis plan and questionnaire included important confounders identified through empirical evidence but was of limited value in developing new hypotheses relevant to the Ottawa Inuit population that the research team could examine further through the ACRA project.

The results of the systematic review are consistent with “black box” epidemiology. The scientific research largely described Inuit sexual health determinants as independent factors acting in isolation. In his book, *The Web of Life*, Capra<sup>252</sup> outlines the limitations of this reductionist view and describes a paradigm shift towards an ecological view that recognizes the fundamental interdependence of all phenomena. According to Capra,<sup>252</sup> an

ecological perspective reflects on “our relationships with one another, to future generations, and to the web of life of which we are a part.” There is evidence that epidemiology is indeed moving away from the “black box” approach and the development of culturally safe epidemiology will contribute to that shift. The cognitive mapping results, meanwhile, closely resemble Capra’s ecological view. Inuit participants framed sexual health determinants as highly complex, intersecting with many other determinants, and focused largely on the broader determinants of health, such as cultural and psychosocial factors.

This thesis is primarily concerned with the methods; specifically, how the two approaches, when applied together, may result in a more accurate and inclusive review of existing evidence and hypotheses. While the review of the Western scientific knowledge was largely limited to published, peer-reviewed journal articles based on rigid scientific methods, the review of Inuit knowledge through cognitive mapping was more adaptable, able to accommodate knowledge that is less structured or filtered. These viewpoints may be considered anecdotal and therefore less weighty as evidence acquired through scientific methods. However, cognitive maps helped to systematize the anecdotes, revealing a rich and diverse spectrum of knowledge, offering insight into the daily realities facing Inuit living in Ottawa.

CM methods may also be useful in reviewing the less structured knowledge of scientific researchers not found in the literature. Further research might examine how scientists and community members can use cognitive mapping as a communication tool with which to share ideas and identify common priorities. Regardless of who is contributing to the maps, this thesis demonstrates that cognitive mapping may be a promising method to uncover knowledge and hypotheses typically excluded from the epidemiological research process.

Epidemiologists are familiar with the benefits of surveying existing scientific knowledge through systematic review, including the continual advancement of knowledge and the avoidance of duplication, prior to conducting new research. The findings from this thesis, however, suggest that a systematic review of the scientific literature may play a necessary but insufficient role in research design and planning as it may uncover only a small portion of existing knowledge. The cognitive mapping with Inuit captured a broader

and more diverse perspective on Inuit sexual health, offering new insights and hypotheses not found through systematic review. In his paper on causal graphs, Robins<sup>253</sup> writes “[a]s epidemiologists, we should always seek highly sceptical subject-matter experts to elaborate the alternative causal theories needed to keep us from being fooled by noncausal associations.” Causal graphing or cognitive mapping is one way to gather and present alternative sources of expert knowledge on the network of factors and relationships contributing to a health outcome, knowledge that may challenge or validate the causal theories published by epidemiologists. In the case of the ACRA project, Inuit organizations and community members represented key subject-matter experts who could elaborate on alternative causal theories on Inuit sexual health.

Had the ACRA research team limited the review of existing evidence to the scientific literature (standard practice in epidemiology), the team may have overlooked a large body of valuable knowledge. As very few studies in the systematic review included urban Inuit and many were out of date, the evidence available in the literature is unlikely to be relevant to Inuit living in Ottawa today. Likewise, a review of local knowledge alone may not be sufficient to understand the current situation around a community health issue. This thesis found each of the reviews provided a unique set of knowledge and hypotheses and allowed the research team to gather a more balanced and complete picture of the existing knowledge from both scientific literature and local Inuit community.

Local knowledge informed several stages of the Inuit ACRA research process, including framing the issue, developing research objectives and hypotheses, and constructing a data analysis plan and questionnaire. The cognitive mapping methods may also play a role in the interpretation and communication of research findings.

Inuit participants believed that the ACRA project should frame the issue of sexual health with a focus on resilience, while emphasizing the broader, upstream determinants of health. This approach does not ignore *risk* but aims to shed light on community *strengths* that may be supported through programs and policies. It also encourages responding to risk from a resilience perspective. In the ACRA project, for example, Inuit participating in the cognitive maps were concerned with the risks of drug and alcohol use among Inuit youth but criticized programs and policies that target Inuit as substance users. Rather, they believed

programs promoting community cohesion and recreation will more effectively reduce substance use and other risky behaviours by engaging and connecting with youth.

This framing of the issue affected the entire research process. From the onset of the project, the research team was cognizant of this strengths-based focus, beginning with research objectives geared towards identifying resilience (or protective) factors and hypotheses that aimed to evaluate the effect of social, economical, political, and cultural factors on Inuit sexual health.

Community input also influenced the Inuit-specific approach. The Ottawa ACRA project originally aimed to include all Aboriginal groups, i.e. First Nations, Métis, and Inuit; however, piloting and community consultation demonstrated a high level of diversity within the Aboriginal population in Ottawa. Community members also expressed concern that a culturally essentialist or “pan-Aboriginal” approach would produce results that are not relevant or appropriate to the unique needs and experiences of First Nations, Métis, and Inuit in Ottawa. Inuit in Ottawa reaffirmed this sentiment in the cognitive mapping sessions where many participants stressed the need for Inuit-specific programs, services, and resources.

Based on prominence in the cognitive maps and centrality in the fuzzy cognitive map, the research team identified priority issues and factors influencing sexual health among Inuit in Ottawa. Holding separate cognitive mapping sessions for Inuit organizations, researchers, Elders, men, younger youth, and older youth allowed the team to consider the priorities of various participating segments of the Inuit population in Ottawa. It is likely that holding separate sessions improved the representativeness (or generalizability) of the mapping results as the team found a substantial degree of diversity across the participating groups. Furthermore, by stratifying the cognitive mapping results by generation, the team was able to better tailor the instruments to create adult- and youth-specific questionnaires.

The team added key variables and potential confounding or modifying factors to the data analysis plan, which ensured their inclusion in the questionnaire and set the stage for statistical analyses that would formally test key hypotheses identified in the scientific and Inuit community.

Fuzzy cognitive mapping (FCM) may also be an effective tool for culturally safe



interpretation and communication of research results. Variables, statistical associations, and odds ratios identified through research may translate into nodes, arrows, and weights in a fuzzy cognitive map to generate a more accessible and comprehensible medium of communication for sharing study findings.

Until recently, the use of FCM as a decision-making tool has been limited to institutional settings where the experts are physicians and other professionals that may be more comfortable with epidemiological concepts and statistics. This thesis examined the application of FCM to identify priorities and map out local knowledge and beliefs with community members that may not be familiar with epidemiology or statistics.

ICART members who participated in the fuzzy cognitive mapping pilot exercise found the visual format of the map to be accessible and helpful in understanding the system of factors contributing to the outcome of interest. It also enabled participants to identify causal relationships that they had previously not considered and helped them to better understand epidemiological concepts such as confounding. Thus, in addition to its application in reviewing local knowledge and beliefs, FCM may also act as a valuable communication and teaching tool in community-based epidemiology. Still, this application of FCM is still relatively new and its potential contribution to culturally safe epidemiology will require further research to identify feasibility and best practices in community-based settings.

The Inuit ACRA research team found that fuzzy cognitive mapping was most effective when conducted with a small number of participants to avoid an excessive number of concepts, which can lead to an overly cumbersome map and prevent the participants from completing the map within a reasonable length of time.

The success of an FCM session also depends on the skills of the facilitator. The facilitator must be aware of the risk of bias in fuzzy cognitive mapping and be equipped with strategies to guide discussion and record concepts in an unbiased way. For this reason, facilitators should receive prior training to understand the risk of bias in the FCM process and develop skills in moderating discussion. This is especially important in culturally safe research where the facilitators are often community members with little or no prior research experience.

The mapping sessions with Inuit in Ottawa provided the team with key knowledge and information that went on to inform several stages of the research process and future CIET projects will benefit from the lessons learned. Projects applying FCM will aim to limit the number of participants to 3-5 individuals to ensure the maps are completed roughly within a 3-hour time period. Greater attention will also be paid to providing facilitators with more extensive training in FCM moderation. In the Inuit ACRA project, a turnover in personnel made it more difficult to build on the Inuit community action research team's training over time. Personnel turnover is an issue that affects many community-based research initiatives and unfortunately can be difficult to avoid.

Culturally safe research methods offer benefits to both communities and epidemiologists. Communities can safely engage in the research that affects their lives with confidence that their interests are systematically built into the research process, from the development of research objectives and hypotheses to the application of evidence. Meanwhile, epidemiologists have access to tools that can facilitate the research process, minimize surprises, increase response rates, improve the validity of the findings, and have higher confidence that the resulting evidence will be more readily adopted by local decision-makers. Building community knowledge into the entire research process also reduces the likelihood of misinterpreting or misusing findings.

With a high level of distrust in research among Inuit, First Nations and Métis communities, many of which have reported feeling like “guinea pigs” and “researched to death,” it is increasingly crucial that new research is considered valuable and necessary by the study population. Otherwise, communities may continue to perceive scientific research with distrust and suspicion. And rightly so. Research that is not in the interests of the community will be plagued with logistical barriers and low response rates, likely leading to invalid findings that will fail to improve the health of the community.

The advancement of culturally safe epidemiology concerns all health research initiatives conducted with Aboriginal communities in Canada but is also relevant to other populations that have been demeaned, disempowered, or misunderstood through research. For example, research on health issues facing immigrants, youth, or sex trade workers is rarely informed by contributions from the target community. Populations that are commonly

labelled as vulnerable or “at risk” may feel marginalized or stigmatized by epidemiological research. These groups may welcome cognitive mapping as a method to communicate their knowledge and concerns and to promote mutual trust and understanding with researchers.

Moving from theoretical discussions to practical applications, this thesis has presented cognitive mapping as a promising method for culturally safe epidemiology. By bridging and recognizing Western scientific and community knowledge as equal contributors, cognitive mapping has the potential to locate culturally safe spaces throughout the research process. Further research should focus on refining cognitive mapping protocols for community-based settings and on identifying and advancing other culturally safe methods in partnership with communities.

Epidemiology offers fundamental tools to understanding and improving community health. The historical misuse of these tools in Aboriginal communities, however, has perpetuated distrust in scientific research. Social scientists and communities are beginning to work towards culturally safe research; however, epidemiologists have yet to contribute to these discussions. Restoring trust in epidemiological research needed to generate high quality scientific evidence in First Nations, Métis, and Inuit communities will hinge on the advancement of culturally safe epidemiology.

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# APPENDICES

## APPENDIX I: Systematic Review Protocol

### TITLE

Determinants of Inuit Sexual Health: A Systematic Review of the Scientific Literature

### RATIONALE

The rationale for the systematic review is to understand the scientific community's belief system around the determinants of Inuit sexual health, as represented by the scientific literature. This will be compared to the belief system of Inuit living Ottawa, expressed in cognitive mapping sessions, to examine whether scientific research is reflective of the hypotheses and priorities of its target population or whether there is a disconnect between the two belief systems.

### OBJECTIVES

The objective of the systematic review is to identify the risk and resilience factors for the transmission of sexually transmitted infections among Inuit in Canada according to the scientific literature.

### METHODS

#### Search Strategy

##### *Published Peer-Reviewed Literature*

As the objective of the search is to capture all factors considered to potentially influence the spread of sexually transmitted infections in Inuit communities, including factors found to be statistically significant as well as those hypothesized to play a role, the search strategy will be deliberately designed to be highly sensitive while sufficiently specific. The references lists of eligible studies will also be scanned for additional articles.

I searched four databases from OVID, including Medline (1950-current), Embase (1947-current), PsycINFO (1806-current), and Healthstar (1966-current), and three databases from EBSCO, including Global Health (insert date), Bibliography of Native North Americans (insert date), and CINAHL (insert date).

While I will tailor the search strategy for each database, the following keywords will be searched in all text for each database:

1. Inuit\* or Eskimo\* or esquimaux or aleut\* or yuit\* or inughuit\* or unanga\* or alutiiq\* or cup'ik\* or yup'ik\* or yupik\* or inup?ia\* or kalaallit\* or native\* adj3 Alaska\*

AND

2. risk\* or resilien\* or prevent\* or behav\* or sex\* or demograph\* or soci\* or health\* or cultur\*

AND

3. HIV or human immunodeficiency virus or STI or STD or sexually transmitted or venereal disease\* or Chlamydia or gonorrh?ea\* or syphilis or Treponema pallidum or herpes or HPV or human papillomavirus or chancroid or Haemophilus ducreyi or trichomon\* or LGV or lymphogranuloma vernerum or Granuloma inguinale or Calymmatobacterium granulomatis or Klebsiella granulomatis or Donovanosis or Bacterial vaginosis or hepatitis B or HBV or hepatitis C or HCV or hepatitis D or HDV or Human T-cell lymphotropic virus type 1 or HTLV-1 or Cytomegalovirus or pediculosis pubis or scabies

### *Grey Literature*

I will also review the grey literature including the following sources:

- Health Canada ([www.hc-sc.gc.ca](http://www.hc-sc.gc.ca))
- Public Health Agency of Canada ([www.publichealth.gc.ca](http://www.publichealth.gc.ca))
- Pauktuutit Inuit Women of Canada ([www.pauktuutit.ca](http://www.pauktuutit.ca))
- Inuit Tapiriit Kanatami ([www.itk.ca/](http://www.itk.ca/))
- National Aboriginal Health Organization ([www.naho.ca](http://www.naho.ca))
- Canadian Aboriginal AIDS Network ([www.caan.ca](http://www.caan.ca))
- Aboriginal Canada Portal ([www.aboriginalcanada.gc.ca](http://www.aboriginalcanada.gc.ca))
- Canadian HIV/AIDS Information Gateway ([www.hivinfovih.ca](http://www.hivinfovih.ca))
- HPV Info Portal ([www.hpvinfos.ca](http://www.hpvinfos.ca))
- US Centre for Disease Control and Prevention ([www.cdc.gov](http://www.cdc.gov))
- State of Alaska Department of Health and Social Services ([www.hss.state.ak.us](http://www.hss.state.ak.us))
- US Indian Health Service ([www.ihs.gov](http://www.ihs.gov))
- Alaska Native Health Board ([www.anhb.org](http://www.anhb.org))
- Alaska Native Tribal Health Consortium ([www.anthc.org](http://www.anthc.org))
- World Health Organization ([www.who.int](http://www.who.int))

- Master's or PhD theses and dissertations

## **Study Selection**

I will export all search results into reference management software (Refworks) and remove duplicate records of the same report by reviewing the titles and abstracts. Myself and a second reviewer (Neil Andersson) will independently review the list of titles and abstracts to exclude articles that are clearly ineligible, i.e. do not study at least one risk or resilience factor for a sexually transmitted infection among Inuit in Canada.

Myself and a second reviewer (Beverley Shea) will then independently review the full-text articles selected in the initial screening process, rigorously applying the inclusion and exclusion criteria. The reviewers will compare their respective selections and a kappa statistic will be calculated to measure the degree of consensus. Discrepancies and disagreements will be resolved through discussion and consensus.

The bibliographies of included studies will be scanned for additional articles.

### *Eligibility Criteria*

Studies will be included if they meet the following inclusion criteria:

1. Primary research (qualitative or quantitative) of any study design
2. Examination or identification of at least one (individual- or community-level) risk or resilience factor, including known intermediates, modifiers, or confounders, for one or more sexually transmitted infection specifically among Inuit in Canada.
3. Studies that focus on broader target groups that include Inuit, such as Aboriginal peoples in Canada, will be included in the review if data on at least one risk or resilience factor is stratified by ethnicity (Inuit-specific).
4. Study samples that are consistently described as "Inuit" but contain a small minority of non-Inuit will be included.

Studies with the following characteristics will be excluded:

1. Studies that do not include Inuit in Canada. Publications that strictly refer to Inuit or as members of a broader Aboriginal group (including First Nations and Métis) will also be excluded.
2. Studies focusing on special risk groups (injection drug users and sex workers).
3. No age or gender restrictions will be applied.
4. No language restrictions will be applied.



## **Data Abstraction and Analysis**

Myself and the second reviewer (BS/CB) will independently extract appropriate information from the included articles using a standardized data abstraction form. Information retrieved from the papers will include the citation, setting, target population, outcome(s) of interest, and determinants of sexually transmitted infections identified. Any discrepancies or disagreements will be resolved between the two reviewers through discussion and consensus.

The identified determinants of sexually transmitted infection will be synthesized by thematic synthesis<sup>62-64</sup> (Thomas, 2008; Barnett, 2009; Dixon, 2005) in which narrative results will be organized into descriptive themes to facilitate summary analysis. The distribution of themes around the determinants of Inuit sexual health within the reviewed literature will then be examined by content analysis<sup>64, 65</sup> (Evans, 2002; Dixon, 2005) in which the distribution of themes will be analyzed qualitatively and quantitatively to identify patterns and comparisons across the included studies and the study characteristics. Specifically, the analysis will aim to determine whether the identified risk or resilience factors for sexually transmitted infections vary by publication date, database or source, setting, and type of sexually transmitted infection to identify possible trends or patterns.

For several reasons, it will not be feasible to conduct a meta-analysis of the review results, i.e. to extract and pool quantitative data from two or more high quality studies on a common outcome of interest (such as HIV infection) to produce a summary result. Firstly, there is a scarcity of Inuit-specific research on any given sexually transmitted infection. Secondly, much of the quantitative evidence that is available is of poor quality. Finally, the review intends to include qualitative research, which is not suitable for meta-analysis. For this reason, both qualitative and quantitative data will be analyzed by thematic synthesis and content analysis.

## **APPENDIX II: Systematic Review Search Strategies**

### **OVID Search Strategies (207+88+107+147+56=605 total)**

#### **Medline Feb 23 (1950-current): 207 results**

1. Inuits/ (2685)
2. (Inuit\* or Eskimo\* or esquimaux or aleut\* or yuit\* or inughuit\* or unanga\* or alutiiq\* or cup'ik\* or yup'ik\* or yupik\* or inup?ia\* or kalaallit\*).mp. (3912)
3. (native\* adj3 Alaska\*).mp. (1333)
4. 1 or 2 or 3 (4640)
5. Adaptation, Psychological/ or Resilience, Psychological/ (58585)
6. exp Risk/ (592955)
7. exp Behavior/ (908413)
8. exp Population Characteristics/ (1070710)
9. exp Sociology/ (834308)
10. exp Psychology, Social/ (526689)
11. exp "health care facilities, manpower, and services"/ (1732197)
12. exp "Delivery of Health Care"/ (612315)
13. exp Self Concept/ (55244)
14. exp Spiritual Therapies/ (10206)
15. Colonialism/ (809)
16. (risk\* or resilien\* or prevent\* or behav\* or sex\* or demograph\* or soci\* or health\* or cultur\*).mp. (4991519)
17. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 (6441350)
18. exp Sexually Transmitted Diseases/ (225936)
19. exp HIV Infections/ (185931)
20. Herpes Genitalis/ (3516)
21. exp Papillomavirus Infections/ (16448)
22. exp Trichomonas Infections/ (4489)
23. Scabies/ (2487)
24. Vaginosis, Bacterial/ (1802)
25. HTLV-I Infections/ (2837)

26. Cytomegalovirus Infections/ (17214)
  27. Lice Infestations/ (1914)
  28. Hepatitis D/ or Hepatitis C/ or Hepatitis B/ (52220)
  29. (HIV or human immunodeficiency virus or STI or STD or sexually transmitted or venereal disease\* or Chlamydia or gonorrh?ea\* or syphilis or Treponema pallidum or herpes or HPV or human papillomavirus or chancroid or Haemophilus ducreyi or trichomon\* or LGV or lymphogranuloma vernerum or Granuloma inguinale or Calymmatobacterium granulomatis or Klebsiella granulomatis or Donovanosis or Bacterial vaginosis or hepatitis B or HBV or hepatitis C or HCV or hepatitis D or HDV or Human T-cell lymphotropic virus type 1 or HTLV-1 or Cytomegalovirus or pediculosis pubis or scabies).mp. (457748)
  30. 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 (500871)
  31. 4 and 17 and 30 (207)
- Medline Updates as of Sept 30, 2010: 11 new results, 0 relevant

**Healthstar 1 Feb 23 (1966-1998): 88 results**

1. Inuits/ (1532)
2. (Inuit\* or Eskimo\* or esquimaux or aleut\* or yuit\* or inughuit\* or unanga\* or alutiiq\* or cup'ik\* or yup'ik\* or yupik\* or inup?ia\* or kalaallit\*).mp. (1785)
3. (native\* adj3 Alaska\*).mp. (424)
4. 1 or 2 or 3 (1960)
5. exp Risk/ (175975)
6. Adaptation, Psychological/ (28337)
7. exp Behavior/ (291399)
8. exp Population Characteristics/ (447003)
9. exp Sociology/ (405911)
10. exp Psychology, Social/ (258552)
11. exp "health care facilities, manpower, and services"/ (846658)
12. exp "Delivery of Health Care"/ (277019)
13. exp Self Concept/ (19242)
14. exp Spiritual Therapies/ (3621)
15. Colonialism/ (196)
16. (risk\* or resilien\* or prevent\* or behav\* or sex\* or demograph\* or soci\* or health\* or cultur\*).mp. (1366602)
17. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 (2036567)
18. exp Sexually Transmitted Diseases/ (93165)

19. exp HIV Infections/ (83647)
20. Herpes Genitalis/ (842)
21. exp Papillomavirus Infections/ (2207)
22. Scabies/ (554)
23. exp Trichomonas Infections/ (850)
24. Vaginosis, Bacterial/ (219)
25. HTLV-I Infections/ (969)
26. Cytomegalovirus Infections/ (5047)
27. Lice Infestations/ (366)
28. Hepatitis C/ or Hepatitis B/ or Hepatitis D/ (17178)
29. (HIV or human immunodeficiency virus or STI or STD or sexually transmitted or venereal disease\* or Chlamydia or gonorrh?ea\* or syphilis or Treponema pallidum or herpes or HPV or human papillomavirus or chancroid or Haemophilus ducreyi or trichomon\* or LGV or lymphogranuloma vernerum or Granuloma inguinale or Calymmatobacterium granulomatis or Klebsiella granulomatis or Donovanosis or Bacterial vaginosis or hepatitis B or HBV or hepatitis C or HCV or hepatitis D or HDV or Human T-cell lymphotropic virus type 1 or HTLV-1 or Cytomegalovirus or pediculosis pubis or scabies).mp. (109846)
30. 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 (137101)
31. 4 and 17 and 30 (88)

**Healthstar 2 Feb 23 (1999-Jan 2010): 107 results**

1. Inuits/ (822)
2. (Inuit\* or Eskimo\* or esquimaux or aleut\* or yuit\* or inughuit\* or unanga\* or alutiiq\* or cup'ik\* or yup'ik\* or yupik\* or inup?ia\* or kalaallit\*).mp. (1031)
3. (native\* adj3 Alaska\*).mp. (818)
4. 1 or 2 or 3 (1516)
5. exp Risk/ (333144)
6. Adaptation, Psychological/ (27941)
7. exp Behavior/ (305047)
8. exp Population Characteristics/ (521196)
9. exp Sociology/ (345590)
10. exp Psychology, Social/ (227156)
11. exp "health care facilities, manpower, and services"/ (616648)
12. exp "Delivery of Health Care"/ (320883)

13. exp Self Concept/ **(26277)**
14. exp Spiritual Therapies/ **(4753)**
15. Colonialism/ **(520)**
16. (risk\* or resilien\* or prevent\* or behav\* or sex\* or demograph\* or soci\* or health\* or cultur\*).mp. **(1560663)**
17. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 **(1988952)**
18. exp Sexually Transmitted Diseases/ **(83633)**
19. exp HIV Infections/ **(76831)**
20. Herpes Genitalis/ **(980)**
21. exp Papillomavirus Infections/ **(5278)**
22. Scabies/ **(322)**
23. exp Trichomonas Infections/ **(457)**
24. Vaginosis, Bacterial/ **(810)**
25. HTLV-I Infections/ **(546)**
26. Cytomegalovirus Infections/ **(3536)**
27. Lice Infestations/ **(325)**
28. Hepatitis C/ or Hepatitis B/ or Hepatitis D/ **(13830)**
29. (HIV or human immunodeficiency virus or STI or STD or sexually transmitted or venereal disease\* or Chlamydia or gonorrh?ea\* or syphilis or Treponema pallidum or herpes or HPV or human papillomavirus or chancroid or Haemophilus ducreyi or trichomon\* or LGV or lymphogranuloma vernerum or Granuloma inguinale or Calymmatobacterium granulomatis or Klebsiella granulomatis or Donovanosis or Bacterial vaginosis or hepatitis B or HBV or hepatitis C or HCV or hepatitis D or HDV or Human T-cell lymphotropic virus type 1 or HTLV-1 or Cytomegalovirus or pediculosis pubis or scabies).mp. **(132518)**
30. 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 **(138536)**
31. 4 and 17 and 30 **(107)**

Healthstar Updates as of Sept 30, 2010: 6 new results, 1 relevant result

**Embase (1947-current): 147 results**

1. Eskimo/ **(970)**
2. (Inuit\* or Eskimo\* or esquimaux or aleut\* or yuit\* or inughuit\* or unanga\* or alutiiq\* or cup'ik\* or yup'ik\* or yupik\* or inup?ia\* or kalaallit\*).mp. **(2446)**
3. (nativ\* adj3 alaska\*).mp. **(915)**
4. 1 or 2 or 3 **(3186)**
5. exp risk/ **(660087)**

6. exp behavior/ **(1008219)**
7. exp population structure/ **(140788)**
8. exp sexual orientation/ **(19224)**
9. exp "social aspects and related phenomena"/ **(709502)**
10. exp social psychology/ **(29050)**
11. exp health care system/ **(189967)**
12. exp health education/ **(89579)**
13. exp health/ **(149164)**
14. exp self concept/ **(51994)**
15. cultural factor/ **(22805)**
16. spiritual healing/ **(448)**
17. political system/ **(3265)**
18. (risk\* or resilien\* or prevent\* or behav\* or sex\* or demograph\* or soci\* or health\* or cultur\*).mp. **(4694076)**
19. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 **(5204869)**
20. exp sexually transmitted disease/ **(52356)**
21. exp Human immunodeficiency virus infection/ **(161835)**
22. exp Chlamydia/ **(12098)**
23. exp Papilloma virus/ **(23354)**
24. trichomoniasis/ **(3021)**
25. scabies/ **(2836)**
26. vaginitis/ **(7566)**
27. Human T cell leukemia virus 1/ **(6781)**
28. cytomegalovirus infection/ **(15029)**
29. pubic pediculosis/ **(209)**
30. Hepatitis delta virus/ or hepatitis B/ or hepatitis C/ **(62585)**
31. (HIV or human immunodeficiency virus or STI or STD or sexually transmitted or venereal disease\* or Chlamydia or gonorrh?ea\* or syphilis or Treponema pallidum or herpes or HPV or human papillomavirus or chancroid or Haemophilus ducreyi or trichomon\* or LGV or lymphogranuloma vernerum or Granuloma inguinale or Calymmatobacterium granulomatis or Klebsiella granulomatis or Donovanosis or Bacterial vaginosis or hepatitis B or HBV or hepatitis C or HCV or hepatitis D or HDV or Human T-cell lymphotropic virus type 1 or HTLV-1 or Cytomegalovirus or pediculosis pubis or scabies).mp. **(450723)**
32. 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 **(486572)**
33. 4 and 19 and 32 **(147)**

Embase Search Update as of Sept 30, 2010: 6 new results, 1 relevant.

**PsycINFO Feb 23 (1806-current): 56 results**

1. inuit/ or alaska natives/ **(685)**
2. (Inuit\* or Eskimo\* or esquimaux or aleut\* or yuit\* or inughuit\* or unanga\* or alutiiq\* or cup'ik\* or yup'ik\* or yupik\* or inup?ia\* or kalaallit\*).mp. **(668)**
3. (nativ\* adj3 alaska\*).mp. **(594)**
4. 1 or 2 or 3 **(1240)**
5. Risk Factors/ **(21591)**
6. Protective Factors/ **(1487)**
7. "Resilience (Psychological)"/ **(3659)**
8. exp Behavior/ **(668694)**
9. Demographic Characteristics/ **(24224)**
10. exp Sexual Orientation/ **(17664)**
11. Sociology/ **(5581)**
12. exp Social Issues/ **(99908)**
13. Social Psychology/ **(9032)**
14. Health Care Services/ or Health Care Delivery/ **(27246)**
15. Public Health Services/ **(1712)**
16. exp Health/ **(64100)**
17. exp Self Concept/ **(49580)**
18. Spirituality/ **(8365)**
19. exp Sociocultural Factors/ **(67359)**
20. exp Social Processes/ **(72948)**
21. Politics/ **(6950)**
22. (risk\* or resilien\* or prevent\* or behav\* or sex\* or demograph\* or soci\* or health\* or cultur\*).mp. **(1499772)**
23. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 **(1641307)**
24. exp Sexually Transmitted Diseases/ **(24423)**
25. human papillomavirus/ **(124)**
26. hepatitis/ **(1140)**
27. (HIV or human immunodeficiency virus or STI or STD or sexually transmitted or venereal disease\* or Chlamydia or gonorrh?ea\* or syphilis or Treponema pallidum or herpes

or HPV or human papillomavirus or chancroid or Haemophilus ducreyi or trichomon\* or LGV or lymphogranuloma venereum or Granuloma inguinale or Calymmatobacterium granulomatis or Klebsiella granulomatis or Donovanosis or Bacterial vaginosis or hepatitis B or HBV or hepatitis C or HCV or hepatitis D or HDV or Human T-cell lymphotropic virus type 1 or HTLV-1 or Cytomegalovirus or pediculosis pubis or scabies).mp. **(30085)**

28. 24 or 25 or 26 or 27 **(33285)**

29. 4 and 23 and 28 **(56)**

PsycINFO Updates as of Sept 30, 2010: 1 new result, 0 relevant

## **EBSCO SEARCH STRATEGIES (107+117+47=271 total)**

### **CINAHL (1981-current): 107 results**

1. (MH "Eskimos") **(353)**
2. (TX "Inuit\*" or "Eskimo\*" or "esquimaux" or "aleut\*" or "yuit\*" or "inughuit\*" or "unanga\*" or "alutiiq\*" or "cup'ik\*" or "yup'ik\*" or "yupik\*" or "inup'ia\*" or "kalaallit\*" or "native\* N3 Alaska\*") **(985)**
3. (1 or 2) **(985)**
4. (MH "Behavior+") **(300792)**
5. (MH "Population Characteristics+") **(395781)**
6. (MH "Sociology+") **(335228)**
7. (MH "Psychology, Social+") **(404553)**
8. (MH "Facilities, Manpower and Services (Non-Cinahl)+") **(679017)**
9. (MH "Health Care Delivery+") **(109641)**
10. (MH "Personality+") **(56019)**
11. (MH "Spiritual Healing+") **(1297)**
12. (MH "Politics+") **(22092)**
13. (TX "risk\*" or "resilien\*" or "prevent\*" or "behav\*" or "sex\*" or "demograph\*" or "soci\*" or "health\*" or "cultur\*") **(1502467)**
14. (4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13) **(1811023)**
15. (MH "Sexually Transmitted Diseases+") **(42375)**
16. (MH "Papillomavirus Infections+") **(2656)**
17. (MH "Scabies") **(322)**
18. (MH "Vaginosis, Bacterial") **(584)**
19. (MH "Cytomegalovirus Infections") **(904)**
20. (MH "Lice Infestations") **(486)**
21. (MH "Hepatitis B") or (MH "Hepatitis C") **(5607)**
22. (MH "Hepatitis D") **(82)**
23. ( TX "HIV" or "human immunodeficiency virus" or "STI" or "STD" or "sexually transmitted" or "venereal disease\*" or "Chlamydia" or "gonorrh?ea\*" or "syphilis" or "Treponema pallidum" or "herpes" or "HPV" or "human papillomavirus" or "chancroid" or "Haemophilus ducreyi" or "trichomon\*" or "LGV" or "lymphogranuloma venereum" or "Granuloma inguinale" or "Calymmatobacterium granulomatis" or "Klebsiella granulomatis" or "Donovanosis" or "Bacterial vaginosis" or "hepatitis B" or "HBV" or "hepatitis C" or "HCV" or "hepatitis D" or "HDV" or "Human T-cell lymphotropic virus



type 1” or “HTLV-1” or “Cytomegalovirus” or “pediculosis pubis” or “scabies”) (60440)  
19. (15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23) (67216)  
20. (3 and 14 and 19) (107)  
CINAHL Updates as of Sept 30, 2010: 3 new results, 1 relevant

### **Global Health (1973-current): 117 results**

1. (TX "Inuit\*" or "Eskimo\*" or "esquimaux" or "aleut\*" or "yuit\*" or "inughuit\*" or "unanga\*" or "alutiiq\*" or "cup'ik\*" or “yup'ik\*” or “yupik\*” or "inup?ia\*" or "kalaallit\*" or “native\* N3 Alaska\*”) (1047)
2. (TX "risk\*" or "resilien\*" or "prevent\*" or "behav\*" or "sex\*" or "demograph\*" or "soci\*" or "health\*" or "cultur\*") (863355)
3. (TX “HIV” or “human immunodeficiency virus” or “STI” or “STD” or “sexually transmitted” or “venereal disease\*” or “Chlamydia” or “gonorrh?ea\*” or “syphilis” or “Treponema pallidum” or “herpes” or “HPV” or “human papillomavirus” or “chancroid” or “Haemophilus ducreyi” or “trichomon\*” or “LGV” or “lymphogranuloma vernerum” or “Granuloma inguinale” or “Calymmatobacterium granulomatis” or “Klebsiella granulomatis” or “Donovanosis” or “Bacterial vaginosis” or “hepatitis B” or “HBV” or “hepatitis C” or “HCV” or “hepatitis D” or “HDV” or “Human T-cell lymphotropic virus type 1” or “HTLV-1” or “Cytomegalovirus” or “pediculosis pubis” or “scabies”) (149945)
4. (1 and 2 and 3) (117)

Global Health Updates as of Sept, 2010: 6 new results, 1 relevant result

### **Bibliography of Native North Americans (1950-current): 47 results**

1. (TX "Inuit\*" or "Eskimo\*" or "esquimaux" or "aleut\*" or "yuit\*" or "inughuit\*" or "unanga\*" or "alutiiq\*" or "cup'ik\*" or “yup'ik\*” or “yupik\*” or "inup?ia\*" or "kalaallit\*" or “native\* N3 Alaska\*”) (11747)
2. (TX "risk\*" or "resilien\*" or "prevent\*" or "behav\*" or "sex\*" or "demograph\*" or "soci\*" or "health\*" or "cultur\*") (34487)
3. (TX “HIV” or “human immunodeficiency virus” or “STI” or “STD” or “sexually transmitted” or “venereal disease\*” or “Chlamydia” or “gonorrh?ea\*” or “syphilis” or “Treponema pallidum” or “herpes” or “HPV” or “human papillomavirus” or “chancroid” or “Haemophilus ducreyi” or “trichomon\*” or “LGV” or “lymphogranuloma vernerum” or “Granuloma inguinale” or “Calymmatobacterium granulomatis” or “Klebsiella granulomatis” or “Donovanosis” or “Bacterial vaginosis” or “hepatitis B” or “HBV” or “hepatitis C” or “HCV” or “hepatitis D” or “HDV” or “Human T-cell lymphotropic virus type 1” or “HTLV-1” or “Cytomegalovirus” or “pediculosis pubis” or “scabies”) (206)
4. (1 and 2 and 3) (47)

BNNA Updates as of Sept 30, 2010: 0 new results

## APPENDIX III: Individual Study Summaries

This section summarizes each of the 22 studies included in the systematic review. The individual study summaries are separated into seven categories based on the type of sexually transmitted infection investigated: HIV/AIDS, human papillomavirus, Chlamydia, gonorrhoea, herpes simplex virus, cytomegalovirus, hepatitis B virus, and sexually transmitted diseases in general. Additional publications of the same study are included under the original publication.

### HIV/AIDS

Three studies from the systematic review identified risk and resilience factors related to HIV/AIDS among Inuit, all of which focused on largely on tertiary prevention for people living with HIV/AIDS.

The study by CAAN<sup>90</sup>, entitled ‘Canadian Aboriginal People Living with HIV/AIDS: Care, Treatment and Support Issues,’ is a quantitative cross-sectional survey of 195 First Nations, Inuit and Métis living with HIV/AIDS across Canada. Published by the Canadian Aboriginal AIDS Network (CAAN) in 2008, the paper was found through the grey literature search from the CAAN website. The study quality was rated ‘weak’ through quality assessment. Inuit data was aggregated with that of First Nations and Métis for data analysis purposes, likely because only 5 Inuit participated in the study (location not specified). The study was nonetheless eligible for inclusion in the systematic review as a small amount of Inuit-specific qualitative and quantitative data was provided. The study objectives were to ‘determine which services and programs currently address and fulfill the needs of Canadian Aboriginal people living with HIV/AIDS,’ ‘identify barriers that prevent or limit access to needed services,’ and ‘to develop policy/practice recommendations for the design of relevant programs.’ CAAN identified the following 5 risk and resilience factors: ‘Access to & Use of Programs, Services, & Other Resources,’ ‘Culturally Relevant Resources,’ ‘Inuit Culture, Traditions, & Way of Life,’ ‘Mental Health & Healing,’ and ‘Communication, Disclosure, & Sharing Experiences.’ Overall, the Jackson et al. study identified 3 structural/demographic factors, 1 behavioural factors, 1 psychosocial factors, and 0 genetic and biological factors related to HIV/AIDS among Inuit.

The study by CAAN<sup>91</sup>, entitled ‘Relational Care: A Guide to Health Care and Support for Aboriginal People Living with HIV/AIDS,’ is a qualitative study of 35 First Nations, Inuit and Métis living with HIV/AIDS in Canada and 52 HIV/AIDS service providers. Published by the Canadian Aboriginal AIDS Network (CAAN) in 2008, the paper was found through the grey literature search from the CAAN website. The study quality was rated as ‘weak’ through quality assessment. Inuit data was aggregated with that of First Nations and Métis for data analysis purposes, likely because only 5 Inuit (all from southern urban centres) participated in the study. The study was nonetheless eligible for inclusion in the systematic review as a small number of Inuit-specific qualitative data (quotes) was provided. The study objectives were to ‘explore the perceptions of cultural concepts of care among APHAs and HIV/AIDS health care providers;’ ‘to document the lived experiences of APHAs regarding culturally competent or incompetent health care;’ and ‘to design a wise practices guide for

HIV/AIDS health care providers who work with APHAs.’ CAAN identified the following 14 risk and resilience factors: ‘Self-esteem, Assertiveness, & Responsibility,’ ‘Mental Health & Healing,’ ‘Social Support, Counselling, & Mentorship,’ ‘Communication, Disclosure, & Sharing Experiences,’ ‘Parenting, Family, & Relationships,’ ‘Access to & Use of Programs, Services, & Other Resources,’ ‘Trust & Respect,’ ‘Culturally Relevant Resources,’ ‘Community Connection & Cohesion,’ ‘Focus on Strength & Resilience,’ ‘Substance Use,’ ‘Knowledge, Information, & Education,’ ‘Physical Health, Biology, & Genetics’ and ‘Testing & Screening.’ Overall, the CAAN study identified 1 structural factor, 3 behavioural factors, 5 psychosocial factors, and 1 genetic and biological factor related to HIV/AIDS among Inuit.

The study by **PHAC**<sup>92</sup>, entitled ‘Aboriginal HIV/AIDS Attitudinal Survey 2006,’ is a quantitative cross-sectional survey of 1597 First Nations, Inuit and Métis across Canada, including 204 Inuit in the Northwest Territories, Nunavut, Nunavik, and Labrador . Published by the Public Health Agency of Canada (PHAC), which commissioned PHAC Research Associates to conduct the study in 2006, the paper was identified through the grey literature search from the PHAC website. The study quality was rated ‘weak’ through quality assessment. Although the study sample included First Nations and Métis as well as Inuit, the study was eligible for inclusion in the systematic review because the Inuit-specific data was analyzed separately. The study objective was to ‘to create an overall picture of Aboriginal peoples’ awareness and knowledge, as well as attitudes and behaviour related to HIV/AIDS, and to isolate patterns of sub-group differences, including demographic and attitudinal patterns.’ The PHAC study identified the following 23 factors: ‘Knowledge, Information, & Education,’ ‘Social Norms, Attitudes, Role Models, & Peer Pressure,’ ‘Trust & Respect,’ ‘Taboo, Stigma, & Discrimination,’ ‘Sex & Gender,’ ‘Sexual Orientation,’ ‘Age & Generation,’ ‘Housing, Employment, & Other Socioeconomic Factors,’ ‘Sharing Needles & Other Personal Items,’ ‘Safe Sex,’ ‘Testing & Screening,’ ‘Parenting, Family, & Relationships,’ ‘Substance Use,’ ‘Self-esteem, Assertiveness, & Responsibility,’ ‘Sex Trade,’ ‘Casual & Multiple Sexual Partners,’ ‘Abstinence,’ ‘Vaccines & Pharmaceuticals,’ ‘Communication, Disclosure, & Sharing Experiences,’ ‘Access to & Use of Programs, Services, & Other Resources,’ ‘Social Support, Counselling, & Mentorship,’ ‘Popular Culture, Internet, & Other Media,’ and ‘Culturally Relevant Resources.’ Overall, the PHAC study identified 11 structural/demographic factors, 9 behavioural factors, 3 psychosocial factors, and 0 genetic and biological factors related to HIV/AIDS.

## **Human Papillomavirus**

Two studies from the systematic review identified risk and resilience factors for human papillomavirus (HPV) among Inuit.

The study by **Hamlin-Douglas et al.**<sup>69,70</sup> was a cross-sectional quantitative survey of 629 Inuit women living in Nunavik, Quebec. The review found the results of the study in two separate papers. ‘Prevalence and Age Distribution of Human Papillomavirus Infection in a Population of Inuit Women in Nunavik, Quebec,’ published by the journal *Cancer Epidemiology, Biomarkers & Prevention* in 2008<sup>69</sup>, was identified from the databases Global Health, Embase, Healthstar, and Medline. ‘Determinants of Human Papillomavirus Infection among Inuit Women of Northern Quebec, Canada,’ published by the journal *Sexually Transmitted Diseases* in 2010<sup>70</sup>, was identified from the databases Global Health, CINAHL,

and Embase. The study objective was to ‘to study the prevalence and age distribution of human papillomavirus (HPV) infection among Inuit women in Nunavik, northern Quebec.’ The 2008 publication identified three risk and resilience factors for HPV among Inuit, including ‘Age & Generation,’ ‘Abstinence,’ and ‘Testing & Screening.’ The 2010 publication identified ten sub-themes including the ‘Age & Generation’ (also identified in the 2008 paper) as well as 9 others: ‘Parenting, Family, & Relationships,’ ‘Knowledge, Information, & Education,’ ‘Nutrition, Physical Activity, & Healthy Lifestyle,’ ‘Casual & Multiple Sexual Partners,’ ‘Geographic Location,’ ‘Housing, Employment, & Other Socioeconomic Factors,’ ‘Substance Use,’ ‘Physical Health, Biology, & Genetics,’ and ‘Safe Sex.’ Overall, the Hamlin-Douglas et al. study identified 5 structural/demographic factors, 6 behavioural factors, 0 psychosocial factors, and 1 genetic and biological factors for HPV among Inuit.

The study by **Healey et al.**<sup>71</sup>, entitled ‘Oncogenic Human Papillomavirus Infection and Cervical Lesions in Aboriginal Women of Nunavut, Canada,’ was a cross-sectional quantitative survey of 1290 Inuit and non-Inuit women living in the Baffin Island and Keewatin regions of Nunavut. Published by the journal *Transmitted Diseases* in 2001, the paper was identified through the bibliographic scan of included studies. The study quality was rated ‘weak’ through quality assessment. Although the study sample included non-Inuit women, the study was eligible for inclusion in the systematic review because the data analysis was stratified by Inuit and non-Inuit status. The study objective was to ‘To determine the prevalence of oncogenic HPVs in Nunavut, and to assess the association between HPV and squamous intraepithelial lesions (SIL). Healey et al. identified five risk and resilience factors for HPV among Inuit, including ‘Age & Generation,’ ‘Geographic Location,’ ‘Knowledge, Information, & Education,’ ‘Nutrition, Physical Activity, & Healthy Lifestyle,’ and ‘Housing, Employment, & Other Socioeconomic Factors.’ Overall, the Healey et al. study identified 4 structural/demographic factors, 1 behavioural factor, 0 psychosocial factors, and 0 genetic and biological factors for HPV among Inuit.

## **Chlamydia**

Three studies from the systematic review identified risk and resilience factors for Chlamydia among Inuit.

The study by **Kordova et al.**<sup>76</sup>, entitled ‘High Prevalence of Antibodies to *Chlamydia trachomatis* in a Northern Canadian Community,’ was a cross-sectional seroepidemiological (quantitative) survey of 135 Inuit and 51 Caucasians in Baker Lake, Nunavut. Published by the *Canadian Journal of Public Health* in 1983, the paper was identified from the Medline database. The study quality was rated ‘weak’ through quality assessment. Although the study sample included non-Inuit and only 73% were Inuit, the study was eligible for inclusion in the systematic review because the data analysis was stratified by Inuit and non-Inuit status. The study objectives were to establish ‘whether residents of a Northern Canadian community...had antibodies to *C. trachomatis*.’ Kordova et al. identified two risk and resilience factors for Chlamydia among Inuit, including ‘Age & Generation’ and ‘Sex & Gender.’ Overall, the Kordova et al. study identified 2 structural/demographic factors, 0 behavioural factors, 0 psychosocial factors, and 0 genetic and biological factors related to Chlamydia among Inuit.

The study by **Hodgins et al.**<sup>75</sup>, entitled ‘The Value of Mass Screening for Chlamydia Control in High Prevalence Communities,’ was a randomized (quantitative) community intervention study of 14 communities in Nunavik, Quebec. Published by the journal *Sexually Transmitted Infections* in 2002, the paper was identified from the databases Healthstar and Medline. The study quality was rated ‘weak’ through quality assessment. Although the study sample included non-Inuit, the study was eligible for inclusion in the systematic review because the authors referred to the participating communities as ‘Inuit communities’ and the interpretation and discussion of the results were specifically geared towards Inuit. The study objectives were to assess ‘the impact of a mass screening campaign for *Chlamydia trachomatis*.’ Hodgins et al. identified four risk and resilience factors for Chlamydia among Inuit, including ‘Age & Generation,’ ‘Sex & Gender,’ ‘Testing & Screening,’ and ‘Access to & Use of Programs, Services, & Other Resources.’ Overall, the Hodgins et al. study identified 3 structural/demographic factors, 1 behavioural factor, 0 psychosocial factors, and 0 genetic and biological factors related to Chlamydia among Inuit.

The study by **Steenbeek et al.**<sup>88,89</sup> was a cross-sectional (quantitative) survey of 181 Inuit residents of a community in the Baffin Island region of Nunavut, followed by a prospective cohort study including 100 individuals randomly selected from the cross-sectional sample. The review found the results of the study in two separate papers. The first paper, a 2005 PhD dissertation entitled ‘An Epidemiological Survey of Chlamydial and Gonococcal Infections in a Canadian Arctic Community: Determinants of Sexually Transmitted Infections among Remote Inuit Populations,’<sup>88</sup> was identified through the grey literature search from a database of Master’s and PhD theses and dissertations. The second paper, entitled ‘An Epidemiological Survey of Chlamydial and Gonococcal Infections in a Canadian Arctic Community’ and published by the journal *Sexually Transmitted Diseases* in 2009<sup>89</sup>, was identified from the databases Global Health, CINAHL, Embase, Healthstar and Medline. As the researcher detected no cases of gonorrhoea, the study only examined risk and resilience factors for Chlamydia. The 2009 publication identified twelve risk and resilience factors for Chlamydia, including ‘Age & Generation,’ ‘Sex & Gender,’ ‘Knowledge, Information, & Education,’ ‘Housing, Employment, & Other Socioeconomic Factors,’ ‘Physical Health, Biology, & Genetics,’ ‘Abstinence,’ ‘Safe Sex,’ ‘Taboo, Stigma, & Discrimination,’ ‘Self-Esteem, Assertiveness, & Responsibility,’ ‘Testing & Screening,’ ‘Access to & Use of Programs, Services, & Other Resources,’ and ‘Vaccines & Pharmaceuticals.’ The 2005 dissertation publication identified 19 determinants for Chlamydia among Inuit, including the 12 identified in the 2009 publication as well as ‘Popular Culture, Internet, & Other Media,’ ‘Sharing Needles & Other Personal Items,’ ‘Substance Use,’ ‘Casual & Multiple Sexual Partners,’ ‘Communication, Disclosure, & Sharing Experiences,’ ‘Trust & Respect,’ and ‘Social Norms, Attitudes, Role Models, & Peer Pressure.’ Overall, the Steenbeek et al. study identified 8 structural/demographic factors, 8 behavioural factors, 2 psychosocial factors, and 1 genetic and biological factors related to Chlamydia among Inuit.

## **Gonorrhoea**

The study by Steenbeek<sup>88</sup> (described above) was the only study from the systematic review that examined gonorrhoea among Inuit as a primary outcome; however, as Steenbeek

did not detect any cases of gonorrhoea, the study identified no risk or resilience factors among Inuit.

## **Herpes Simplex Virus**

Two studies from the systematic review identified risk and resilience factors for herpes simplex virus among Inuit.

The study by **Hildes et al.**<sup>74</sup>, entitled ‘Neutralizing Viral Antibodies in Eastern Arctic Eskimos,’ was a cross-sectional seroepidemiological (quantitative) survey of 240 Inuit in various communities, mainly on Baffin Island, in the eastern arctic. Published by the *Canadian Journal of Public Health* in 1959, the paper was identified from the Embase database. The study quality was rated ‘weak’ through quality assessment. The study objective was to ‘provide more information on virus diseases [including herpes simplex virus]’ in the participating communities. Hildes et al. identified two risk and resilience factors for herpes simplex virus among Inuit, including ‘Age & Generation’ and ‘Geographic Location.’ Overall, the Hildes et al. study identified 2 structural/demographic factors, 0 behavioural factors, 0 psychosocial factors, and 0 genetic and biological factors related to herpes simplex virus among Inuit.

The study by **Nicolle et al.**<sup>84</sup>, entitled ‘Cross-sectional seroepidemiologic study of the prevalence of cytomegalovirus and herpes simplex virus infection in a Canadian Inuit (Eskimo) community,’ was a cross-sectional seroepidemiological (quantitative) survey of 155 Inuit and 11 Caucasian residents of Chesterfield Inlet, Nunavut (then Northwest Territories). Published by the *Scandinavian Journal of Infectious Disease* in 1986, the paper was identified from the databases Global Health, Embase, Healthstar and Medline. The study quality was rated ‘weak’ through quality assessment. Although the study sample included non-Inuit, the study was eligible for inclusion in the systematic review because more than 90% of the sample was Inuit, the authors referred to the community as an ‘Inuit community’ and the interpretation and discussion of the results were specifically geared towards Inuit. The study objective was to determine the serologic profile for herpes simplex virus and cytomegalovirus in the participating community. Nicolle et al. identified two risk and resilience factors for herpes simplex virus, including ‘Age & Generation’ and ‘Sex & Gender.’ Overall, the Nicolle et al. study identified 2 structural factor, 0 behavioural factors, 0 psychosocial factors, and 0 genetic and biological factors related to herpes simplex virus among Inuit.

## **Cytomegalovirus**

Three studies from the systematic review identified risk and resilience factors for cytomegalovirus (CMV) among Inuit.

The study by **Nicolle et al.**<sup>84</sup> (described above) identified ‘Age & Generation’ and ‘Sex & Gender’ as determinants for cytomegalovirus among Inuit. Overall, the Nicolle et al. study identified 2 structural factor, 0 behavioural factors, 0 psychosocial factors, and 0 genetic and biological factors related to CMV among Inuit.

The study by **Preiksaitis et al.**<sup>86, 87</sup> was a cross-sectional seroepidemiological (quantitative) survey of 9,928 Inuit, Dene and non-native residents of various communities in the Northwest Territories, including Inuvialuit and present day Nunavut, and 4,184 residents of Edmonton, Alberta. The review found the results of the study in two separate papers. ‘Seroepidemiology of Cytomegalovirus Infection in the Northwest Territories of Canada,’ published by the journal *Arctic Medical Research* in 1988<sup>86</sup>, was identified from the databases Healthstar and Medline. ‘Comparative Seroepidemiology of Cytomegalovirus Infection in the Canadian Arctic and an Urban Center,’ published by the *Journal of Medical Virology* in 1988<sup>87</sup>, was identified from the databases Embase, Healthstar and Medline. Although the study sample included non-Inuit residents and only 52% Inuit, the study was eligible for inclusion in the systematic review because the results provided Inuit-specific data. The study objective was to ‘determine the prevalence and possible patterns of transmission of CMV among the native [Inuit and Dene] peoples.’ Both publications identified the sub-themes ‘Age & Generation’ and ‘Sex & Gender’ as determinants for CMV among Inuit. Overall, the Preiksaitis et al. study identified 2 structural/demographic factors, 0 behavioural factors, 0 psychosocial factors, and 0 genetic and biological factors related to CMV among Inuit.

## **Hepatitis B Virus**

Nine studies from the systematic review identified risk and resilience factors for hepatitis B virus (HBV) among Inuit.

The study by **Baikie et al.**<sup>66, 67 66, 66, 66, 67, 67</sup> was a cross-sectional seroepidemiological (quantitative) survey of 1506 Inuit and non-Inuit residents of various communities in the northern Labrador. The review found the results of the study in two separate papers. ‘The Epidemiology of Hepatitis B Virus Infection in Northern Labrador, Canada,’ published by the journal *Arctic Medical Research* in 1988<sup>66</sup>, was identified from the databases Healthstar and Medline. ‘Epidemiologic features of hepatitis B virus infection in northern Labrador,’ published by the *Canadian Medical Association Journal* in 1989<sup>67</sup>, was identified from the databases Embase, Healthstar and Medline. Although the study sample included non-Inuit residents and only 47% of the sample was Inuit, the study was eligible for inclusion in the systematic review because the results provided Inuit-specific data. The study objective was to determine the prevalence of HBV in the participating communities. The 1988 publication identified three risk and resilience factors for HBV among Inuit, including ‘Age & Generation,’ ‘Geographic Location,’ and ‘Sex & Gender’ as determinants for HBV among Inuit. The 1989 publication identified two risk and resilience factors for HBV, including ‘Age & Generation’ and ‘Geographic Location.’ Overall, the Baikie et al. study identified 3 structural/demographic factors, 0 behavioural factors, 0 psychosocial factors, and 0 genetic and biological factors related to HBV among Inuit.

A study by **Larke et al.**<sup>77</sup>, entitled ‘Epidemiology of Hepatitis B in the Canadian Arctic,’ was a cross-sectional seroepidemiological (quantitative) survey of 221 residents of Arctic Bay and 33 residents of Nanisivik, Nunavut. Published by the journal *Circumpolar Health* in 1982, the paper was identified from the bibliographic scan of included studies. The study quality was rated ‘weak’ through quality assessment. Although the study sample included non-Inuit residents, the study was eligible for inclusion in the systematic review

because the results provided Inuit-specific data. The study objective was to collect ‘data on the epidemiology of hepatitis B among populations in remote areas of northern Canada. Larke et al. identified three risk and resilience factors for HBV among Inuit, including ‘Age & Generation,’ ‘Sex & Gender,’ and ‘Geographic Location.’ Overall, the Larke et al. study identified 3 structural/demographic factors, 0 behavioural factors, 0 psychosocial factors, and 0 genetic and biological factors related to HBV among Inuit.

Another study by **Larke et al.**<sup>78</sup>, entitled ‘Hepatitis B in the Baffin Region of Northern Canada,’ was a cross-sectional seroepidemiological (quantitative) survey of 3,271 residents of various communities on Baffin Island, Nunavut. Published by the journal *Circumpolar Health* in 1984, the paper was identified from the bibliographic scan of included studies. The study quality was rated ‘weak’ through quality assessment. Although the study sample included non-Inuit residents, the study was eligible for inclusion in the systematic review because over 90% of the sample was Inuit and the interpretation and discussion of the results were specifically geared towards Inuit. The study objective was to determine the pattern of HBV infection in the participating community. Larke et al. identified three risk and resilience factors for HBV among Inuit, including ‘Age & Generation,’ ‘Sex & Gender,’ and ‘Geographic Location.’ Overall, the Larke et al. study identified 3 structural/demographic factors, 0 behavioural factors, 0 psychosocial factors, and 0 genetic and biological factors related to HBV among Inuit.

Another study by **Larke et al.**<sup>79</sup>, entitled ‘Extension of the epidemiology of hepatitis B in circumpolar regions through a comprehensive serologic study in the Northwest Territories of Canada,’ was a cross-sectional seroepidemiological (quantitative) survey of 14,198 Inuit, Dene and non-native residents of the Northwest Territories, including Inuvialuit and present day Nunavut. Published by the *Journal of Medical Virology* in 1987, the paper was identified from the bibliographic scan of included studies. The quality was rated ‘weak’ through quality assessment. Although the study sample included non-Inuit residents, the study was eligible for inclusion in the systematic review because the results provided Inuit-specific data. The study objective was to ‘determine the prevalence and possible patterns of transmission of HBV infection. Larke et al. identified ‘Geographic Location’ as a determinant of HBV among Inuit. Overall, the Larke et al. study identified 1 structural factor, 0 behavioural factors, 0 psychosocial factors, and 0 genetic and biological factors related to HBV among Inuit.

A study by **Minuk et al.**<sup>80</sup>, entitled ‘Hepatitis virus infection in an isolated Canadian Inuit (Eskimo) population,’ was a cross-sectional seroepidemiological (quantitative) survey of 720 residents (671 Inuit and 49 Caucasian) of Baker Lake, Nunavut. Published by the *Journal of Medical Virology* in 1982, the paper was identified from the bibliographic scan of included studies. The study quality was rated ‘weak’ through quality assessment. Although the study sample included non-Inuit, the study was eligible for inclusion in the systematic review because over 90% of the sample was Inuit, the authors referred to the participating community as an ‘Inuit settlement’ and the interpretation and discussion of the results were specifically geared towards Inuit. The study objective was to determine ‘prevalence of hepatitis A virus (HAV), hepatitis B virus (HBV) infection, and chronic liver disease’ in the participating community. Minuk et al. identified four risk and resilience factors for HBV among Inuit, including ‘Age & Generation,’ ‘Sex & Gender,’ ‘Inuit Culture, Traditions, & Way of Life,’ and ‘Sharing Needles & Other Personal Items.’ Overall, the Minuk et al. study



identified 3 structural/demographic factors, 1 behavioural factor, 0 psychosocial factors, and 0 genetic and biological factors related to HBV among Inuit.

Another study by **Minuk et al.**<sup>83</sup>, entitled ‘Occult Hepatitis B Virus Infection in a North American Community-based Population,’ was based on the cross-sectional seroepidemiological (quantitative) survey of 720 residents in Baker Lake, Nunavut studied in Minuk et al. 1982<sup>80</sup>. Published by the *Journal of Hepatology* in 2005, the paper was identified from the databases Embase, Healthstar and Medline. The study quality was rated ‘weak’ through quality assessment. The study objective was to document the prevalence of occult HBV in the participating community. Minuk et al. identified three risk and resilience factors for HBV among Inuit, including ‘Age & Generation,’ ‘Sex & Gender,’ and ‘Physical Health, Biology & Genetics.’ Overall, the Baikie et al. study identified 2 structural/demographic factors, 0 behavioural factors, 0 psychosocial factors, and 1 biological/genetic factor related to HBV among Inuit.

Another study by **Minuk et al.**<sup>81</sup>, entitled ‘The Changing Epidemiology of Hepatitis B Virus Infection in the Canadian North,’ was a cross-sectional seroepidemiological (quantitative) survey of 172 residents (164 Inuit and 8 Caucasian) of Chesterfield Inlet, Nunavut. Published by the *American Journal of Epidemiology* in 1985, the paper was identified from the databases Global Health, Embase, Healthstar and Medline. The study quality was rated ‘weak’ through quality assessment. Although the study sample included non-Inuit, the study was eligible for inclusion in the systematic review because more than 90% of the sample was Inuit, the authors referred to the participating community as an ‘Inuit settlement’ and the interpretation and discussion of the results were specifically geared towards Inuit. The study objective was to determine the prevalence and distribution of HBV in the participating community. Minuk et al. identified three risk and resilience factors for HBV among Inuit, including ‘Age & Generation,’ ‘Sex & Gender,’ and ‘Geographic Location.’ Overall, the Minuk et al. study identified 3 structural/demographic factors, 0 behavioural factors, 0 psychosocial factors, and 0 genetic and biological factors related to HBV among Inuit.

Another study by **Minuk et al.**<sup>82</sup>, entitled ‘Pre-core Mutant Infections in the Canadian Inuit,’ was a cross-sectional seroepidemiological (quantitative) survey of 176 Inuit in five Nunavut communities, including Rankin Inlet, Chesterfield Inlet, Baker Lake, Repulse Bay, and Coral Harbour. Published by the *Journal of Hepatology* in 2000, the paper was identified from the databases Healthstar and Medline. The study quality was rated ‘weak’ through quality assessment. The study objective was to ‘determine whether the biochemical and serologic profile of HBV carriers in the Canadian Inuit population continues to reflect inactive disease and to document the prevalence of pre-core mutant infections in this population.’ Minuk et al. identified three risk and resilience factors for HBV among Inuit, including ‘Age & Generation,’ ‘Sex & Gender,’ and ‘Physical, Biological & Genetic Factors.’ Overall, the Minuk et al. study identified 2 structural/demographic factors, 0 behavioural factors, 0 psychosocial factors, and 1 biological/genetic factor related to HBV among Inuit.

The study by **O’Leary et al.**<sup>85</sup>, entitled ‘A Mathematical predictive model to Study the Effect of Hepatitis B Virus Vaccine and Antivirus Treatment among the Canadian Inuit Population,’ applied a mathematical predictive model using data on hepatitis B incidence, prevalence, and vaccination coverage. Published by the *European Journal of Clinical*

*Microbiology & Infectious Diseases* in 2010, the paper was identified from the databases Global Health, Healthstar and Medline. As no quality assessment tool was available to evaluate mathematical prediction models, the study quality could not be determined. Although the data in the mathematical predictive model included non-Inuit, the study was eligible for inclusion in the systematic review because the interpretation and discussion of the results were specifically geared towards Inuit. The study objective was to ‘predict trends of hepatitis B virus (HBV) among the Inuit population over the next 50 years.’ O’Leary et al. identified three risk and resilience factors for HBV among Inuit, including ‘Vaccines & Pharmaceuticals,’ ‘Testing & Screening,’ and ‘Access to & Use of Programs, Services, & Other Resources.’ Overall, the O’Leary et al. study identified 1 structural/demographic factor, 2 behavioural factors, 0 psychosocial factors, and 0 genetic and biological factors related to HBV among Inuit.

### **Sexual Health and Sexually Transmitted Infections**

Two studies from the systematic review identified risk and resilience factors for sexual health and sexually transmitted infections in general among Inuit.

The study by **Cole**<sup>68</sup>, entitled ‘Youth sexual health in Nunavut: A needs-based survey of knowledge, attitudes and behaviour,’ was a cross-sectional survey of 102 high school and college students in Iqaluit, Nunavut. Published by the journal *Circumpolar Health* in 2004, the paper was identified from the databases Healthstar and Medline. The study quality was rated ‘weak’ through quality assessment. Although the study sample included non-Inuit residents, the study was eligible for inclusion in the systematic review because the results provided Inuit-specific data. The study objective was to ‘address the need for culturally specific data on beliefs and behaviours in order to design and implement appropriate public health interventions.’ Cole identified twelve risk and resilience factors for sexual health among Inuit, including ‘Safe Sex,’ ‘Knowledge, Information, & Education,’ ‘Culturally Relevant Resources,’ ‘Abstinence,’ ‘Communication, Disclosure, & Sharing Experiences,’ ‘Mental Health & Healing,’ ‘Testing & Screening,’ ‘Self-Esteem, Assertiveness, & Responsibility,’ ‘Age & Generation,’ ‘Parenting, Family, & Relationships,’ ‘Safe Place,’ and ‘Nutrition, Physical Activity, & Healthy Lifestyle.’ Overall, the Cole study identified 5 structural/demographic factors, 5 behavioural factors, 2 psychosocial factors, and 0 genetic and biological factors related to sexual health among Inuit.

The study by **Healey**<sup>72, 73</sup> was a qualitative study including in-depth interviews with nine Inuit women living in Nunavut. The review found the results of the study in two separate documents, a published paper and a PowerPoint presentation. The paper, ‘entitled ‘Tradition and Culture: An Important Study of Inuit Women’s Health,’ was published by the *Journal of Aboriginal Health* in 2008<sup>72</sup> and was identified through the grey literature search from the National Aboriginal Health Organization website. The PowerPoint presentation, entitled ‘Inuit Women’s Wellness,’<sup>73</sup> was identified through the grey literature search on the Pauktuutit Inuit Women of Canada website. The study quality was rated ‘weak’ through quality assessment. The study objective was to ‘explore Inuit women’s perspectives on their health and well-being [including sexual health].’ In the paper published in 2008, Healey identified five risk and resilience factors for sexual health among Inuit women, including ‘Age & Generation,’ ‘Parenting, Family, & Relationships,’ ‘Abstinence,’ ‘Communication,

Disclosure, & Sharing Experiences,' and 'Self-esteem, Assertiveness, & Responsibility.' The PowerPoint presentation also identified the sub-themes 'Parenting, Family, & Relationships' and 'Self-esteem, Assertiveness, & Responsibility,' as well as five additional factors: 'Knowledge, Information, & Education,' 'Sexual Violence & Other Abuse,' 'Substance Use,' 'Nutrition, Physical Activity, & Healthy Lifestyle,' and 'Sex & Gender.' Overall, the Healey study identified 5 structural/demographic factors, 4 behavioural factors, 1 psychosocial factors, and 0 genetic and biological factors related to sexual health among Inuit.

## APPENDIX IV: Qualitative Analysis of Systematic Review and Cognitive

The sections below describe the qualitative, in addition to quantitative, analyses for each sub-theme, juxtaposing the results of the systematic review and cognitive mapping.

### *Abstinence*

Five of the 22 studies in the systematic review identified concepts related to the abstinence. These studies tended to focus on delayed sexual initiation (e.g. “age at first intercourse,” “let’s talk about having sex too early” and “it’s okay to wait until you’re older to be sexually active”). Three of the six cognitive mapping sessions referred to abstinence, also focusing on delayed sexual initiation (e.g. “just say it ‘wait’” and “try to set a goal to wait until you’re mature”). Overall, the two reviews showed a similar perspective on abstinence as a determinant of Inuit sexual health.

### *Access to & Use of Programs, Services, & Other Resources*

Six studies in the systematic review identified concepts related to access to and use of programs, services, and other resources. For the most part, the literature focused on the *use* of resources such as screening and disease management programs, healing and sharing circles, and traditional medical services. The review found some exceptions in the grey literature, including one study that indicated having a “warm” and “gentle” health care provider encourages the use of and access to health services. Another study that found some Inuit believe “people living with HIV/AIDS experience difficulty obtaining housing, health care or employment,” indicating one’s HIV/AIDS status can be a barrier to access.

Four of the cognitive maps identified concepts around this sub-theme. Unlike the literature, the Inuit perspective tended to emphasize *access to* more than *use of* programs, services, and other resources. Barriers to access included the cost of services and feeling uneasy with health facilities and providers (e.g. “free services,” “Inuit-friendly centres” and “hospitals can be intimidating”). Meanwhile, Inuit stressed that knowing where to go and what is available can facilitate access (e.g. “knowing where to go for help,” “knowing where to get tested” and “more information about what services are available”). Participants also identified cultural relevancy as an important facilitator, indicating that having “Inuit-specific health services,” “networks and services tailored to the Ottawa Inuit community,” “initiatives geared towards Inuit,” and “knowing where to go...places that access the N number” can strongly determine whether Inuit can or are willing to access services to improve their sexual health.

Overall, the Western scientific and Inuit review did not reveal a similar perspective on this sub-theme, with the literature focusing on the *use of* and the cognitive maps focusing on *access to* programs, services, and other resources. Pointing to the limitations of defining “access” strictly in terms of entry into or “use” of the health care system, Penchansky and

Thomas<sup>183</sup> propose that “access” be defined by five dimensions: availability, accessibility, accommodation, affordability, and acceptability. *Availability* refers to the supply of services in relation to the clients’ volume and type of needs; *accessibility* to the location of services in relation to the location of clients; *accommodation* to the manner in which services are delivered (such as hours of operation) in relation to the clients’ ability to accommodate; *affordability* to the cost of services in relation to the clients’ income, ability to pay and level of health insurance; and *acceptability* to the provider’s personal and practice characteristics in relation to the client’s expectations and preferences.

Discussions in the cognitive mapping sessions suggest Inuit are concerned with this broader definition of access. Inuit participants indicated that the existence of programs and services is insufficient and described a number of obstacles to using or being able to use these resources. Although there is little Inuit-specific research on this issue, several studies have documented the barriers to access facing Aboriginal peoples in Canada, including geographic isolation, stigma, discrimination, socioeconomic factors, language, and a lack of culturally appropriate services.<sup>184-188</sup> Inuit health organizations and service providers in Ottawa have expressed strong interest in the results of the ACRA survey to understand the barriers to access specifically among Ottawa Inuit and apply these findings to better target the city’s hidden Inuit population.

#### *Adaptation to Urbanization, Westernization, & Other Changes*

None of the 22 studies included in the systematic review referred to the adaptation to urbanization, westernization, and other changes as a determinant of Inuit sexual health.

Three of the cognitive mapping sessions identified concepts related to this sub-theme. Several participants referred to the adjustments and difficulties of moving to a city or outside of one’s community (e.g. “sense of anonymity in the city,” “Inuit moving to cities are quick to adapt to changes,” and “Inuit social relationships that are away from home create a family environment”). Others also talked about adapting to sociocultural changes, including the status of Inuit culture in the context of Westernization (e.g. “cultural adaptation”) and changing gender roles (e.g. “men do not know what their role is in the household”).

As this sub-theme was unique to the Inuit perspective, the two knowledge systems did not agree on adaptability to change as a determinant of Inuit sexual health. Scientific research in Inuit and other Aboriginal communities, however, have documented the many ways in which acculturation, or cultural change, and the way in which communities and individuals adapt can have substantial health implications, including physical, mental and spiritual well-being.<sup>111, 112, 189, 190</sup> Since colonization, Inuit communities have experience dramatic changes that affect their health. Some examples include the shift from a nomadic to sedentary lifestyle and the impact that climate change has had on the environment and wildlife in the arctic, ultimately disrupting peoples’ livelihoods, nutrition, and way of life.<sup>189</sup> More recently, scholars have looked at how urbanization and the severance of family and other social support systems can have important psychological consequences.<sup>191</sup> While acknowledging the potential hardships, Inuit participating in the cognitive mapping sessions indicated that urbanization can also have positive effects, such as improved access to

services and decreased stigma against people living with HIV/AIDS. The Inuit ACRA survey will help to uncover some of the subtleties of how urbanization and cultural adaptation is affecting Inuit sexual health in Ottawa.

### *Age & Generation*

In the systematic review, 18 of 22 included studies identified factors related to age and generation, most of which focused exclusively on age, for example, by stratifying the data by age group. Thus, in the scientific literature, age was typically viewed as a demographic characteristic that could potentially act as a confounding or modifying factor in data analysis. There were some exceptions (e.g. “parents should learn to talk to their kids about sex and how to avoid STIs” and “let’s talk about having sex too early”), which depict age and generation not simply as a unidimensional variable but rather one that can intersect with other determinants.

This sub-theme arose in five of the six cognitive maps with Inuit who, unlike the Western scientific literature, placed a greater emphasis on generation than on age group (e.g. “bridge intergenerational gap” and “giving information to younger generation”). Inuit also linked age and generation with other determinants such as communication (e.g. “be more open with children”), parenting (e.g. “open communication between children and parents”), self-esteem (e.g. “making Inuit kids confident”), role models (e.g. “role models for younger kids”), and education (e.g. “educate at early age”).

Overall, the Western scientific and Inuit reviews did not indicate a similar perspective on age and generation as a determinant of Inuit sexual health, with the literature focusing more on *age* or age group as a demographic category and the cognitive maps focusing on *generation* as it intersects with other influencing factors. A possible explanation for this difference in perspective may be that Inuit community members are more intimately connected to the issues under discussion. For most epidemiologists conducting research, the immediate priority is to measure variables and analyze data to understand the distribution of health outcomes in a population. Members of the study population, however, may not find it useful to view these factors as “independent risk factors.” Rather, community member experience these factors in everyday life and may not find it necessary to determine a statistical interaction between variables in a regression model to appreciate the complexity in which factors such as age, gender, socioeconomic status, and culture influence health.

### *Casual & Multiple Sexual Partners*

Three studies in the systematic review referred to casual and multiple partners, which were identified as potential risk factors for sexually transmitted infection. Three of the Inuit groups raised the issue of sex with casual or multiple partners, which was identified as an independent risk factor (e.g. “monogamy,” “don’t have multiple partners,” and “discourage promiscuity”). Overall, the Western scientific and Inuit reviews indicated a similar perspective on this sub-theme, both with a relatively straightforward view on the influence of casual and multiple sexual partners on Inuit sexual health.

### *Communication, Disclosure, & Sharing Experiences*

Six studies from the systematic review referred to communication, disclosure, and sharing experiences. This sub-theme intersected with other health determinants such as stigma (e.g. “I didn’t know how to share my story with my family saying that I was diagnosed with HIV”); parenting (e.g. “parents should learn to talk to their kids about sex and how to avoid STIs”); and assertiveness (e.g. “don’t be afraid to ask and speak up about sex”).

All six cognitive maps included concepts around communication, disclosure and sharing experiences. Inuit linked this sub-theme with knowledge (e.g. “sharing of knowledge”); trust (e.g. “trust elders when they (people) need to discuss in confidence”); parenting (e.g. “open communication between children and parents”); safe place (e.g. “safe place to discuss”); testing (e.g. “asking partners to get tested”); and cultural relevancy (e.g. “Inuit observing and learning methods are done by comprehension, i.e. face to face with a person affected by HIV/AIDS”).

While there were minor differences in how the two reviews framed the issue of communication, overall the Western scientific literature and Inuit appeared to share a similar perspective on this sub-theme, both emphasizing the importance of open communication within families, intimate relationships, and communities.

### *Community Connection & Cohesion*

The systematic review found one study that referred to community connection and cohesion, citing an Inuk living with HIV/AIDS who noted the importance of connecting with other Inuit.

Of the six Inuit groups, only the younger youth did not identify this sub-theme. Typical concepts included “support from other Inuit,” “community pride,” and “trust within the culture.” Participants recommended fostering community cohesion through traditional food (e.g. “traditional food brings the community together-important”) and community activities (e.g. “community activities for people to be included”). Inuit also linked this sub-theme to other sexual health determinants such as respect (e.g. “Inuit tend to respect and protect each other”) and social support (e.g. “support from other Inuit”).

Although the mention of community connection and cohesion in the literature was similar to those identified in the cognitive maps, only 1 of the 22 studies mentioned this sub-theme, which appeared in five of the six cognitive maps. Thus, overall, the Western scientific literature and Inuit did not appear to share a common perspective on the importance of community cohesion as a determinant for Inuit sexual health. A substantial body of research in Aboriginal and non-Aboriginal populations has looked at the health benefits of community cohesion or “social capital,” including community networks, norms, and trust. The studies suggest people who connect and have a sense of belonging with a broader community gain psychological and other health benefits, mediated through social support and collaboration.<sup>192-195</sup> Ottawa Inuit agreed that there is positive relationship between community

cohesion and health. To examine this relationship further, the Inuit ACRA survey asked respondents about their level of participation in community activities and other related questions, which the research team can link to health behaviours and outcomes.

### *Culturally Relevant Resources*

Four studies in the systematic review considered the role of culturally relevant resources, referring to the benefits of Inuit-specific sexual health education, the use of traditional healing for people living with HIV/AIDS, and incorporating Inuit language, tradition, and Elders into HIV/AIDS care, education, and information. Thus, the literature suggests cultural relevancy may help to improve Inuit education and access to resources.

Of the six groups of Inuit, all but the younger youth identified concepts related to this sub-theme. Typical concepts included “Inuit-specific health services” and “networks and services tailored towards the Ottawa Inuit community with elders, families that give adequate services.” Emphasis was placed on the involvement of Elders in programming and services (e.g. “elder input-elders’ advice. Exposing this matter or teaching Elders more about this concern”). Inuit believed cultural relevancy can promote sexual health through improved access to resources (e.g. “advertising drop-in places for Inuit to go and learn more about health resources on bulletins”); knowledge translation (e.g. “translation of information into Inuktitut”); and counselling (e.g. “Elders’ advice/counselling”).

Although this sub-theme was more prominent in the cognitive maps, overall the Western scientific literature and Inuit participants appeared to share a similar perspective on culturally relevant resources as a determinant of Inuit sexual health. Both suggested that programs, services and other resources that incorporate Inuit culture, knowledge, and beliefs help to promote Inuit sexual health by increasing the acceptability and accessibility of these resources. Although there is little Inuit-specific research, studies in other communities and contexts have affirmed the advantages of culturally appropriate resources.<sup>107, 108, 196, 197</sup>

### *Focus on Strength & Resilience*

One study in the systematic review referred to strength or resilience in the context of Inuit sexual health. This qualitative study quoted an Inuk woman living with HIV/AIDS who re-established her strength after being diagnosed HIV positive.

Three of the six Inuit groups talked about strength and resilience (e.g. “important to look at strengths of Inuit-what creates resilience” and “focus on the positive”). Inuit linked resilience to adaptability (e.g. “adjusting to changing times”) and the legacy of colonization (e.g. “overcoming historical dominance of whites”).

Overall, the Western scientific literature and Inuit participants appeared have a different perspective on this sub-theme. While the literature included one minor reference to resilience, this sub-theme was much more prominent in the Inuit review, where resilience played a central role in an Inuk’s response to adversity or change, including urbanization, Westernization, and cultural loss. This difference in perspective was not surprising.



Epidemiological studies are often criticized for focusing on health ‘problems’ and their ‘risk’ factors, which can be demoralizing and stigmatizing for the study population. Communities are increasingly requesting a resilience approach to health research that recognizes local successes and strengths.

### *Geographic Location*

Eight studies in the systematic review identified geographic location as a health determinant. In all cases, the authors viewed geographic location as a basic demographic characteristic that could act as a confounding or modifying factor for other indicators, i.e. data was stratified by community or region.

Two of the six Inuit groups discussed the health implications around geography. Unlike the scientific literature, Inuit focused on geographic location as a barrier or change to which Inuit must adapt, such as moving from a small remote community to a large city in the south (e.g. “Inuit moving to cities are quick to adapt to changes”).

Overall, the Western scientific and Inuit reviews did not indicate a common perspective on this sub-theme. This issue of geographic was more frequently raised in the Western scientific perspective; however, the literature largely focused on *community* or *region* simply as a demographic category. Inuit participants, however, saw it something more complicated and talked at length about the advantages and challenges involved in moving from a remote northern community to a southern urban centre. On an individual level, geographic migration can affect access to services and social support, but can also have a broader impact by facilitating disease transmission between communities.<sup>198-200</sup>

### *History & Legacy of Colonization*

The systematic review did not find any studies that referred to the history or legacy of colonization. Only the Inuit organizations raised the issue of colonization (e.g. “overcoming historical dominance of whites” and “overcoming colonization”).

As this sub-theme was unique to the Inuit perspective, the two reviews did not indicate a shared view on history and legacy of colonization as a determinant of Inuit sexual health. The increasing application of postcolonial theoretical frameworks in Aboriginal health research, however, indicates that this may be changing as researchers realize how the legacy of colonization continues to influence the health of Aboriginal peoples today.<sup>6, 7, 106, 168-170, 172-174</sup>

### *Housing, Employment, & Other Socioeconomic Factors*

The systematic review found four studies examined the role of housing, employment, and other socioeconomic factors in determining Inuit sexual health. For the most part, the studies considered employment, income, and socioeconomic status as socio-demographic

indicators, although one study looked at how HIV status can act as a barrier to accessing housing and employment.

Two of the six cognitive maps included this sub-theme. One group highlighted the HIV risk among Ottawa's homeless and recommended this population be targeted for HIV/AIDS education. The other group indicated the need to provide more opportunities for Inuit to improve their socioeconomic well-being.

Overall, the Western scientific and Inuit reviews indicated a similar perspective on this sub-theme, both identifying socioeconomic factors such as shelter, employment and income as promoters of good sexual health among Inuit. Still, it was surprisingly that this issue did not have a larger presence in the literature or the cognitive maps considering the large and growing body of literature on the social determinants of health.<sup>164-167, 201-203</sup>

### *Inuit Culture, Traditions, & Way of Life*

Two studies in the systematic review referred to Inuit culture, traditions, or way of life. One study published in 1982 indicated scarification, a form of tradition tattooing, as a risk factor while another study discussed the benefits of accessing traditional medicines and ceremonies for Inuit living with HIV/AIDS.

Four of the six cognitive maps identified Inuit culture as a sexual health determinant. Inuit participants discussed how culture intersects with many other factors to influence health such as knowledge and education (e.g. "changing education system to include Inuit history" and "teaching of cultural values-pass on"); adaptation (e.g. "cultural adaptation"); self-determination ("reclaim Inuit traditions"); and resilience (e.g. "important to look at strengths of Inuit-what creates resilience").

Although there was some commonality between the two knowledge reviews, overall the Western scientific and Inuit reviews did not indicate a shared perspective on Inuit culture. In the cognitive maps, this sub-theme was more central and complex, interconnected with many other factors to influence Inuit sexual health. In epidemiology, the depiction of culture as a determinant of health is controversial. When concepts around culture arose during the cognitive mapping sessions, the tone was almost invariably positive as participants highlighted the complex ways in which Inuit knowledge, tradition, values, and way of life can act as protective factors. All too often, however, health researchers have inappropriately categorized Aboriginality simply as a risk factor for disease. Despite good intentions, this culturally essentialist approach can encourage stigma and discrimination by painting all Aboriginal peoples as diseased or unfortunate. When developing the Inuit ACRA questionnaire, the research team was cognizant of this common misuse of cultural health determinants and carefully ensured the questionnaire reflected the Inuit perspective.

### *Justice & Reconciliation*

The systematic review of the scientific literature did not find any studies that identified justice or reconciliation as a determinant of Inuit sexual health.

Only one of the six Inuit groups raised this sub-theme. Inuit Elder talked about justice and reconciliation in the context of sexual violence (e.g. “better justice system for victims for victim of rape for safety of women and children who have been main prey”). They highlighted the importance of incorporating Inuit culture into the treatment of sexual offenders (e.g. “Inuit traditional justice system used to be where a group of Inuit would isolate the molester from the community make them understand what they have done was wrong at a camp”). The Elders also identified some current criminal justice initiatives in Inuit and other Aboriginal communities that are incorporating cultural tradition and values.

As the sub-theme was unique to the Inuit perspective, the two knowledge reviews did not indicate a shared view on justice or reconciliation as determinants of Inuit sexual health. Outside of the published scientific literature, however, there is some evidence of culturally attuned criminal justice initiatives that have emerged in response to the over-representation of Inuit and other Aboriginal peoples in the Canada’s criminal justice system. The Nunavut Community Justice Program, for example, supports local programs in Inuit communities that are based on Inuit traditional knowledge (Inuit Qaujimagatunqangit) and emphasize prevention and healing at the community level to shift away from complete reliance on mainstream approaches such as formal charges, court appearances and incarceration.<sup>204</sup> Many of these programs have adopted a restorative justice approach in which victims and offenders are brought together to work towards reconciliation.

### *Knowledge, Information, & Education*

Seven studies in the systematic review suggested knowledge, information, or education as determinants of Inuit sexual health. In most cases, the researchers measured or referred to knowledge or education level as basic indicators.

All six groups of Inuit identified this sub-theme. Like the Western scientific literature, Inuit suggested knowledge or education level as a health indicator; however, for Inuit, the issue of knowledge and education seemed to have a more complicated role in determining sexual health. Inuit participants linked this sub-theme to several other factors such as culture (e.g. “change education system to include Inuit history”); cultural relevancy (e.g. “translation of information into Inuktitut”); access to services (e.g. “more information about what services are available to Inuit”); self-determination (e.g. “building Inuit capacity”); social support (e.g. “knowing where to go and who to turn to when diagnoses with HIV”); and parenting (e.g. “teaching parents what diseases are out there”).

Overall, the Western scientific and Inuit knowledge reviews did not indicate a shared perspective on knowledge, information, and education. While both identified level of education and sexual health knowledge as important indicators of sexual health, Inuit appeared to view the influence of this sub-theme as farther reaching, complexly linked to many other contributing factors.

### *Mental Health & Healing*

Three studies in the systematic review suggested mental health and healing as determinants of Inuit sexual health. One study cited youth who identified the “emotions and problems that can be involved with sexuality,” while the others cited Inuit living with HIV/AIDS who talked about the mental distress after being diagnosed and the benefits of attending healing circles.

Three of the six cognitive maps included this sub-theme. Inuit talked about mental health as it intersects with other sexual health determinants including leisure (e.g. “long walks also contribute to clearing mind and wellbeing”); sexual violence (e.g. “healing in all areas related to HIV/STI or sexual activity-offering this to those affected, i.e. rape victims”); and social support (e.g. “knowing where to go and who to turn to when diagnosed with HIV. Room to heal with guidance/direction”).

Although this sub-theme was more central in the cognitive maps, overall the Western scientific and Inuit knowledge reviews indicated a similar perspective on this sub-theme, with both identifying mental distress and opportunities for healing as key issues for people living with HIV/AIDS. Research confirms there are a number of mental health issues related to HIV/AIDS. People living with HIV/AIDS are more prone to depression and other mental health conditions.<sup>205-207</sup> Meanwhile, one’s mental health may affect their risk of being infected in the first place<sup>206, 208, 209</sup> and, once diagnosed with AIDS, can determine their ability to access and adhere to antiretroviral treatment.<sup>206, 210-212</sup> Many scholars believe that mental health deserves more attention in HIV/AIDS prevention and treatment programs<sup>206, 207, 212</sup> and it appears Inuit in Ottawa agree.

### *Nutrition, Physical Activity, & Healthy Lifestyle*

Four studies in the systematic review identified nutrition, physical activity, or healthy lifestyle as determinants of Inuit sexual health. Three of the four studies pointed to smoking as a basic health indicator and one study cited Inuit women who associated living an unhealthy, “dramatic lifestyle” with “drinking, partying, drug use, and high-risk sexual activity” and its impact on self-esteem.

Four of six cognitive maps included this sub-theme. Inuit believed that a healthy lifestyle, including a healthy diet and physical activity, is important for one’s well-being. In the cognitive maps, this was also closely related to other determinants such as recreation (e.g. “gyms and community sporting events”); mental health (e.g. “long walks also contribute to clearing mind and wellbeing”); education (e.g. “education on nutrition is needed for those who are HIV positive-diet is important to health”); and community services (e.g. “food banks/feasts”).

Overall, the Western scientific and Inuit knowledge reviews did not indicate a shared perspective on this sub-theme. While the literature focused on *risk* and the dangers associated with a healthy lifestyle, including smoking, substance use, and “high-risk” sexual activity, the cognitive maps focused on *resilience* and the benefits of a healthy lifestyle, including good nutrition and physical activity. Extensive research has confirmed the physical and psychological health benefits of good nutrition and physical activity for people living

with HIV/AIDS (PLHA).<sup>213-215</sup> Physical activity can increase CD4+ counts, diminish the severity and frequency of symptoms, and increase muscle mass, while improving self-esteem, mood, and quality of life for PLHA.<sup>213, 216</sup> HIV infection and associated treatments can disrupt metabolism and an adequate diet is vital to ensuring intake of essential nutrients and preventing excessive weight loss or gain.<sup>217-219</sup>

### *Parenting, Family, Relationships*

Five studies in the systematic review identified concepts parenting, family or relationships as determinants of Inuit sexual health. Some referred to marital status, number of lifetime births, or other related demographic characteristics. Others brought up more complex issues including the difficulty of disclosing one's HIV positive status to their family and the importance of parents talking about sex and STIs with their children,

Five of the six cognitive maps included this sub-theme. As in the literature, Inuit noted the value of discussing sexual health with their children (e.g. "open communication between children and parents" and "parents/youth talk about sex"). In addition, Inuit talked about educating parents about current sexual health issues (e.g. "parents should be taught about resources around HIV & coping" and "teaching parents what diseases are out there"). Inuit also viewed parents and family as key sources of social support and guidance (e.g. "parental guidance" and "understanding who you can go to for help, i.e. counsellor/trusted friends or family").

Although this sub-theme was more central in the cognitive maps, overall the Western scientific and Inuit knowledge reviews indicated similar perspectives on parenting, family, and relationships as determinants of Inuit sexual health. Both emphasized that discussion and education around sexual health and sexually transmitted infections should begin at home where parents and family should play a central role.

### *Physical Health, Biology, & Genetics*

The systematic review included five studies that identified physical health, biology, or genetics as sexual health determinants. Two studies referred to a history of sexually transmitted infections as a baseline characteristic or indicator of risk for future infection while another two studies examined how different hepatitis B virus genotypes influence the latency of the virus among HBV-infected Inuit. The fifth study quoted an HIV-positive Inuk who acknowledged, "I know alcohol doesn't help with our problems, our health. It'll only make it worse," identifying the link between physical health and substance use.

Two of the six cognitive maps included this sub-theme. Some noted the risk of sexually transmitted infections for people living with HIV/AIDS while others emphasized the importance of radio shows and other media for immobile community members such as the elderly, the sick, or the disabled.

Although there were slight variations in how the literature and cognitive maps framed this sub-theme, the Western scientific and Inuit knowledge reviews indicated similar

perspectives on physical health, biology, and genetics as determinants of Inuit sexual health. Both noted that one's physical health and biology, including immobility, substance abuse, or immunodeficiency due to previous or existing STIs (particularly HIV/AIDS), can directly or indirectly affect one's sexual health.

### *Popular Culture, Internet, & Other Media*

Two studies in the systematic review suggested popular culture, internet and other media can influence Inuit sexual health. In both cases, the researchers referred to the various sources of sexual health information, including television, radio, newspapers, magazines, and internet.

Three of the six cognitive maps included this sub-theme. Some Inuit highlighted the use of media such as internet and radio as a means of communication and interaction between Inuit up north and those living in the south and as a means to reach immobile community members. Inuit youth noted that “sex on TV desensitizes sex” and warned that sharing revealing photos over the internet might put youth at risk for unwanted sexual attention or activity. Internet also emerged to be an important source of sexual health information for youth (e.g. “Google it!”). Thus, Inuit linked media to issues around community cohesion, communication, physical health, social norms, and sexual abuse.

Although there was some commonality between the two reviews, overall there were important differences between the Western scientific and Inuit perspective on popular culture, internet, and other media as a determinant of Inuit sexual health. While both reviews identified the role of popular culture as a prominent source of sexual health information, Inuit participating in the cognitive maps appeared to view this sub-theme as having a broader, more complex impact on sexual health. Inuit mentioned both positive and negative aspects, noting how popular culture and media can promote community cohesion and access to information, while sometimes having an adverse effect with respect to social norms, attitudes, and even sexual violence. Internet use in Inuit communities is increasing and there are several initiatives underway that take advantage of its potential benefits, including the promotion of Inuit language, traditional knowledge and way of life.<sup>220, 221</sup> When it comes to sexual health, however, it will be important to be mindful that while internet and media can increase access to information and social support, particularly to those living in remote regions, it may also increase exposure to sexually explicit content, which has been linked to unhealthy sexual attitudes and behaviour among youth in other populations.<sup>222, 223</sup>

### *Recreation, Arts, & Leisure*

None of the studies in systematic review suggested recreation, arts, or leisure as determinants of Inuit sexual health.

Four of the six Inuit groups identified concepts around this sub-theme. In the cognitive maps, recreation, arts and leisure was interconnected with several other sexual health determinants including access to programs (e.g. “sport activities”); culturally relevant

resources (e.g. “carving program”); and physical activity (e.g. “gyms and community sporting events”). Participants believed that recreational activities are important to keep Inuit (especially youth) occupied, stressing that boredom can lead to involvement in high risk behaviours such as substance use. Research in other populations suggests this belief is founded.<sup>123-126</sup>

As this sub-theme was unique to the Inuit perspective, the two knowledge reviews did not indicate a shared view on recreation, arts, or leisure as determinants of Inuit sexual health. While this sub-theme was absent in the literature, Inuit spoke at length about how sport and leisure activities can keep youth occupied, promote self-confidence, reduce risky behaviour, and remain connected with Inuit culture and tradition. Participation in recreational activities in the community as it relates to sexual health is something that will be examined through the Inuit ACRA survey. Prior to interpretation and reporting, the study findings will be presented and discussed with local Inuit organizations. These organizations will offer a much needed insight and may find the results valuable for program planning and advocacy.

### *Research & Surveillance*

None of the studies in the systematic review suggested research or surveillance as sexual health determinants.

Three of the six Inuit groups identified concepts around this sub-theme. Inuit men and youth emphasized the benefits of research to acquire knowledge and discover new treatments for HIV and other STIs (e.g. “Statistics/risk groups awareness” and “find a cure”). Meanwhile, Inuit Elders emphasized the risks of externally-driven or culturally unsafe research and the benefits of Inuit-owned research (e.g. “Inuit community...are equal partners in research-partners. There needs to be acknowledgements for those contributing in research” and “trust-not guinea pigs-safe place”).

As this sub-theme was unique to the Inuit perspective, the two knowledge reviews did not indicate a shared perspective on research as a determinant of Inuit sexual health. Participating Inuit view research not simply as a means of acquiring new knowledge and information, but as a complex issue linked to cultural relevancy, self-determination, and trust. Scholars and communities alike have recognized distrust and culturally unsafe research practices in Inuit and other Aboriginal communities as major barriers to research and many have proposed alternative theoretical and methodological frameworks to overcome them.<sup>6, 15, 16, 23, 29</sup>

### *Social Norms, Attitudes, Role Models, & Peer Pressure*

Two studies in the systematic review of the Western scientific literature suggested social norms, attitudes, role models or peer pressure as sexual health determinants. In both cases, the authors noted the presence or absence of social norms and attitudes towards HIV/AIDS and other STIs and those infected, raising the issue of stigma and discrimination.

This sub-theme appeared to be more important from the Inuit perspective with

concepts identified by all six Inuit groups. Unlike the scientific literature, Inuit focused on how external factors, such as parents, friends, and popular culture, can affect social norms and attitudes. Participants discussed how this sub-theme relates to other determinants to influence sexual health, such as resilience (e.g. “victims who are strong – that have resilience can be a source of strength for others”) and parenting (e.g. “role model to your children”). Uniquely, youth linked this sub-theme to self-assertiveness (e.g. “do your own thing” and “don’t be a follower. Be a leader”) and pop culture (e.g. “sex on TV desensitizes sex”).

Although there was some commonality between the two reviews, overall there were important differences between the Western scientific and Inuit perspectives on this sub-theme. While both identified the role of social norms and attitudes on sexual health behaviour and outcomes, Inuit participating in the cognitive maps appeared to view this sub-theme as having a broader, more complex impact on sexual health.

### *Safe Place*

Only one study in the systematic review suggested safe place as a determinant of Inuit sexual health. The study cited Inuit youth who noted the importance of knowing “where to go to get information and help.”

Four of the six Inuit groups identified concepts related to this sub-theme. Participants talked about safe place as it relates trust in research (e.g. “trust-not guinea pigs-safe place”); social support (e.g. “mentorship-to show a safe place & someone to trust for the person affected by HIV/AIDS”); friends and family (e.g. “understanding who you can go to for help, i.e. counsellor/trusted friends or family”); and mental health (e.g. “knowing where to go to and who to turn to when diagnosed with HIV. Room to heal with guidance/direction”).

Although this sub-theme was raised in both reviews, overall it was more common and central in the cognitive maps, suggesting the participating Inuit viewed having a safe place or haven as a more complex determinant of sexual health. Safe havens may include any place where one can feel safe with a trusted friend, relative, health provider, or other support person, whether it be a community centre, school, health centre or home.

### *Safe Sex*

Four of the 22 studies in the systematic review suggested safe sex as a determinant of Inuit sexual health. The literature identified both facilitators and barriers to condom use. For example, teaching young people how to use condoms properly was identified as a facilitator to condom use while barriers included the difficulty of planning ahead and worrying that suggesting a condom would offend one’s partner or imply that they have an STI. Thus, safe sex was related to factors such as knowledge and stigma.

All six groups of Inuit identified concepts around this sub-them. As in the literature, Inuit identified barriers to condom use, such as drinking alcohol, as well as facilitators, including the provision of condoms by elders, free and easy access to condoms, and workshops and teaching on safe sex. Inuit discussed how safe sex intersects with other



determinants such as taboo (e.g. “embarrassment to get condoms”); access (e.g. “free condoms. Easily accessible”); substance use (e.g. “when drinking carry condoms to help prevent from diseases”); and education (e.g. “teaching safe sex” and “workshops on safe sex”).

Although this sub-theme was more central in the cognitive maps, overall, the Western scientific and Inuit knowledge reviews indicated similar perspectives on this sub-theme, with both identifying a link with taboo and knowledge. The prominence of safe sex in the literature and cognitive maps was nevertheless lower than expected considering it is one of the most highly recognized preventers of STI transmission. This may be the result of increased research into the more upstream sexual health determinants, acknowledging that safe sex is not always a choice.<sup>224-226</sup> Rather, there are many factors such as gender-based violence, relationship power and substance use that can influence the use of condoms and other safe sex practices. That both the Inuit and Western Scientific reviews spoke to the many barriers and facilitators of safe sex suggests the low prevalence of this sub-theme may be due to this shift in focus to the upstream determinants of sexual health.

### *Self-esteem, Assertiveness, & Responsibility*

Five of the 22 studies in the systematic review suggested self-esteem, assertiveness, or responsibility as determinants of Inuit sexual health. The scientific literature highlighted issues of denial (e.g. “I still don’t accept this disease I am carrying”), control (such as control over condom use), responsibility (such as planning ahead to use a condom), and assertiveness (e.g. “don’t be afraid to ask and speak up about sex”). One study cited Inuit women who suggested that women who engaged in risky behaviour did so as a result of low self-esteem and as a means to seek validation, particularly from men. This study also raised the issue of personal respect and ownership: “[Talking about sexual health] says a lot about personal respect . . . and I just think that it’s just a really big area that we’ve allowed to kind of run away from us, and [we] have to take that back.”<sup>75</sup> Thus, the Western scientific literature suggested links with other determinants such as safe sex and communication.

All six groups of Inuit identified concepts around this sub-theme. Inuit participants raised issues similar to those in the scientific literature, including denial (e.g. “Misconception of ‘that it will not happen to me’”), responsibility (e.g. “know your limits” and “self-education”), ownership (e.g. “Taking ownership”), and assertiveness (e.g. “asking partners to get tested”). Inuit also suggested links with parenting (e.g. “Parents taking responsibility”); education (e.g. “Self education” and “Building Inuit capacity”); testing (e.g. “Asking partners to get tested”); research (e.g. “People (Inuit community) are equal participants in research-partners”); gender (e.g. “Men do not know what their role is in the household”); and peer pressure (e.g. “Don’t be a follower. Be a leader”).

Although there was some commonality between the two reviews, overall there were important differences between the Western scientific and Inuit perspective on this sub-theme. While both identified denial, responsibility, and assertiveness as key determinants of sexual health, Inuit participating in the cognitive maps appeared to view this sub-theme as having a broader, more complex influence. In particular, issues that were unique to the Inuit

perspective included self-education, self-determination in research, assertiveness in the face of peer-pressure, personal versus parental responsibility, and the effect of changing gender roles. In other populations, research has demonstrated that self-esteem and assertiveness are well-known determinants of sexual health behaviour<sup>175-179</sup> and the cognitive maps suggest this is likely the case among Inuit in Ottawa as well.

### *Sex & Gender*

The systematic review found 14 studies that suggested sex or gender as a determinant of Inuit sexual health. Of these, 12 studies focused on sex (male or female), portraying this sub-theme as a demographic variable by which data should be stratified, i.e. as a potential confounding or modifying factor.

Four of the six Inuit groups identified concepts relating to this sub-theme. In general, Inuit viewed sex and gender in the social context of gender roles and discrimination and not simply a demographic characteristic. For example, Inuit suggested links with other determinants such as parenting (e.g. “Gender roles in parenting”); self-esteem (e.g. “Men do not know what their role is in the household”); discrimination (e.g. “Gender equality” and “There is too much discrimination to women who caught HIV from being raped”); sexual violence and justice (e.g. “Better justice system for victims of rape for safety of women and children who have been main prey”).

Overall, the Western scientific and Inuit knowledge reviews did not indicate a shared perspective on this sub-theme, with Inuit recognizing sex and gender as having a broader, more complex relationship with sexual health. While the literature focused on *sex* (male or female) as a demographic category, the cognitive maps focused more on *gender* as it intersects with issues around family life, discrimination, sexual violence, and justice to influence Inuit sexual health. Most epidemiological research stratifies results by sex, as did many studies included in this systematic review, but a full gender-based analysis is rare. A gender-based analysis framework goes far beyond a stratified analysis, recognizing that the differences between men and women are influenced by a variety of factors, including class, socio-economic status, age, sexual orientation, gender identity, race, ethnicity, geographic location, education and physical and mental ability.<sup>227-229</sup> Discussions with Inuit in Ottawa indicate that gender has a complex relationship to sexual health in this population and a full gender-based analysis would be relevant to a study such as the Inuit ACRA project.

### *Sex Trade*

The systematic review only found one study that suggested sex trade as a determinant of Inuit sexual health. This study identified “sex trade workers” as a risk group for HIV.

As in the literature, sex trade did not figure prominently in the cognitive maps. This sub-theme was only found in two cognitive maps, including the concepts “don’t use prostitutes” and “do not pay for sex (prostitutes).”

Overall, the two knowledge reviews indicated similar perspectives on sex trade as a

determinant of Inuit sexual health, identifying sex trade workers and their clients as susceptible to sexually transmitted infections. As with condom use, sex trade is widely recognized as a risk group for STI transmission and yet it did not figure prominently in this review. Again, this may reflect a shift to the upstream determinants of health as research demonstrates that entrance into sex trade work is rarely a choice, but rather a means of survival through difficult circumstances such as violence, poverty, homelessness, and drug addiction.<sup>230-233</sup>

### *Sexual Orientation*

The issue of sexual orientation was raised in only study, which identified “gay men” as a risk group for HIV.

Two of the six Inuit groups identified concepts around this sub-theme. Unlike the literature, Inuit focused on reducing stigma against homosexuality. For example, typical concepts included “Awareness of who can catch HIV. Not just gay/lesbians alone. Acknowledging the disease that anyone can catch it,” “Community acceptance of gays and lesbians,” “Be open about self if you are gay male/female and do not be ashamed,” and “stigma of being homosexual/marginalized.” Thus, Inuit discussed sexual orientation as it relates to knowledge, social norms, discrimination and self-esteem.

Overall, the Western scientific and Inuit knowledge reviews did not indicate a shares perspective on this sub-theme, with Inuit recognizing sexual orientation as having a broader, more complex relationship with sexual health. While the literature merely identified homosexuality as a risk factor for STIs, the cognitive maps emphasized the many factors that intersect with sexual orientation to influence the experiences and sexual health of homosexual men and women. This also signifies a broadening perspective on the determinants of HIV and other sexually transmitted infections. While homosexual men were among the first HIV risk groups to be identified in the early 80s, the relative significance of sexual orientation has diminished as our understanding of HIV’s complex epidemiology improves. Research shows that the role of sexual orientation in HIV transmission varies across different populations. Due to the lack of Inuit-specific research, very little is known about the distribution of HIV among Inuit in Canada.

### *Sexual Violence & Other Abuse*

Only one study in the systematic review suggested sexual violence and other abuse as a determinant of Inuit sexual health. This study cited Inuit women who believed that women living a “risk-filled lifestyle,” including drinking, partying, drug use, and high-risk sexual activity, were more likely to be exposed to situations where they might be sexually assaulted or end up in situations of violence.

Four of the six Inuit groups identified concepts related to this sub-theme. Inuit talked about sexual violence as it relates to social support (e.g. “Must have support when sexually abused. Someone to go to when raped”); mental health and healing (e.g. “Healing in all areas

related to HIV/STI or sexual activity-offering this to those affected, i.e. rape victims”); culturally relevant justice (e.g. “Inuit traditional justice used to be where a group of Inuit would isolate the molester from the community to make them understand that they have done was wrong” and “Elder intervention Programs which help with men who are troubled (molesters)”); and gender discrimination (e.g. “There is too much discrimination to women caught HIV from being raped”).

Although raised in both reviews, this sub-theme was more common and more central in the cognitive maps, where sexual violence appeared to have a broader, more complex impact on sexual health. Inuit identified several connections with other sexual health determinants including social support, healing, justice, gender, discrimination, and cultural relevancy. Research in other populations has shown women who experience violence are less able to negotiate safe sex and more vulnerable to HIV and other sexually transmitted infections.<sup>234-236</sup> Due to the sensitive nature of this issue, research on sexual violence is difficult to conduct and Inuit-specific research is especially rare.

### *Sharing Needles & Other Personal Items*

Three studies in the systematic review suggested sharing needles or other personal items as a determinant of Inuit sexual health. Two studies identified sharing needles for injection drug use as a risk factor for STI transmission, while another identified sharing needles from scarification, an Inuit traditional form of tattooing. One of the studies also discussed social attitudes and beliefs on whether HIV is transmittable through the sharing of items such as toothbrushes and toilet seats. Thus, in the literature, sharing personal items was linked to substance use, cultural traditions and social attitudes.

Three of the six Inuit groups identified concepts around this sub-theme. Participants talked about the need for needle and crack pipe exchange programs, referring to drug use and access to services. Inuit youth also warned against sharing personal items such as toothbrushes, razors, and sex toys to decrease one’s risk of sexually transmitted infection.

Although there was some commonality between the two reviews, Western science and Inuit did not appear to share a common perspective on this sub-theme. While both identified sharing needles for drug use as a risk factor for disease transmission, Inuit went further by discussing how harm reduction programs and other services may help drug users reduce their risk of infection. With little or no research available, it is difficult to determine whether and to what extent this is a concern for Inuit in Canada. The Inuit ACRA survey includes questions on this issue and the research team hopes to learn more about needle and other risky sharing practices among Inuit in Ottawa.

### *Social Support, Counselling, & Mentorship*

Only two of the studies in the systematic review identified the social support, counselling, or mentorship as determinants of Inuit sexual health. In both cases, the studies referred to the level of support from family and friends for people living with HIV/AIDS

after disclosing their HIV status.

This sub-theme figured more prominently in the Inuit review, with concepts identified by all six Inuit groups. Participants discussed how social support intersects with other factors such as community cohesion (e.g. “Support from other Inuit”); mental health (e.g. “A ‘positive’ result (STI) is mentally disturbing – someone needs to be there to provide guidance and support”); family (e.g. “Understanding who you can go to for help, i.e. counsellor/trusted friends or family”); services (e.g. “Help lines”); trust and safe places (e.g. “Mentorship – to show a safe place & someone to trust for the person affected by HIV/AIDS” and “Safe place to discuss – trust is needed, a person who is able to council/provide advice”).

Although there was some commonality between the two reviews, there were important differences between the Western scientific and Inuit perspective on this sub-theme. While both identified the need for support from family and friends for people living with HIV/AIDS, Inuit viewed this sub-theme as having a broader, more complex impact on sexual health. Research in other populations affirms that social support plays an important role in the prevention and management of HIV/AIDS and other sexually transmitted infections. There is evidence that greater social support can increase disclosure of HIV status, improve adherence to antiretroviral drug treatment, and enhance mental health and quality of life for people living with HIV/AIDS.<sup>237-239</sup> Social support may also help to prevent the transmission of sexually transmitted infections by reducing risky sexual behaviour.<sup>240, 241</sup>

### *Substance Use*

Five studies in the systematic review suggested substance use, including drug and alcohol use, as a determinant of Inuit sexual health. One study discussed substance use in the context of an unhealthy “dramatic lifestyle,” while another cited an Inuk woman who talked about regaining her strength after struggling with alcoholism. Thus, the literature linked this sub-theme with an unhealthy lifestyle and the importance of resilience.

Five of the six Inuit groups identified concepts around this sub-theme. Participants talked about drug and alcohol use as it relates to sharing needles (e.g. “don’t share needles”); access to programs (e.g. “program for safer needles/crack pipe”); family role models (e.g. “Drug use at home normalizes behaviour”); and safe sex (e.g. “When drinking carry condoms to help prevent from diseases”).

Although there was some variation in how this sub-theme was raised in the literature and cognitive maps, the Western scientific and Inuit knowledge reviews indicated similar perspectives on substance use as a determinant of Inuit sexual health. Both suggested that substance can directly increase one’s risk for infection through sharing needles or cause someone to find themselves in a dangerous situation in which their judgment or ability to assert themselves is compromised, potentially leading to sexual violence or risky sexual behaviour. There is plenty of research supporting the link between substance use and risky sexual behaviour or adverse sexual health outcomes in Aboriginal<sup>136-139</sup> and non-Aboriginal<sup>140-143</sup> populations alike; however, without culturally-specific data, it is difficult to

tailor prevention or harm reduction programs to the Inuit context.

### *Taboo, Stigma, & Discrimination*

Two studies in the systematic review suggested taboo, stigma, or discrimination as determinants of Inuit sexual health. One study focused on the stigma around condom use (e.g. insisting on using a condom with one's partner might offend them or imply that they have an STI) while the other raised the issue of stigma and discrimination towards people living with HIV/AIDS and the resulting misconceptions and intolerant attitudes. Thus, in the literature, this sub-theme was linked to safe sex and social attitudes or beliefs.

Four of the six Inuit groups identified concepts around this sub-theme. Participants talked about taboo, stigma and discrimination as it relates to education and generation (e.g. "Educating the older generation that people affected with HIV/AIDS are safe-it's okay to socialize for example"); gender-based violence (e.g. "There is too much discrimination to women who caught HIV from being raped"); sexual orientation (e.g. "Stigma of being homosexual/marginalized"); safe sex (e.g. "Embarrassment to get condoms"); access to testing services (e.g. "Mandatory testing may discourage participation"); and social support, (e.g. "Instilling values of support and acceptance").

Although there was some commonality between the two reviews, there were important differences between the Western scientific and Inuit perspective on this sub-theme. While both denounced the stigma around condom use and discriminatory attitudes towards people living with HIV/AIDS (PLHA) as barriers to good sexual health, Inuit participating in the cognitive maps viewed this sub-theme as having a broader, more complex impact. Research confirms that stigma and discrimination against PLHAs can discourage disclosure of HIV status, testing, access to needed health services, and adherence to treatment.<sup>242-245</sup> This can lead to adverse mental and physical health outcomes and compromise their ability manage their HIV/AIDS. From a prevention standpoint, stigma can hinder the success of and participation in HIV/AIDS education and awareness, safe sex, harm reduction and other prevention initiatives.<sup>244, 246, 247</sup>

### *Testing & Screening*

Seven studies in the systematic review suggested testing or screening as determinants of Inuit sexual health. Some studies viewed this sub-theme as a basic characteristic or indicator, simply recording whether study participants had undergone previous testing or screening (e.g. had a Pap test in the last 3 years). Other studies talked about this sub-theme as it relates to access (e.g. the availability of a screening program or related services); gender (e.g. the importance for women to seek regular Pap smears) and stigma (e.g. unwillingness to be tested for HIV due to the associated stigma).

Four of the six Inuit groups identified concepts related to this sub-theme. Inuit talked about testing and screening as it relates to safe places (e.g. "Testing can be intimidating"); mental health and social support (e.g. "A 'positive' result (STI) is mentally disturbing-

someone need to be there to provide guidance and support”); communication (e.g. “Asking partner to get tested”); access to services (e.g. “How to entice people to get tested?”); substance use and harm reduction (e.g. “Mandatory testing for needle-exchange programs”); and cultural relevancy (e.g. “Testing at TI or other Inuit-friendly centres”).

Although there was some commonality between the two reviews, there were important differences between the Western scientific and Inuit perspective on this sub-theme. While both encouraged the use of testing and screening programs to promote Inuit sexual health, Inuit viewed this sub-theme as having a broader, more complex impact on sexual health. Although the effect on sexual behaviour and STI incidence is debated, research supports the overall value of testing and screening. By detecting HIV and other STIs early, patients can become aware of their status, potentially reduce further transmission by informing previous and future sexual partners and practice safe sex, seek treatment when it is most effective, and ultimately slow the progression of disease.<sup>248-251</sup>

### *Trust & Respect*

Three studies in the systematic review suggested trust and respect as determinants of Inuit sexual health. One study cited an HIV-positive Inuk stressing the importance of having people who they trust and can go to for help. Another found that Inuit who were less respectful of the rights of people living with HIV/AIDS were more likely to hold certain misconceptions about HIV/AIDS. The third study cited an Inuk participant who noted “Using a condom shows you care.” Thus, in the literature, trust and respect was linked to social support, knowledge and awareness, stigma, and safe sex.

Three of the six cognitive maps included concepts related to this sub-theme. Participants talked about trust and respect as it relates to social support (e.g. “Understanding who you can go to for help, i.e. counsellor/trusted friends or family”); safe places and communication (e.g. “Safe place to discuss-trust is needed, a person who is able to council/provide advice”); culture and community cohesion (e.g. “Trust within the culture”); and research (e.g. “Trust-not guinea pigs-safe place”).

Although there was some variation in how this sub-theme was raised in the literature and cognitive maps, the Western scientific and Inuit knowledge reviews indicated similar perspectives on trust and respect as determinants of Inuit sexual health. While the literature and the cognitive maps linked this sub-theme with various other health determinants, both emphasized the importance of having a trustworthy mentor, friend, or family member to turn to for help, advice, and support.

### *Vaccines & Pharmaceuticals*

Three studies in the systematic review suggested vaccines or pharmaceuticals as determinants of Inuit sexual health. One study identified hepatitis B immunization as a predictor of HBV rates among Inuit and another examined the effectiveness of a Chlamydia and gonorrhoea treatment program. The third study identified Inuit attitudes and beliefs

around HIV treatment, including effectiveness, access, and a preference to seek treatment outside of one's community due to stigma. Thus, this sub-theme was linked to access and stigma.

Only one of the Inuit groups mentioned pharmaceuticals. Inuit youth suggested scientists "find a cure," with reference to research and development.

Overall, the Western scientific and Inuit knowledge reviews did not indicate a shared perspective on this sub-theme as a determinant of Inuit sexual health. While the cognitive maps only identified the sub-theme once, referring to pharmaceutical research, the literature focused on immunization and treatment programs and barriers to use and access.



## APPENDIX V: Additional Tables

**Table 2 Characteristics of Studies Included in Systematic Review**

Reference	Source	Study Design	Setting/Population	Outcome(s) of Interest	Quality Rating
Baikie et al. 1988 <sup>69</sup>	Healthstar Medline	Cross-sectional seroepidemiological survey (quantitative)	Residents of various Northern Labrador communities	Hepatitis B Virus	Weak
Baikie et al. 1989 <sup>70</sup> (based on Baikie et al. 1988)	Embase Healthstar Medline	Cross-sectional seroepidemiological survey (quantitative)	Residents of various Northern Labrador communities	Hepatitis B Virus	Weak
Cole 2004 <sup>71</sup>	Healthstar Medline	Cross-sectional survey (quantitative)	High school and college students in Iqaluit, Nunavut	Knowledge, attitudes and behavior around sexual health, including STIs	Weak
Hamlin-Douglas et al. 2008 <sup>72</sup>	Global Health Embase Healthstar Medline	Cross-sectional epidemiological survey (quantitative)	Inuit women in various communities in Nunavik, Quebec	Human Papillomavirus	Weak
Hamlin-Douglas et al. 2010 <sup>73</sup> (based on Hamlin-Douglas et al. 2008)	Embase Global Health CINAHL	Cross-sectional epidemiological survey (quantitative)	Inuit women in various communities in Nunavik, Quebec	Human Papillomavirus	Weak
Healey et al. 2001 <sup>74</sup>	Bibliography Scan	Cross-sectional epidemiological survey (quantitative)	Inuit women in various communities in Nunavut	Human Papillomavirus	Weak
Healey 2008 <sup>75</sup>	Grey Literature Search	In-depth interviews (qualitative)	Inuit women in a Nunavut community	Health and well-being, including sexual health and STIs	Strong
Healey nd <sup>76</sup> (based on Healey 2008)	Grey Literature Search	In-depth interviews (qualitative)	Inuit women in a Nunavut community	Health and well-being, including sexual health and STIs	Strong
Hildes 1959 <sup>77</sup>	Embase	Cross-sectional seroepidemiological survey (quantitative)	Inuit in various eastern arctic communities, Canada (mainly Baffin Island, Nunavut)	Herpes Simplex Virus (among other non-STI viruses)	Weak
Hodgins et al. 2002 <sup>78</sup>	Healthstar Medline	Randomized intervention trial (quantitative)	Residents of various remote communities in Nunavik, Quebec	Chlamydia	Weak
Kordova et al. 1983 <sup>79</sup>	Medline	Cross-sectional seroepidemiological survey (quantitative)	Residents of Baker Lake, Nunavut	Chlamydia	Weak
Larke et al. 1982 <sup>80</sup>	Bibliography Scan	Cross-sectional seroepidemiological survey (quantitative)	Residents of Arctic Bay and Nanisivik, Nunavut	Hepatitis B Virus	Weak
Larke et al. 1984 <sup>81</sup>	Bibliography Scan	Cross-sectional seroepidemiological survey (quantitative)	Residents of various communities in the Baffin Zone, Nunavut	Hepatitis B Virus	Weak
Larke et al. 1987 <sup>82</sup>	Bibliography Scan	Cross-sectional seroepidemiological survey (quantitative)	Residents of various communities in Northwest Territories (including Inuvialuit and Nunavut)	Hepatitis B Virus	Weak
Minuk et al. 1982 <sup>83</sup>	Bibliography Scan	Cross-sectional seroepidemiological survey (quantitative)	Residents of Baker Lake, Nunavut	Hepatitis B Virus	Weak
Minuk et al. 1985 <sup>84</sup>	Global Health Embase	Cross-sectional seroepidemiological survey (quantitative)	Residents of Chesterfield Inlet, Nunavut	Hepatitis B Virus	Weak

	Healthstar Medline				
Minuk et al. 2000 <sup>85</sup>	Healthstar Medline	Cross-sectional seroepidemiological survey (quantitative)	Residents of various Inuit communities in Nunavut	Pre-core mutant variant of Hepatitis B Virus	Weak
Minuk et al. 2005 <sup>86</sup>	Embase Healthstar Medline	Cross-sectional seroepidemiological survey (quantitative)	Residents of Baker Lake, Nunavut	Occult Hepatitis B Virus	Weak
Nicolle et al. 1986 <sup>87</sup>	Global Health Embase Healthstar Medline	Cross-sectional seroepidemiological survey (quantitative)	Residents of Chesterfield Inlet, Nunavut	Cytomegalovirus and Herpes Simplex Virus	Weak
O'Leary et al. 2010 <sup>88</sup>	Global Health Healthstar Medline	Mathematical model using epidemiological datasets (quantitative)	Inuit population, Canada (region not specified)	Hepatitis B Virus	n/a
Preiksaitis et al. 1988a <sup>89</sup>	Healthstar Medline	Cross-sectional seroepidemiological survey (quantitative)	Residents of various communities in Northwest Territories (including Inuvialuit and Nunavut)	Cytomegalovirus	Weak
Preiksaitis et al. 1988b <sup>90</sup> (based on Preiksaitis et al. 1988a)	Embase Healthstar Medline	Cross-sectional seroepidemiological survey (quantitative)	Residents of various communities in Northwest Territories (including Inuvialuit and Nunavut)	Cytomegalovirus	Weak
Steenbeek 2005 <sup>91</sup>	Grey Literature Search	Cross-sectional epidemiological survey and prospective cohort study (quantitative)	Inuit residents of a community in Baffin Region, Nunavut	Chlamydia and Gonorrhoea	Weak
Steenbeek 2009 <sup>92</sup> (based on Steenbeek 2005)	CINAHL Global Health Embase Healthstar Medline	Cross-sectional epidemiological survey and prospective cohort study (quantitative)	Inuit residents of a community in Baffin Region, Nunavut	Chlamydia and Gonorrhoea	Weak
CAAN 2008a <sup>93</sup>	Grey Literature Search	Cross-sectional survey (quantitative)	Aboriginal Peoples Living with HIV/AIDS (APLAs) across Canada (location of Inuit participants not specified)	Treatment, care and support for APLAs	Weak
CAAN 2008b <sup>94</sup>	Grey Literature Search	Focus groups, semi-structured interviews (qualitative)	Aboriginal Peoples Living with HIV/AIDS (APLAs) across Canada (Inuit participants recruited in southern urban centres)	APLAs' perceptions & experiences of health care	Weak
PHAC 2006 <sup>95</sup>	Grey Literature Search	Cross-sectional survey (quantitative)	Aboriginal Peoples across Canada, including Inuit in Northwest Territories, Nunavut, Nunavik, & Labrador	Attitudes Towards HIV/AIDS	Weak

**Table 2 Themes and Sub-themes Identified in the Scientific Literature**

	Baillie et al. 1988 <sup>69</sup> , 1989 <sup>70</sup>	Cole 2004 <sup>71</sup>	Hamlin-Douglas et al. 2008 <sup>72</sup> , 2010 <sup>73</sup>	Healey et al. 2001 <sup>74</sup>	Healey 2008 <sup>75</sup> , nd <sup>76</sup>	Hildes 1959 <sup>77</sup>	Hodgins et al. 2002 <sup>78</sup>	Kordova et al. 1983 <sup>79</sup>	Larke et al. 1982 <sup>80</sup>	Larke et al. 1984 <sup>81</sup>	Larke et al. 1987 <sup>82</sup>	Minuk et al. 1982 <sup>83</sup>	Minuk et al. 1985 <sup>84</sup>	Minuk et al. 2000 <sup>85</sup>	Minuk et al. 2005 <sup>86</sup>	Nicolle et al. 1986 <sup>87</sup>	O'Leary et al. 2010 <sup>88</sup>	Preksaitis et al. 1988a <sup>89</sup> , b <sup>90</sup>	Steenbeek, 2005 <sup>91</sup> , 2009 <sup>92</sup>	CAAN 2008a <sup>93</sup>	CAAN 2008b <sup>94</sup>	PHAC 2006 <sup>95</sup>	TOTAL	
Age	+	+	+	+	+	+	+	+	+	+	-	+	+	+	+	+	+	+	+	-	-	+	18	
Sex	+	-	-	-	+	+	+	+	+	+	-	+	+	+	+	+	-	+	+	-	-	-	+	14
Geographic Location	+	-	+	+	-	+	-	-	+	+	+	-	+	-	-	-	-	-	-	-	-	-	-	8
Knowledge	-	+	+	+	+	-	-	-	-	-	-	-	-	-	-	-	-	-	+	+	+	+	7	
Use of Resources	-	-	-	-	-	-	+	-	-	-	-	-	-	-	-	-	+	-	+	+	+	+	6	
Parenting	-	+	+	-	+	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	5	
Socioeconomic Factors	-	-	+	+	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	-	-	-	4	
Culture	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	-	-	2	
Culturally Relevant Resources	-	+	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	+	+	4	
Discrimination	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	-	-	+	2	
Popular Culture	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	-	-	-	2	
Social Norms	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	-	-	+	2	
Safe Place	-	+	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	
Community Cohesion	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	1	
Sexual Orientation	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	
Sexual Violence	-	-	-	-	+	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	
Colonization	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0	
Justice	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0	
Research	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0	
<b>Structural/demographic Factors (total)</b>	<b>3</b>	<b>5</b>	<b>5</b>	<b>4</b>	<b>5</b>	<b>2</b>	<b>3</b>	<b>2</b>	<b>3</b>	<b>3</b>	<b>1</b>	<b>3</b>	<b>3</b>	<b>2</b>	<b>2</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>8</b>	<b>3</b>	<b>5</b>	<b>11</b>	<b>78</b>	
Testing	-	+	+	-	-	-	+	-	-	-	-	-	-	-	-	-	+	-	+	-	+	+	7	
Communication	-	+	-	-	+	-	-	-	-	-	-	-	-	-	-	-	-	-	+	+	+	+	6	
Abstinence	-	+	+	-	+	+	-	-	-	-	-	-	-	-	-	-	-	-	+	-	-	-	5	
Substance Use	-	-	+	-	+	-	-	-	-	-	-	-	-	-	-	-	-	-	+	-	+	+	5	
Safe Sex	-	+	+	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	-	-	+	4	
Healthy Lifestyle	-	+	+	+	+	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	4	
Multiple Partners	-	-	+	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	-	-	+	3	
Pharmaceuticals	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	-	-	-	-	-	3	
Sharing Personal Items	-	-	-	-	-	-	-	-	-	-	-	+	-	-	-	-	-	-	+	-	-	-	3	
Sex Trade	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	1	
Recreation	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0	
<b>Behavioural Factors (total)</b>	<b>0</b>	<b>5</b>	<b>6</b>	<b>1</b>	<b>4</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>2</b>	<b>0</b>	<b>8</b>	<b>1</b>	<b>3</b>	<b>9</b>	<b>41</b>	
Self-Esteem	-	+	-	-	+	-	-	-	-	-	-	-	-	-	-	-	-	-	+	-	+	+	5	
Mental Health	-	+	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	+	-	3	
Trust	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	-	+	+	3	
Social Support	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	+	2	
Resilience	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	-	1	
Adaptation to Change	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0	
<b>Psychosocial Factors (total)</b>	<b>0</b>	<b>2</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>2</b>	<b>1</b>	<b>5</b>	<b>3</b>	<b>14</b>		
Biology	-	-	+	-	-	-	-	-	-	-	-	-	-	+	+	-	-	-	+	-	+	-	5	
<b>Biological &amp; Genetic Factors (total)</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>5</b>	
<b>TOTAL</b>	<b>3</b>	<b>12</b>	<b>12</b>	<b>5</b>	<b>10</b>	<b>2</b>	<b>4</b>	<b>2</b>	<b>3</b>	<b>3</b>	<b>1</b>	<b>4</b>	<b>3</b>	<b>3</b>	<b>3</b>	<b>2</b>	<b>3</b>	<b>2</b>	<b>19</b>	<b>5</b>	<b>14</b>	<b>23</b>	<b>138</b>	