

ABORIGINAL ENVIRONMENTAL HEALTH ISSUES

Researchers' and Decision-Makers' Perceptions of Knowledge Transfer and Exchange Processes

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CONTENTS



	Executive Summary	6
I.	Background Information	9
II.	Environmental Scan Objectives	10
III.	Methods	11
A.	Sample and Recruitment	11
B.	Data Collection	13
C.	Data Analysis	13
D.	Member Checking	13
IV.	Environmental Scan Results	15
A.	Sample Description	15
B.	Factors Influencing Knowledge Transfer and Exchange	17
1.	Development of Relationships to Facilitate Research Processes	17
2.	Perceptions of the Environmental Health Research Process	20
3.	Integration of Empirical Research and Traditional Knowledge	24
4.	Barriers and Facilitators to the Utilization of Research Evidence in Decision Making	26
C.	Key Elements to Promote Knowledge Transfer and Exchange	27
1.	Crafting Key Messages	27
2.	Selecting Credible Messengers	27
3.	Communication Channels and Dissemination Strategies	28
D.	Recommendations for Researchers Conducting Environmental Health Research in Collaboration with Aboriginal Communities	29
V.	Discussion	31



EXECUTIVE SUMMARY



Background Information

Environmental health policy is commonly developed to promote health and human well-being in our communities and to reduce preventable injuries and diseases caused by physical, chemical or biological hazards in outdoor and indoor environments. The development of environmental health policies is a highly political process and policy outcomes have diverse and varied impacts on individuals, groups, economic interests, and geographic regions.

Globally there is increasing momentum to utilize research evidence derived from Western scientific methods and to adopt 'evidence-informed' or 'evidence-based' policy development processes in lieu of 'opinion-based' policy (Segone, 2008). Significant resources and time are invested in the production of research-based knowledge that, if effectively transferred to decision makers, could be used to inform policy and practice decisions and subsequently improve population health outcomes (Lavis et al., 2003). It has been documented, however, that there are significant time lags between the points of knowledge creation and its utilization in decision-making (Graham et al., 2006). Within the context of conducting environmental health studies within

Aboriginal communities, the opportunity to utilize Traditional Knowledge in decision-making processes also exists.

One of the goals of the National Collaborating Centre for Aboriginal Health (NCCAH) is to support the development of public health practices and policies through knowledge translation and knowledge exchange. To achieve this goal, identification and understanding of the sources and types of knowledge, and the various communication channels that are valued and utilized by both researchers and decision-makers within Canadian Aboriginal health settings, is required. The interplay between research evidence, often developed and guided based on the philosophic perspectives of Western researchers, and Indigenous Traditional Knowledge and their influences on policy development are not well understood and also require exploration.

Environmental Scan Objectives

To gain insight into the current state of knowledge transfer and exchange (KTE) processes within the field of Aboriginal Environmental Health, the NCCAH funded and collaborated on this environmental scan to identify and describe the processes by which

environmental health researchers and decision-makers working with Aboriginal communities can communicate and share different types of evidence related to environmental health issues affecting First Nations, Métis and Inuit populations.

The specific objectives of the environmental scan were to:

1. Identify the challenges and opportunities for translating and exchanging different types of knowledge (research and traditional) between environmental health researchers and internal and external decision-makers working with Aboriginal communities.
2. Identify the different communication channels used to disseminate and retrieve different types of evidence and identify sources of knowledge effectively used by the different stakeholder groups.
3. Identify factors that influence the research utilization in decision-making processes.

Methods

Using the principles of fundamental qualitative description, intensity sampling was used to identify and recruit three groups of stakeholders recognized as experts in their fields:

1. Environmental health researchers (n=10)
2. Decision-makers employed within Provincial/Territorial or Federal Departments responsible for portfolios relevant to environmental health (n=9 external decision-makers)
3. Individuals responsible for developing, implementing or coordinating environmental health policies or programs within Aboriginal communities (n=9 internal decision-makers)

Each participant was interviewed in a face-to-face or telephone interview and the resulting data was analyzed using directed content analysis.

Factors Influencing Knowledge Transfer and Exchange (KTE)

Two essential elements are required to facilitate the successful transfer and exchange of evidence between the knowledge producers and decision-makers at all levels. Whether the evidence is derived from empirical studies or from Traditional Knowledge, it is necessary that:

1. Relationships characterized by trust, respect, empowerment and equity must be initiated and nurtured; and
2. KTE activities need to be negotiated and implemented throughout the entire course of the research process.

Within the context of Aboriginal communities, participatory action research (PAR) methods were highlighted as ideal models for the conduct of environmental health research. This collaborative approach to research that emphasizes shared power and decision-making throughout the research process is further discussed in the CIHR Guidelines for Health Research Involving Aboriginal People (CIHR, 2007). Such methods provide multiple benefits including:

1. Providing communities with opportunities to identify and refine research questions that address priority community concerns;
2. Providing opportunities for communities to develop their own research capacity; and
3. Facilitating the integration of KTE activities throughout the project.

Given that both Aboriginal communities and researchers associated with government agencies or universities invest significant resources in the production of research evidence using Western scientific methods, there is a need to ensure that these findings are effectively translated and shared with different audiences of decision-makers, including Aboriginal communities. To facilitate this process, researchers need to develop skills in crafting key messages emerging from their studies, must be able to identify credible messengers to deliver the findings, and need to be able to identify effective communication channels and dissemination strategies to share the information, for as one researcher commented, “lengthy reports just gather dust.”

Across this environmental scan, core factors for promoting KTE, particularly in the transfer of scientific data to Aboriginal communities, were identified. The primary recommendations focused on developing communication strategies at the beginning of the project and integrating KTE strategies throughout the research project, particularly by involving local community members in the planning and conduct of the research. It is also essential for researchers to identify cultural brokers, individuals with knowledge of both local community values and beliefs and the skill to interpret scientific data, to act as bridges between researchers and communities (Jezewski, 1990). Cultural brokers play pivotal roles in both assisting with the

crafting of key messages and disseminating information to the community.

Given the complexity of the language of environmental health work, there is a specific need to translate the technical jargon of environmental health studies into lay language. To increase the relevance of the data it is also important, whenever possible, to tailor the messages and highlight the local relevance of the findings. Specific to environmental health findings, it is particularly salient for stakeholders to recognize that these issues are easily politicized and that messages should present a balance of information. Any messages highlighting environmental risks to communities must be carefully crafted and shared first with the community.

In regards to communication channels and dissemination strategies, it was recognized that strategies need to be identified that are specific to each community. However, the common elements of the recommendations included:

1. Releasing results first to the community prior to disclosure to other target audiences; and
2. Utilizing multiple approaches, including interactive face-to-face strategies supported by Internet or paper-based communication tools

There was also support for use of materials with visual graphics or images of the natural world.

¹‘Aboriginal’ is used throughout this report to refer to all groups of First Nations, Inuit and Métis peoples of Canada collectively.



I. BACKGROUND INFORMATION



Environmental health policy is commonly developed to promote health and human well-being in our communities and to reduce preventable injuries and diseases caused by physical, chemical, or biological hazards in outdoor and indoor environments. The development of environmental health policies is a highly political process and policy outcomes have diverse and varied impacts on individuals, groups, economic interests and geographic regions. In some jurisdictions, environmental health issues such as water quality or food inspection have been perceived to be ‘falling through the cracks’ because of a lack of clarity about which level of government is responsible for addressing specific environmental health hazards. Globally there is increasing momentum to utilize research evidence derived from Western scientific methods and to adopt ‘evidence-informed’ or ‘evidence-based’ policy development processes in lieu of ‘opinion-based’ policy (Segone, 2008). Significant resources and time are invested in the production of research-based knowledge that, if effectively transferred to decision makers, could be used to inform policy and practice decisions and subsequently improve population health outcomes (Lavis et al., 2003). It has been documented, however, that there are significant time lags between the points of

knowledge creation and its utilization in decision-making (Graham et al., 2006).

Additionally, in the adoption of ‘evidence-informed’ decision-making there is an interesting paradox in that different stakeholder groups have unique definitions of what constitutes “evidence.” Researchers tend to define evidence as knowledge systematically developed using the scientific process whereas individuals responsible for practice, managerial, or policy decisions more broadly define evidence to include scientific research and locally relevant information (Lomas et al., 2005). Many Aboriginal environmental health issues are interesting case studies as decision-makers in public and private sectors have worked to develop strategies for integrating both research evidence and Traditional Knowledge (TK). This has occurred particularly in regard to nutrition and health, conservation, land and resource management, and environmental assessment projects (Ellis, 2005; Mauro & Hardison, 2000; Milburn, 2004; Wahbe et al., 2007). Ellis (2005) defines Traditional Knowledge as “a cumulative, collective body of knowledge, experience, and values held by societies with a history of subsistence” (p. 66). In the literature, Traditional Knowledge may also be referred to as Traditional Aboriginal Knowledge,

Traditional Indigenous Knowledge or more specifically, First Nations Traditional Ecological Knowledge (TEK) (Houde, 2007) and Inuit Qaujimagatuqangit (IQ) (Bird, 2006) referring to Inuit knowledge about the land and environment.

One of the goals of the National Collaborating Centre for Aboriginal Health (NCCA)H) is to support the development of public health practices and policies through knowledge translation and knowledge exchange. To achieve this goal, identification and understanding of the sources and types of knowledge, and the various communication channels that are valued and utilized by both researchers and decision-makers within Canadian Aboriginal health settings, is required. The interplay between research evidence, often developed and guided based on the philosophic perspectives of Western researchers, and Indigenous Traditional Knowledge, and their influences on policy development are not well understood and also require exploration.

II. ENVIRONMENTAL SCAN OBJECTIVES



To gain insight into the current state of knowledge transfer and exchange (KTE) processes within the field of Aboriginal Environmental Health, the NCCAH funded and collaborated on this environmental scan to identify and describe the processes by which environmental health researchers and decision-makers working with Aboriginal communities can communicate and share different types of evidence related to environmental health issues affecting First Nations, Métis and Inuit populations. For the purposes of this environmental scan, a formal definition of “environmental health” was not provided to participants. Instead, participants determined their own definitions and responses including such diverse issues as the effects of second hand smoke, mould in housing, contaminants in food and airborne toxins.

The specific objectives of the environmental scan were to:

1. Identify the challenges and opportunities for translating and

exchanging different types of knowledge (research and traditional) between environmental health researchers and internal and external decision-makers working with Aboriginal communities.

2. Identify the different communication channels used to disseminate and retrieve different types of evidence and identify sources of knowledge effectively used by the different stakeholder groups to develop environmental health policies and programs.
3. Identify factors that influence the utilization of research evidence by individuals involved in making decisions around environmental health policies.

Permission to conduct this environmental scan was received from both the McMaster Faculty of Health Sciences/Hamilton Health Sciences Research Ethics Board and the University of Northern British Columbia Research Ethics Board.



III. METHODS

To understand the unique perspectives that different decision-making actors hold about factors that influence KTE processes, it was determined that a qualitative approach would provide us with the tools to select a sample of expert key informants and conduct an in-depth exploration of their experiences and perspectives. The principles of fundamental qualitative description (Sandelowski, 2000) were utilized to guide decisions around sampling, data collection, and analysis. This type of qualitative approach has been used to provide a comprehensive summary of facts and events, using the ‘everyday’ language of the participants, and has commonly been implemented by researchers and evaluators who require answers to questions about specific events or phenomena (Sandelowski, 2000).

A. Sample and Recruitment

KTE strategies generally involve the communication of information from one

type of actor to another, or the exchange of information between different groups. Most KTE models and concepts are focused primarily on identifying effective and efficient approaches for moving Western scientific research evidence from researchers into decision-making processes used by front-line professionals, administrators and policy analysts.

Wingens (1990) argues that these models have historically been influenced by the ‘two-communities’ theory in that researchers and decision-makers work and function in different cultures with distinct and sometimes conflicting values, beliefs, norms, ways of thinking, language and knowledge. The cultural differences between the two different environments are often used as a rationale to explain the non-utilization of research evidence in decision-making. This two-community theory is illustrated in Smylie et al.’s (2003) description that following the passing of the Indian Act, “health researchers and policy makers were external to Aboriginal



communities, and largely employed by the Federal government” (p. 142). However, in the current context of Aboriginal self-governance, increasingly more health policy makers are sought and employed internally, which has essentially created ‘three communities.’

Given the identification of these three unique groups of stakeholders, we made the decision to purposefully sample individuals from three distinct groups: 1) environmental health researchers (researchers); 2) external environmental health decision-makers working at Provincial/Territorial or Federal levels of government (external decision-makers); and 3) environmental health policy makers employed internally by an Aboriginal community (internal decision-makers). To ensure that we would be able to capture in-depth and rich descriptions of the current state of KTE with respect to environmental health issues impacting Canadian Aboriginal

communities, intensity sampling was used. Intensity sampling is a sub-type of purposeful sampling where information-rich participants are identified who can provide a comprehensive description of the phenomenon under study and who can provide multiple examples about barriers, and facilitating influences (Patton, 1990). Using this sampling strategy, we identified and recruited researchers and decision-makers who were well connected to the field and who were recognized either nationally or within their local jurisdictions as experts in the transfer, utilization and uptake of different types of evidence in developing environmental health policies and programs in Aboriginal communities. To achieve data saturation, we estimated recruiting a total sample of 30 individuals into the study, with 10 participants in each of the three sub-categories of participants. The inclusion criteria for the study were: 1) confirmation of experience conducting environmental health research with

Aboriginal communities OR employed in a role as an external or internal decision-maker involved in the development or implementation of environmental health policies impacting Aboriginal communities; and 2) the ability to speak and read English. It was also the intent of the research team to identify participants from different geographical regions across Canada and who worked with different Aboriginal cultures (e.g. First Nations, Inuit or Métis).

Dr. Chris Furgal, Indigenous Environmental Studies, Trent University, and the NCCAH both assisted with the development of an initial list of potential participants, particularly researchers and external decision-makers, who met the above criteria. Ms. Tara Marsden, past Research Associate, NCCAH, also assisted in the identification and the personal recruitment of internal decision-makers. In addition, a process of snowball sampling was also utilized,

whereby at the end of each interview, the study participant was invited to recommend an 'expert' in the field who he/she perceived would have valuable experiences and information to share about KTE. Additionally, to facilitate the process of identifying and recruiting internal decision-makers, a list of key contacts for the Provincial Territorial Organizations affiliated with the Assembly of First Nations was developed and members meeting the inclusion criteria were invited to participate. All potential study participants initially received an email inviting them to participate in the environmental scan. The project staff (Amy Montour and Sandy Brooks) then followed up the email with telephone contact(s) to explore and then confirm the individual's interest in participating.

B. Data Collection

All participants provided informed consent, indicating their agreement to participate in the environmental scan. Each participant completed an in-depth, semi-structured interview facilitated by one of two project assistants (AM and SB). The interviews lasted approximately 60-90 minutes and permission to audio-record each interview was requested. Primary data were collected between August 2008 and May 2009; member checking was conducted between August and November 2009.

To specifically capture the unique differences in activities conducted by researchers and decision-makers, two distinct semi-structured interview guides (Appendix A) were developed using concepts from the knowledge transfer theoretical framework developed by Lavis and colleagues (2003). Additional questions were also added to explore the nature of utilizing or integrating Traditional Knowledge into the decision-making processes. As the environmental scan progressed, the interview guides were adapted to facilitate the exploration of

new or unique themes that were emerging. Participants were also asked to complete a short demographic questionnaire. Additionally, participants were requested to share (if available) relevant documents that illustrated past or current KTE activities. In appreciation of his/her time, each participant was given an honorarium in the form of a \$25.00 gift card to the Chapters/Indigo online bookstore.

C. Data Analysis

All of the recorded data were transcribed verbatim. The principles of directed content analysis (Hsieh & Shannon, 2005) guided the coding and analysis of each transcript. Each individual transcript was cleaned by one of the two project assistants and then read in full by one of the two project assistants and by Dr. Susan Jack (SJ). Initial coding categories were determined by using the questions and core concepts from the interview guide. Each transcript was reviewed and data were coded and grouped into these pre-determined categories. New ideas and concepts that emerged in the course of the interview resulted in the development of novel categories. A brief summary of the key findings, grouped by category, was developed for each transcript. A small sample of these summaries, along with a copy of the original transcript, were sent

to two of the other project collaborators (MD, CF) so they could confirm that no key findings had been omitted from the summaries. Data coded to the categories were then synthesized by participant subgroup and compared across participant groupings. Throughout the report, numerous direct quotes are used to illustrate core concepts that emerged from the data and to give voice to the different, and complementary, perspectives across stakeholders.

D. Member Checking

Once data collection and analysis was completed, a process of member checking was undertaken. Member checking is a technique used to promote data credibility. In this process, the interpretation of the participant's interview data is shared back to the participant, who then has the opportunity to comment on the accuracy of the interpretation. The Final Report and Executive Summary were sent to all 28 study participants via email. They were asked to provide feedback, either through a second telephone interview or in writing, on the study findings and to share their impressions of the interpretation of the data. At least two attempts (one by telephone, one by email) were made to contact each participant.







IV. ENVIRONMENTAL SCAN RESULTS

A. Sample Description

A sample of 28 Canadian environmental health researchers, internal and external decision-makers participated in this environmental scan. Overall, 22 researchers, 12 external decision-makers, and 45 internal decision-makers were invited to participate in the environmental scan. Despite the utilization of multiple recruitment strategies and frequent attempts to contact potential participants by email and telephone, we experienced a high rate of 'lack of response' from individuals approached (see Table 1 next page). Reasons given for declining to participate included:

1. lack of time
2. perceived lack of expertise in the topic or
3. currently on leave or sabbatical from current position

This sample consisted of 10 researchers, nine external decision-makers and nine internal decision-makers. Individuals

who consented to participate were geographically located in six different provinces. Given the different geographical regions that the participants represented, the majority of the interviews (n=26) were conducted by telephone. At the request of two participants, two of the interviews were conducted face-to-face. One participant also chose to provide written responses to the questions posed in addition to completing the interview.

A total of 15 participants responded to the request for feedback during the member checking process. Two of these respondents (one researcher and one internal decision-maker) stated they would be unable to provide input on the findings due to workloads and the timeframe involved. Four researchers, five external decision-makers and five internal decision-makers shared their thoughts and impressions about emerging interpretations of the data. The majority of the participants confirmed the accuracy of the data, had generally

Table 1. Stakeholder Response to Invitation to Participate

Stakeholder Group	Invited	Consented to participate/interview completed	Declined	# agreed to participate but did not follow through//confirm date for interview	No response to email or telephone invitations
Researchers	22	10	9	0	3
External decision-makers	12	9	0	2	1
Internal decision-makers	45	9	11	8	17

positive reactions to the report and expressed their appreciation of being asked to provide further input. Several participants commented that it was very helpful to have all the issues and different perspectives synthesized in one document. Participants from each of the three groups of stakeholders commented that the importance of the relationship between researchers and decision-makers was clearly captured and described, and that they were pleased to see the focus on integrating empirical evidence and Traditional Knowledge. The researchers who responded confirmed that the findings were validating for them and reflective of their experiences; however, they felt more emphasis should be put on the importance of involving the community in the crafting of key messages and the use of visual means of disseminating research findings. One researcher commented that he was quite familiar with the perspectives of the internal decision-makers but was pleasantly surprised to see the insights of the external decision-makers that were

presented in the data. Within the external decision-maker group, there was agreement that the themes were reflected accurately, with a strong focus on communication and collaboration strategies. Among the internal decision-makers there was consensus that the findings were accurate; however, it was suggested that issues of consent and confidentiality could be addressed more fully.

Overall, the participants had an average of 14 years of experience in their current positions (Table 2), so this purposeful sample was well positioned to provide in-depth descriptions about the utilization of research evidence in the field of environmental health and to provide commentary about the environmental, political and social factors influencing research and TK access, utilization and uptake in the development of environmental health policy impacting Aboriginal communities. This level of experience also facilitated their abilities to describe individual factors influencing research utilization.

The researchers conducted studies in a broad range of fields on a variety of relevant topics including: ocean science, fisheries and marine science, environmental health, risk assessments, health services, anthropology, environmental contaminants and human toxicology, pharmacology, northern climate change and contaminants, and natural resource and wildlife management.

All of the external decision-makers who participated were employed at a manager level or higher within their respective departments; nine of the external decision-makers worked within a Federal agency or department and one external decision-maker worked within a Provincial Ministry. All of these decision-makers confirmed that they were responsible for developing or implementing either environmental health policy for First Nations or Inuit communities, conducting environmental impact assessments, or coordinating relevant national programs. The nine internal decision-makers were employed by, and working within, First

Table 2. Demographic Characteristics

Stakeholder Group	Gender	Mean Age (range)	Mean years experience in current position
Researchers (N=10)	Male n=5 (50%) Female n=5 (50%)	47 years (38-67)	14 (8-23)
External decision-makers (N=9)	Male n=7 (78%) Female n=2 (22%)	52 years (36-65)	16 (5-38)
Internal decision-makers (N=9)	Male n=5 (56%) Female n=4 (44%)	47 years (27-65)	11 (1-35)

Nations or Inuit communities in roles responsible for analyzing environmental health policy or implementing programs impacting environmental health outcomes. No internal decision-makers working specifically with Métis communities were identified or agreed to participate in the study.

B. Factors Influencing Knowledge Transfer and Exchange (KTE)

Two essential elements are required to facilitate the successful transfer and exchange of evidence between the knowledge producers and decision-makers at all levels. Whether the evidence is derived from empirical studies or from Traditional Knowledge, it is necessary that:

1. Relationships characterized by trust, respect, empowerment and equity must be initiated and nurtured; and
2. KTE activities need to be negotiated and implemented throughout the entire course of the research process.

1. Development of relationships to facilitate research processes

“That relationship-building between the researcher and the community has really been key to having the communities accept the research that is produced.”

-Federal Government Manager

For successful KTE to occur, relationships at all levels must be initiated and nurtured throughout a research project. This includes relationships between Federal/Provincial/Territorial departments and regional Aboriginal organizations, and between the leadership and members of Aboriginal communities and the research teams who conduct studies within these areas. There was consensus among all 28 participants in the environmental scan that researchers interested in conducting studies within Aboriginal territories must seek consent from community leadership, engage community members in the process and through the act of relationship building, and identify opportunities to develop community capacity to participate in or conduct their own research. It was also consistently acknowledged that this process required researcher presence in the community, which often took a lengthy period of time and was not accomplished without a great deal of patience. Without a relationship built on trust however, the researcher runs a significant risk of not having access to the community and will lack the necessary permission to collect data.

Internal decision-makers highlighted that it is vital for researchers to understand that each Aboriginal community is unique and may, therefore, have their own specific protocols and etiquette

for the conduct of research. As a basic foundation, internal decision-makers identified that researchers generally need to seek permission to conduct research from the Chief or Band Council. Gaining entry to a community can be facilitated by identifying and connecting with a trusted community member who can act as a guide and introduce the research team to the community leadership such as the Chief and Council, the Elders’ Council or the Matriarch of Women.

It is important for the researcher to physically travel to the community, meet face-to-face with community leadership and members, and introduce him/herself by providing both personal and professional background information. It was explained that often researchers try to establish their credibility by describing their links with different universities or government departments or by listing their degrees. However, several internal-decision makers explained that greater credibility is gained by sharing information about one’s personal self, family and community. This assists members of the Aboriginal community in creating cognitive maps to understand how the researcher is connected to others. Meeting face-to-face also assists in breaking down any suspicions held about the researcher. Often early meetings are quite social in nature and are intended





to explore how a potential project can meet the needs of the community. As one participant explained it, however, this “takes a lot of investment, but they [the researchers] realize they really simply have to keep going back.” This is a significant challenge, especially for new investigators, because at the study proposal stage, they often lack the funds to travel to a community to explore its interest in participating.

A strong relationship between researchers and a community will provide benefits to both groups. One internal decision-maker commented that having a good relationship with the community is cost effective as it can result in a more efficient use of limited grant money. If the community sees that a researcher is committed and willing to work for their benefit, they are more likely to provide “in kind” types of support and services. Another internal decision-maker shared that a researcher’s contribution to helping the community resolve a question or concern about the environment will be balanced by community leadership

promoting participation in the study and by identifying key social networks. It is essential for the relationships to be characterized by respect, equity and empowerment. One internal-decision maker, with extensive experience working with researchers and government agencies, provided these examples of relationships not balanced with respect, equity or empowerment:

If I get a university coming to me and saying, “Boy, we really like Native people, they are just so wonderful. We want to work with you.” Oh boy and then you say to them, “Well do you have any money?” They go, “No.” “And when you’re done, will we have a new palisade built?” And they say, “No.” You say, “Oh fine.” You’re treating us like little children. You respect us greatly and think we’re wonderful but you’re not, you’re not giving any equity and you’re not giving any empowerment. So I’m sorry I don’t want to work with you. If you say ... I’ll give you another example. I really don’t have too much respect for you but I’ll pay you, I’ll pay you good money to do this but it’s really not going to build your palisade, it’s not going to be empowering for you.

And right away what the people say now is you want to treat us like prostitutes because you want to pay us but you have no respect for us; that’s really not going to help us. It’s going to help you but not us. Ok? Nobody wants to work that way. So again people disappear from the table. The last one is, and this is the one that the government uses a lot of, we really don’t have any respect for you. We don’t have any money for you. Say for example on environmental issues or health issues. But boy, you better do it or we’re going to come down on your ass. You know with the environmental assessment acts and all these types of things, that’s what they’re saying. You won’t do this and we’re going to come right down on you. But you’re given no respect, you’re given no equity to do it.

Respect for the community is demonstrated through truthfully and clearly communicating the study objectives; seeking to understand the worldviews of the Aboriginal community; understanding the needs and concerns of the community; and identifying strategies to successfully navigate through conflict. Researchers entering into communities

can also establish respect by genuinely listening and learning about local concerns and identifying the questions the community needs answered. The same internal decision-maker further explained the process of developing respect:

So now when you have a problem in one of these relationships you find that you say, "Ok, what are the tools of respect?" Well one of the basic ones is communication. How do we talk to you? And remember, sometimes maybe it takes three meetings to just communicate who we are and what we want to do. Well, there's good communication. Am I listening to what they say and respecting what they say? That's another one. And so there's a lot of times there when we're talking at cross purposes and we are saying, "oh man, I'm using this term to mean this. Is that what it means to you?" And they go, "No, no, no, that means this", and you go, "Ah, ok I didn't understand that," and it causes tension at the table. So by, you know, exchanging information, understanding, communication, having a way to mediate those problems, that all shows respect for the process when you create a lot of zeal, when you do the right respectful things.

One way of demonstrating equity is by valuing different types of evidence, and particularly by valuing the knowledge that is shared by the community. The internal decision-maker quoted above continued by saying:

The universities that come into the First Nations communities talk to the Elders. Elders pour out their hearts to them, as we believe that knowledge is powerful when it's shared. [But then the researcher] runs away and does his PhD and you never hear about it again. But the knowledge that was in that article, was the [knowledge] of the Elder, so why isn't he an author if there are papers to be produced from it? And what happens there is, if you do make that person an author, suddenly you add great credibility, right, to the process. That Elder is now acknowledged that he, he is seen as one of those scientists, one of those people who adds a valuable contribution to the

world of science. What happens from that is you gain more respect. When you gain more respect, you also gain more equity. When we gain more equity, we can empower ourselves to do more.

Through long-established relationships, the knowledge held by researchers may also come to be valued and they may be called upon by the community as a consultant to provide suggestions about sources of information or to provide expert opinions on emerging issues. As one internal decision-maker commented, *"the goal is to move from having a researcher and a community to having a research community, with each player working in his area of expertise."*

The concept of empowering communities to develop the skills, knowledge and capacity to independently conduct research about their local environments was an important theme that emerged from many of the interviews with both internal decision-makers and several external decision-makers who collaborate with government programs that fund Aboriginal communities to conduct research. Involving community members in research can often also provide employment opportunities.

From a First Nations' perspective, frustrations can develop when attempting to build relationships with researchers and government employees who seek their involvement in projects. One significant frustration is that many Aboriginal peoples may live a significant portion of their lives in single communities and this allows the community to develop a collective historical memory of the activities and events that have occurred locally. However, within academic and governmental organizations, individuals frequently shift positions and roles, and with this, memory of past work done with Aboriginal communities is lost. As a result, many communities express frustration at continually developing

new relationships with individuals from the same organizations. This loss of corporate memory of past relationships, programs, and community assessments was also acknowledged by several of the decision-makers working within Federal departments.

The majority of external decision-makers confirmed the importance of taking time to develop relationships. It was highlighted that some Federal departments may act as liaisons to link environmental health researchers with Aboriginal communities who are interested in conducting research. Many of the external decision-makers also confirmed the importance of meeting with Aboriginal leaders several times before conducting impact assessments or environmental health studies; attending social events and feasts so that communities could get to know the researcher on a personal level; and engaging the community by seeking their input about the study questions and integrating their ideas into the research process. One external decision-maker expressed that:

You've got to recognize that if you're a non-indigenous person walking into an indigenous community, you are going to be a true outsider and you cannot just walk in and say well I have credentials. Credentials are of interest but really not that terribly important to indigenous communities. They want to know who you are and what you're all about. So you will have to come in and be prepared to build confidence, trust, whatever, with that community before you can even start with any kind of research. That could take considerable time. ... It's going to take you considerable time to build the trust to incorporate and engage their ideas into your research.

Not surprisingly, in addition to providing entrée to a community and in identifying local priorities, an established relationship with key community members can also facilitate the processes of data collection,

interpretation and dissemination. Researchers acknowledged that actively involving local community members as members of the research team can assist with the resolution of practical challenges such as knowing who, and how, to contact different individuals, and how to organize community meetings. As one researcher explained:

It's absolutely essential to have more than one, as many as possible, contacts within the community. If a non-aboriginal researcher goes in without much history with the community, if they don't know how to organize, they can't get things done. Like you can try to organize for days and days on end, you can spend as much energy you want and you'll have very little turnout for your effort because you don't have the trust. People won't respond to your calls, you can't cold call people. And then you're put in the hands of the one person who's a capable organizer and they'll do it without even barely blinking, they'll turn out the entire group of people that you'd like to have... So having the right person organizing with you and having that person have power within the project, be funded and have decision-making power and power to help generate, co-generate questions...is absolutely essential.

But for some researchers, frustrations have been experienced when they perceive that they are genuinely working to develop relationships and understand issues from the perspectives of Aboriginal communities, but they do not perceive equal reciprocity from the community in understanding that researchers often work within tight timelines and methodologic boundaries. One researcher explained:

We try to talk to everyone we can, or they said they wanted to talk but where are they now? "Well you know, we were there for a week". You know, that kind of stuff. So it's, it's like we're [the researchers] making an effort. But partially, the people don't understand the situation that we're in. It's like the fact that we [researchers] don't understand Aboriginal communities very well and that's certainly true, but I have

to say, on the other hand, Aboriginal [communities] don't understand the situation that scientific researchers find themselves in.

Many government programs, such as the Northern Contaminants Program, Indian and Northern Affairs Canada (www.ainc-inac.gc.ca/nth/ct/ncp/index-eng.asp), actively promote and require the involvement of local community members on research teams. The challenge for many researchers, however, is that research grants are often not substantive enough to cover the costs of frequent trips to remote communities that are required to facilitate relationship development. From a researcher perspective, they identified that telephone contact is often more efficient and more cost-effective for discussing communities' potential interests in collaborating or in setting up study protocols, but there is acknowledgment that this approach is not favoured by First Nations communities.

2. Perceptions of the environmental health research process

Through the discussions with decision-makers and researchers about the most effective strategies to disseminate information, one primary recommendation was repeated in the majority of interviews: KTE strategies must be negotiated at the beginning of a project and integrated throughout the entire research process and not be considered as an 'add-on' at the end of a project. Participants from each of the three stakeholder groups also provided extensive descriptions of successful past and current environmental health research processes. Challenges that each group continues to experience in the conduct of research around environmental health issues such as the measurement of contaminants in traditional foods, exposure to environmental toxins, and strategies to manage local community resources were also identified.

One internal decision-maker commented that,

"There's just a mindset that needs to maybe change at the academic level of how to do research with, as well as within, traditional Territories."

From a KTE perspective, it is a positive finding to see that such a paradigm shift is occurring in the conduct of environmental health research. Much of the current research being conducted in Aboriginal communities, and in particular Inuit communities, is being developed using participatory models, where researchers and communities work collaboratively and as equal partners through all phases of the research, including the first stage of identifying and refining the research question. A genuine invitation to collaborate on projects of relevance to the community provides an incentive for the community to participate. One First Nations internal decision-maker explained:

So reaching out, going door to door, and having that early relationship, really helps to prevent [resistance to research]. Especially if [the researcher] can provide benefits so that they [the community] have a vested interest to provide critique and to give you feedback because they know that they'll get benefit. The better and more accurate your research is, the more they benefit. So having that incentive that there's...they'll get something out of it really helps, helps them care, I think. And it makes sense. I mean that's in any community, right? Not just for First Nations.

Several participants identified the need for, or identified existing programs (e.g. First Nations Environmental Health Innovation Network www.fnehin.ca and ArcticNet www.arcticnet.ulaval.ca), that serve as bridges linking communities with environmental health questions with researchers who have the knowledge and expertise to partner in answering these questions. It was identified however, that if organizations develop researcher databases, it is important to keep them updated and to ensure that

Aboriginal community leaders can access the information by the Internet *and* by connecting with a consultant over the telephone. As one internal First Nations decision-maker explained,

"I'd rather call the person I know. I'm the type of person, where I just call her up and ask for the [information]...if she knows of something that is relevant to me."

Multiple researchers and external and internal decision-makers with expertise in Northern or Inuit community environmental health issues again identified the Northern Contaminants Program (NCP), and its affiliated Regional Contaminant Committees, as the ideal case study for developing collaborative partnerships in research and for supporting capacity development so that Northern communities can secure funding to conduct their own studies or local assessments. It is important to note that the NCP funds communities, not researchers. As one external decision-maker from a Federal department summarized:

Our focus is to be more on the concept of trying to convince or engage indigenous communities in doing their own research, gathering their own data, interpreting their own data, and using it for decision-making within their own communities.

Being actively involved in informing and influencing environmental health policy was described as empowering by one internal decision-maker, who also stated that they are no longer waiting for the government to come in and say:

"Yes, we will do this for you." Instead the Band put up the funding and started saying, "Okay, go for it, let's do this." So it was something that [we were] taking the initiative to say, "We need to do this for us and let's go forward on it."

Several participants identified that conducting more collaborative research, especially when it has been built on foundations of strong relationships, has been a positive experience. One external decision-maker shared:

The real thing about Indigenous communities... is that once they decide they want to participate, they really do. They really want to be part of it. They want to take ownership... they become very proud of the fact that they can work with this [project].

From the perspectives of multiple external decision-makers and researchers, they perceived that at the current time, differences may exist between Inuit and First Nations communities in their levels of interest in participating in

environmental health research. It was hypothesized that issues of climate change and environmental contaminants may currently have more immediate relevance to Inuit communities while many First Nations communities may be focused on issues of higher priority and relevance in their communities such as substance abuse, violence, infectious diseases, housing conditions and diabetes.

A small number of external decision-makers identified an additional barrier or potential point of tension around conducting collaborative research with First Nations communities. They felt that negotiations to conduct research can often become highly politicized around issues that they feel they have no ability to influence and which researchers do not have the skills or training to respond to. As one Federal level decision-maker explained:

First Nations [often] are very concerned about issues that have gone on in the past. Residential schools have started to get resolved a little bit but there are still a lot of gaps there where some people have got payouts and other people that thought they should haven't, if you know what I mean. So there's still a lot of bitter and political issues related to that as well as many other things that have gone on in the past, which



again we can't, we can't address them but often times they take up a lot of time in our meetings.... But again, often times we can get down to business with the Inuit communities while sometimes our first or second meetings with First Nations tend to be getting these other...the baggage out of the way, ok?

This tension may also be exacerbated by two additional, but related factors:

1. A history of exploitation by researchers and communities' mistrust of researchers; and;
2. Aboriginal communities' fatigue of "being researched." As one internal decision-maker, responsible for coordinating environmental assessments within a First Nations community explained:

I don't think researchers fully appreciate until they've either worked for a Band or have a lot of experience with First Nations just how quickly First Nations get tired of research. There's been lots of research and very little that came back to the community, or had a real impact on policies or decision making. And so there's a cynical attitude often as people are often saying, "Well what's the use? Whatever, it's not important."

All three groups of stakeholders commented on a number of other political issues or concerns that made environmental health research and policy-making challenging. As one external decision-maker commented, "Each First Nation band is an individual nation." There is such variation in political structure and government from community to community that it is difficult to generalize processes or policies for working within different communities. In some provinces and territories, it is possible to use organizations such as the Assembly of First Nations to act as bridges to reach communities, but in other jurisdictions such organizations do not exist and there is no centralized way to connect.

It was also made clear that it is essential to understand the political and power

structure of a community in order to work effectively within it. If a researcher or decision maker doesn't have a good understanding of the complex political structure within a community, he or she may fail to acknowledge Elders or others of importance. This can lead to misunderstandings and may be seen as lack of respect. However, it is not just the political structure within the First Nations communities that can be complex.

Multiple levels of government and various government departments need to be involved and consulted when policies are being created which further complicates the issues. It is also unclear at times under whose jurisdiction or mandate a particular issue or problem falls. The changeable nature of governments must also be taken into consideration. In some First Nations communities, the local leadership is unstable and changes frequently. As one internal decision-maker commented:

The way we designed it, first of all, we tried to identify an intern, a First Nations intern, a partner within each of the communities that we could have with that person as the go-to person to be in touch with and that person who could help enhance the in-community outreach and the trust. But in the end we couldn't do that. There was too much turnover and not enough time and energy in these often very small communities, and some of these communities are 150, 250 people. So having a program person really understand the nature of what we're doing and to be on top of it, and to be around for more than a year or two, was a real challenge. So we found that we had to deal with, you know, instabilities within each community at the political level, Band Council level, and at the program level. So despite our best intention, this remains a challenge.

Similarly, changes in Federal and Provincial governments can also present challenges. With changes in government come changes in political agendas and priorities. This in turn can affect funding for environmental health issues, making

it difficult to conduct long-term or longitudinal studies.

Several stakeholders commented on the impact of "political agendas" on research. In some cases, research might be encouraged by a First Nations community because that community wants to use the results of the study to negotiate with government or industry. On the other hand, that same community may refuse to have research conducted or have the results released because they do not want the situation in their community exposed. Governments may want to use research to further a political agenda, when the research itself may not benefit the community concerned. In this case the political agenda of the government may outweigh the needs of the community. For many First Nations communities, the historical mistrust of the government and of research may lead them to question closely what the agenda or motivation to conduct research is.

One other emerging tension is that sometimes studies conducted in a small community provide results of high value and relevance to the local population but may have limited generalizability to other communities or value to the government agency that sponsored the project. Participatory models of research are continuing to be refined in this field so that academic researchers can achieve their goals while communities simultaneously have opportunities to build research capacity and have their specific environmental health concerns addressed. Particularly from the perspectives of researchers and external decision-makers, the conduct of research needs to involve negotiation and willingness from government, academia AND Aboriginal communities to come to consensus on the topics to investigate and the methods most suitable to answer the research questions.

When KTE processes were discussed, it was endorsed by many participants



that all communication plans should be negotiated and identified at the beginning of any single research project. Some researchers also cautioned that at this stage it is important to clearly articulate the potential outcomes of the research study to the community and to ensure that community expectations of what the project can, and cannot achieve, are understood and managed. One of the most significant benefits of participatory research projects is that KTE activities inherently occur when community members participate in the research process in that it provides opportunities to be intimately involved in the analysis and interpretation of data as it emerges. Through these activities comes understanding of the findings and opportunities to share this new information with other community members. One researcher commented:

Essentially what it means to me is that it involves, whomever you're working with, be it First Nations or an organization, they're involved in the entire process. Hopefully, the research idea comes from them, their questions, and that they're involved in the design, you know the methodology.... So ensuring that whatever the researchers will come up with [as findings] don't just sit on a shelf; they're actually used.

The full benefits of establishing relationships and conducting collaborative research on KTE outcomes are explained at length by one external decision-maker:

[When there is a] relationship between the researcher and the community, reflected in the reports, people are providing their perspectives, their views, their understanding of what is happening, and particularly in the stage of interpretation of results. From the view of a classic scientific approach where relationships between the scientists and the community are not very strong, there hasn't been really a mutual, a kind of cross-pollination of approaches, of views, of perspectives, and then the quality of the outcome usually is weaker. However, on the other hand, there are projects where researchers did take time to develop this relationship, to ask the right questions, to consult with the Elders of the communities, to consult with other power groups like women's circle and youth groups, and really, in the set up of their projects try to understand why the community sees this topic as important. If that happens, then it increases actually the researchers' capacity often to incorporate Traditional Knowledge perspectives into this research and give an opportunity to knowledge holders in the communities to actually, to provide their perspectives in the project, which actually

gives a result from the projects that are quite unlike anything else that you can't get through the traditional scientific approach. So this becomes more of an action research, it becomes more research that is up taken almost immediately after its completion by the community. And this is where actually the general benefit of this research is. That although it is not published as often, but you know the First Nations people that we work with, they often say well that's not why we do this research. We do this research because we want to know, because this impacts our long-term plans that impacts what we do, in particular how we hunt, how we fish, what we do, and you know if this is a good project, then we add the results of this project to what we know and as far as we are concerned, they say sometimes that's good enough.

It was identified that in many research contracts, the community and research team are now responsible for providing a communication plan and contracting how the information will be shared back to the community. Unanimously, there was consensus across stakeholder groups, that researchers and government departments have a responsibility to first report findings back to the community in which data or samples were collected. It was

*Canadian Institutes of Health Research Guidelines for Health Research Involving Aboriginal People (2007).

strongly recommended that negotiations about processes to disseminate findings and data ownership be conducted at the beginning of any project. Within these discussions, strong opinions were expressed about: 1) researchers' formal practices of publishing findings in peer reviewed journals and; 2) First Nations' rights to protect the community knowledge, including Traditional Knowledge and findings from studies conducted locally, by following the principles of ownership, control, access and possession (OCAP) (First Nations Centre, 2007).

First Nations internal decision-makers who participated in this environmental scan expressed their perspectives that the issue of ownership of intellectual property is an issue that must be discussed and negotiated. It was acknowledged that although different First Nations communities had differing levels of knowledge and levels of adherence to the OCAP principles, researchers who hope to have findings shared publicly should negotiate permission to do so with community leadership. Acknowledgment of this intention should be outlined clearly in the process of obtaining informed consent.

Some researchers who participated expressed concern that if the OCAP principles are followed to the full extent, leading ultimately to the perception that researchers have few rights to the data they have collected, there may be the potential risk of a decrease in the number of researchers interested in collaborating with First Nations communities. The rationale is that without access to the data collected or permission to publish in peer-reviewed journals, there could be a significant impact on the tenure-status and promotion of new academic investigators. Several of the researchers expressed hope that if mutually trusting relationships are developed with communities, then potential mistrust of

researchers' mismanagement of data will be decreased. Hope was also expressed that within the boundaries of these relationships, processes that respected both the community and researchers' goals could be established. As one researcher commented:

The [CIHR guidelines] did have some very important impacts because one of the things we put in the research agreement is that locals and the Elders who have given the knowledge for the plants that have been mentioned by Elders of a joint community, we have to go and send the papers ... the scientific papers that we make, we prepare, have to go through a review process. So it adds exactly 3 months to it before we can even think of submitting a paper [to a peer-reviewed journal]. We have to go through this 3 month process of where we prepare a lay summary in English that's translated into Cree, and there are two dialects of Cree, and then they want a coastal and the inland, so we have liaison officers at each Band Council that take care of making sure it gets to the Elders and they get to figure out if there is Traditional Knowledge they prefer be withheld. Then if they have any suggestions for changes it gets back to us, we modify it, submit it again, and then only then can we submit it to a journal.*

Tensions and concerns still exist around the issues of informed consent and confidentiality. While researchers believe that informed consent, confidentiality and anonymity are concepts that they use to protect those that participate in research, some of the other participants expressed different perceptions. One internal decision-maker commented that ethical guidelines, including consent and confidentiality, serve to protect the interests of the researchers, not the community. He felt that these concepts do not fit with the cultural context of First Nations communities. Several stakeholders also reinforced that issues of consent need to be discussed at great length during the beginning stages of a research project, and that consent to

participate in research did not necessarily mean consent or permission to release the findings.

3. Integration of empirical research and traditional knowledge

The majority of stakeholders acknowledged that at a fundamental level, scientists and Aboriginal communities hold different worldviews about processes for 'knowing the world in which we live' and the types of evidence or information valued in decision-making. The two worldviews were apparent even in the way in which stakeholders defined "environmental health." Internal decision-makers often felt they could not or should not differentiate between "environment" and "health" as all things are connected, while other types of stakeholders were more likely to see the two as separate. Given the extensive intrinsic knowledge many Aboriginal people have of the land and environment, meeting the challenge of identifying processes that respect and utilize both forms of knowledge in decision-making is pivotal in environmental health discussions.

Within both government and academic departments and Aboriginal communities, it is apparent that there is an increasing appreciation of the knowledge valued by 'others' and a subsequent shift in culture. Some researchers perceived that communities, particularly those communities with close geographic or social links to universities or long established relationships with research teams, had increasing interest in accessing and utilizing scientific evidence. One researcher shared that:

My impression after a number of years working in the North is that things have really turned in the sense that the value of science is recognized in the communities and the value of working with the scientific community is seen as important, and you know part of the reason why that's now the case that may not have been awhile ago is that people have more control over their

own lands and have land claims agreements in the same place and self-government agreements in some instances that they need to know what's going on for their own governance, governance of themselves. So you know science questions are really common in my experience now.

From an internal decision-maker perspective, it was presented that there is value in adopting and utilizing scientific evidence in that it facilitates a community's ability to have open dialogues with government departments, where 'science' is the language most commonly spoken and understood. Some communities have also identified that when attempting to mobilize government departments to respond to local environmental hazards or toxins, adopting scientific language in their communication ensures the community's messages are more likely to be picked up by the media. Most importantly, when action is required, scientific evidence can be a powerful tool to 'prove' or support the conclusions from anecdotal or community knowledge.

Based on the data from the internal decision-makers, it was determined that the credibility of scientific evidence to Aboriginal decision-makers will be evaluated on the basis of: 1) its relevance to the community; 2) the perceived agenda of the researcher; and 3) the source of funding for the research project. It was cautioned, however, that historical research practices have resulted in many communities lacking trust in both researchers and the findings of scientific studies. As one external decision-maker explained:

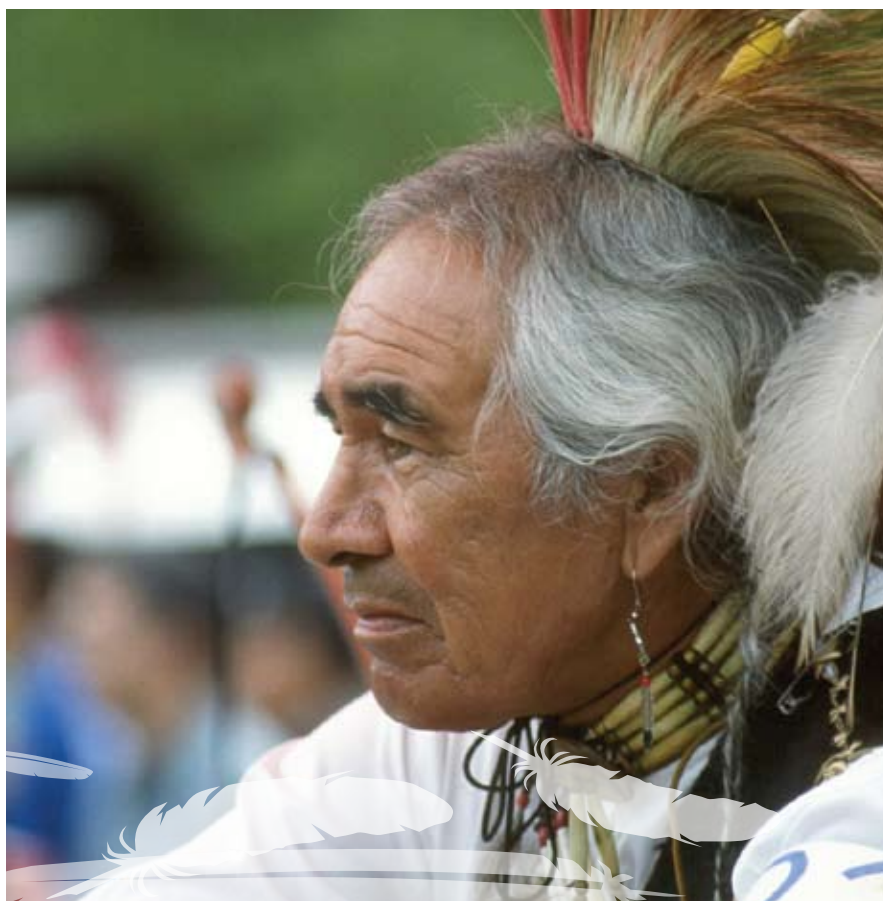
Historically, in the past, it has been government or industry coming in with highly paid professionals with three or four degrees standing up in front of the community and saying, and this is not just an indigenous community, this is any small community, and saying, "We know everything, we've got it all worked out, here's

the science", and they'll show some graphs and figures and experiments. And then assume that the community will just accept it. And some communities have in the past – again indigenous and non-indigenous – and some have been hurt by that and everybody now is a little bit apprehensive when government comes in and says, "Trust me, I'm here to help you."

Several researchers had experienced similar situations, and one researcher stated:

First of all, whether as a scientist you're government-based or university-based you're viewed as ivory tower. If you're working as a government scientist, you're viewed as a government agent and government agents have been responsible in the past, distant past or not so distant past, for all sorts of violations of human rights and to this day, there's all sorts of baggage that is very dangerous and culturally laden.

The greater cultural shift, however, is occurring amongst government and academic departments, where there is increasing acknowledgment of the value of understanding and seeking out Traditional Knowledge when working in the environmental health field. There was an acknowledgement from participants that in government policy shops, written knowledge and scientific evidence are more frequently used than oral or anecdotal knowledge. However, there was also general consensus that Traditional Knowledge is valuable in identifying and refining research questions, providing cultural and spiritual insight about the phenomena under study, and providing interpretations of scientific data that make sense to the local community. It was consistently expressed by all three types of stakeholders that the two types of knowledge are different and distinct





but are complementary to each other, and that they should be equally valued. As one external decision-maker explained, a more holistic understanding of environmental issues arises, when different perspectives are examined:

I think we've been trying to integrate this two-eyed seeing approach. Whereby there's the indigenous worldview and then there's the western scientific worldview, and then seeing that there's a greater power when those two worldviews are combined into one effort. And that's what the [government program] is trying to encapsulate, and at the same time embodying the principles of ecosystem-based research.

Researchers gaining entry into Aboriginal communities also need to have increasing awareness that Traditional Knowledge may be accepted and viewed by that community as more credible than the scientific data they are presenting. As one health professional in a First Nations community commented:

You cannot go into a First Nations community or an Inuit region if you are not ready to listen to what people have to say about their own experiences and their own types of evidence.

The sharing and exchange of Traditional Knowledge, however, also has the

potential to create tensions between Aboriginal communities, government departments, and researchers. Some of the tensions around OCAP principles and the sharing of Traditional Knowledge were described earlier. It is essential that if Traditional Knowledge is shared with a research team in the course of a research project, this information is only shared or disseminated publicly once the knowledge and consent of the community has been obtained, and processes have been put in place to acknowledge those that shared the information. One internal decision-maker expressed that:

I can see some challenges where some of the Elders and knowledge holders don't want to share anything anymore because they've been ripped off too much. So they've already put their wall up. They don't want to participate.

4. Barriers and facilitators to the utilization of research evidence in decision-making

There was consensus across stakeholder groups regarding both the barriers and facilitating influences to the use of research evidence by Aboriginal communities in the development of local environmental health policy, whether that policy is aimed at directing change in individual behaviours (e.g. around the consumption of traditionally harvested foods) or

to reducing community exposure to known contaminants. There are several characteristics about the nature of scientific evidence in the field of environmental health that may lead to its limited uptake in Aboriginal communities. First, as identified above, some individuals and communities mistrust scientific information based on their past experiences with researchers. Second, it is often difficult to validate information about environmental health issues as the community may be inundated with excessive amounts of information about a specific topic, much of which may present conflicting findings. Third, sometimes when individuals perceive that the government has already made a decision about a policy or change in the community and then present data to support this decision, this results in increased suspicion of the data and a propensity to ignore the findings. Finally, the language used in many impact or environmental assessments is often highly technical and jargon-laden, resulting in decreased comprehensibility of the findings and thus limited utility of the data.

In many communities, individuals may also lack the tools and skills to effectively access research evidence and then to critically appraise it. It was noted that

many remote or Northern communities still lack consistent access to high-speed Internet or computers. There was high consensus among all decision-makers that the most important facilitating factor to increase utilization of research evidence is to involve community members in the design and conduct of local projects.

C. Key Elements to Promote Knowledge Transfer and Exchange

Given that both Aboriginal communities and researchers associated with government agencies or universities invest significant resources in the production of research evidence using Western scientific methods, there is a need to ensure that these findings are effectively translated and shared with different audiences of decision-makers, including Aboriginal communities. To facilitate this process, researchers need to develop the skills in crafting key messages emerging from their studies, be able to identify credible messengers to deliver the message, and identify effective communication channels and dissemination strategies to share the information, for as one researcher commented, “lengthy reports just gather dust.”

1. Crafting key messages

An important step in the KTE process is for researchers to identify what specific findings will be communicated to target audiences. Given the highly technical nature of environmental health studies, it is essential that key messages be crafted using plain language and limited jargon. It was recommended that in preparing reports, key messages should be developed by synthesizing findings from multiple projects or reports. It is also important to include different perspectives about the issue, to allow the decision-maker to have increased understanding of the phenomenon under perspective. In communities where the project has been

conducted using participatory methods, any community concerns that were raised in the development stage of the project should be also prioritized as key messages at the end of the project.

Researchers should strive to develop key messages that are relevant to, and resonate with, the community. One proposed strategy to achieve this goal is to deliver the key message as a story and when possible, integrate Traditional Knowledge to assist in the interpretation of findings. It was also highlighted that key messages in presentations to the community should focus on the study results and not on the scientific intricacies of the methods used to collect and analyze the data.

Given that environmental health studies are often focused on measuring toxin exposure or environmental contaminants, it was recommended that messages around risks should be developed with caution to avoid alarming community members. It is important to present a balance of both risks and benefits and to examine the issue from a culturally-sensitive position. Researchers should also be aware that if findings and key messages are preponderantly negative, then the community may perceive that the study will put their community in a ‘bad light,’ and they may choose to not permit the information to be released or may not utilize the findings.

Community partners should play a key role in crafting key messages. As one researcher shared:

This is best done with community partners so we always have the right language and perspective. Whenever we do the crafting ourselves, the KT is less effective. Also, piloting and evaluating the effect of messages before general dissemination has proven worthwhile.

Cultural brokers, individuals who hold a personal understanding of the beliefs, values and traditions of the community

and have the knowledge and skills to interpret impact assessments or research findings, may be employed to assist researchers in crafting culturally relevant key messages. For example, one researcher shared that:

Messages need to be relayed back to the community and that's where stakeholders, including the health authority, need to work with me, so I will put the results into the proper context.

One of the internal decision-makers interviewed identified that one of his key roles is to act as a cultural broker for researchers. He explained that he,

“learned how to just bring the information back to the community, back to them really simple and in really simple terms, and I explain [to researchers] how [they] can explain all those technical terms.”

Cultural brokers can also assist researchers and government decision-makers in identifying messages or findings that may be questioned or challenged by the local community and assist them in preparing appropriate responses. As one Federal external decision-maker shared:

You cannot control the message. You may have a message but you're going to be challenged on a lot of different fronts. It is good to have others with you or at least some answers to perceived questions that you think you'll get asked by the community. So we don't tend to just walk into a community with a small little piece of information.

We tend to, if we have something specific to give them, we sit down actually, and this is where we do work with AFN [Assembly of First Nations] and ITK [Inuit Tapiriit Kanatami], and sit down and say, ok if we go into the community with this kind of information, what are the issues that you would think will flare up? And then we try to get answers or bring in people who might be able to answer those kinds of questions before. We don't tend to just walk in cold.

2. Selecting credible messengers

In addition to crafting key messages, cultural brokers may also be effectively

used to assist research teams in disseminating the key messages. Often these cultural brokers were identified by stakeholders as local health professionals, members of the Regional Contaminants Committees, a member of the local Environment Committee, or community members who had been involved in the studies at different levels. Cultural brokers are knowledgeable about how to effectively share information and know where community members can be accessed. An example was given from an internal decision-maker that:

The field workers working in the project and learning about it, it's capacity building for those people and they get the knowledge and learn how the scientific side of everything works, but they also have the Traditional Knowledge and the knowledge of the community on the other side and know how to interpret that data. They're a bridge between the scientific side and the community side.

Similarly, an external decision-maker who works predominantly with First Nations populations explained that:

That's why when we communicate with certainly First Nations and Aboriginal organizations we, we try to ensure that there's someone that's part of a team that has a trusted voice in that community, that's

part of the team delivery information to them. So it's not just coming from strangers that are coming from outside of the region. It's coming from a person or people that are trusted in that community and would basically have some understanding of the cultural sensitivity or issues that are very specific to that region or that community that have to be taken into consideration; issues that a general researcher or even a health practitioner would not necessarily be aware of. So it's critical to have those types of people involved in a team approach.

One external decision-maker expressed that although cultural brokers have great value, there could be challenges in the role. *I believe this is a role that will continue to grow in demand and importance; however, it will be a challenge for many First Nations to fill such roles as they risk being criticized or ostracized for co-opting their First Nation worldview, so the value of the 'two-eyed seeing approach' needs to be embraced and promoted by both sides. This is the only way there will be harmonious and effective working relationships.*

In many communities, researchers, particularly those who have invested in relationship development, are also viewed as credible messengers. However, it was noted that not all scientists have the skills

to be effective communicators. Across several stakeholder interviews, participants talked about their positive experiences when researchers and cultural brokers worked together to share results as part of community tours or local presentations. It was explained that in some communities it is important to have the researcher present the information first-hand, and be available to answer specific questions, but that the cultural broker is also present to support the translation and interpretation of the messages.

3. Communication channels and dissemination strategies

When communicating the results of any environmental health project, it is essential that the results be presented first to the community in which the data were collected. The processes for communicating results back to a community should be negotiated at the start of a project and may vary from community to community. At this stage it is important to clarify with the community the procedures for communicating the information (written or oral formats), the languages that the information should be translated into, and the importance of including pictures or graphics in any written materials or oral presentations. The majority of the knowledge dissemination documents or materials developed within communities expressing environmental health messages effectively used vivid images and graphics, particularly of natural environments.

Overall, the common theme is that it is essential to use multiple different strategies to communicate a message and that face-to-face interactive dissemination strategies are more effective for transmitting information compared to paper reports. However, products such as websites, newsletters, or brief reports can play important supporting roles in disseminating information. All stakeholders shared examples of different communication and dissemination



strategies. The most common approaches included: radio ads or participation in radio call-in shows (particularly in Northern communities), attending community presentations, conducting community tours or workshops, attending relevant committee meetings, and preparing and distributing newspaper articles, newsletters, posters, flyers, or presenting a poster display at a community social event. At the time of the interviews, none of the stakeholders who were interviewed had conducted or completed any evaluations of the effectiveness of the dissemination strategies.

D. Recommendations for Researchers Conducting Environmental Health Studies in Collaboration with Aboriginal Communities

Each of the stakeholders who participated in this environmental scan had extensive experiences and knowledge of the work required to successfully complete and disseminate findings from environmental health studies that were conducted to examine issues of relevance to Aboriginal communities in Canada. Throughout the interviews, many of the stakeholders shared their personal 'lessons learned' and passed along advice for new researchers, or investigators new to this field, interested in collaborating on this type of work.

Lessons learned from experienced researchers

1. Researchers must be genuine, honest in their intentions and arrive in the community with the intent to conduct good science and improve the health outcomes of the community.

"People [in the north] have seen outsiders pull the wool over their eyes, is a nice way to put it, for generations and they're pretty good at detecting when it's crap."

2. Although a researcher may have established 'legitimacy' and status in his/her university based on accomplishments and degrees, these alone will not grant you entry into the community.
3. Respect for all members of the community must be demonstrated before the research project can be initiated.
4. Findings must be translated in terms that the target audience can understand, using concepts that are part of their worldviews. For example, if the audience does not have a clear understanding of the concept of "percentage":
"you can explain it to them every single time or you can use a pie chart instead."
5. It is important to identify a mentor who has experience and established relationships in Aboriginal communities.

Recommendations for researchers from internal decision-makers

1. Discover the priorities of the community and identify what their specific environmental health needs and concerns are. It is essential that the research be conducted from the perspective of the local Aboriginal community.
2. Relationships are at the heart of all successful research projects, so take the time to build them.
3. Send a letter of request, or present ideas in person, to the Chief or Council. Be prepared that the Council may choose to survey or seek input from the community about the relevance or need for your project. However, the research team needs to be available to personally engage with the community and not just leave it to the Council to seek the communities' permission to collaborate on the project.
4. Be transparent about the study goals and objectives. Clearly highlight the

potential risks and benefits of the study outcomes to the community.

5. While it is important to identify the community's priorities and needs, a researcher may not be able to meet them and has a responsibility to clearly articulate what he/she can or cannot accomplish for the community.
6. Address any concerns directly that the community may have about the proposed methods for collecting data or samples.
7. Be "up front" about grant money, especially if a funding body requires that a researcher partner with an Aboriginal community in order to secure research funding.
8. Seek genuine involvement of community members in multiple different aspects of the research project.


Recommendations for researchers from external decision-makers

1. Identify key contacts and networks to assist in building a bridge into the community rather than "going into the community cold."
2. Be genuine in both the desire to assist and also to learn from the community.
3. Always share study or assessment findings first with the community leadership and then identify the appropriate public forum to share the results with the broader community.
4. Provide the community with a firm commitment that the final study results will be returned to and shared with the community, and that this is not just a project where the needed information will be collected, removed, then published externally.
5. Recognize and appreciate that although the worldviews of researchers, policy makers and Aboriginal communities are all different, valuable information and wisdom can be gained from each group.






V. DISCUSSION



A purposeful sample of decision-makers working internally in First Nations or Inuit communities, decision-makers working externally in a variety of Provincial and Federal departments, and environmental health researchers shared their extensive expertise and knowledge about the factors influencing KTE processes. Although each group of stakeholders had unique worldviews about environmental health research, their primary conclusions were similar. The credibility of the data collected in this environmental scan was enhanced by the triangulation of these three data sources and the resultant convergence of findings across stakeholder groups. The primary limitation of the environmental scan is that, despite extensive recruitment efforts, we were unable to recruit the intended number of internal and external decision-makers. There were numerous reasons for this. As we subsequently learned through this study, our recruitment methods did not fit well with what internal decision-makers identified as keys to the



engagement process for First Nations communities. For example, given our interest in sampling experts from across Canada, our environmental scan protocol procedures did not facilitate opportunities for face-to-face interactions. Additionally, while the NCCAH assisted with the identification and invitation to many potential internal decision-makers, the majority of the invitations were sent ‘cold’ by email through the project at McMaster University.

What all stakeholder groups shared is that the development of relationships built on trust between researchers and Aboriginal communities will provide a foundation for both the successful conduct of research and implementation of KTE strategies. Second, KTE strategies are most effective when the community collaborates with researchers on all phases of the research project. This latter recommendation is similarly echoed throughout the broader KTE literature that recommends that researchers involve decision-makers in

identifying priority research questions, developing study protocols, and participating in the collection, analysis and interpretation of data.

Given the current emphasis on the conduct of participatory research in Aboriginal communities, this innovative field may emerge with important recommendations on how to manage these unique collaborations that will be of value to all other health researchers. For communities that lack established connections with universities or have no history of working with government-run environmental health programs, and for new investigators to the field, opportunities to develop productive relationships may be limited. The concept of developing databases or infrastructures to link researchers and communities interested in addressing similar environmental health issues was endorsed with the provision that the databases be kept current and that individuals have options to access them via telephone or Internet.

By its very nature, environmental health is an issue that is examined from many different perspectives by researchers from such diverse fields as toxicology, sociology, public health, medical anthropology, and biology. The conduct of this work in collaboration with Aboriginal communities introduces another worldview by which to explore and understand the environment in which we live. The uniqueness of this situation is that it presents true opportunities for the transfer and exchange of different and unique types of evidence between the stakeholder groups. Often the emphasis in KTE literature is to focus on the transfer of research evidence to decision-makers. Within this study, the opportunities and challenges of transferring research evidence to Aboriginal communities and transferring Traditional Knowledge to researchers and external decision-makers were explored. There was also acknowledgment of the value and roles



of both types of evidence for informing environmental health policies. Issues surrounding the intellectual property rights of data collected within the context of environmental health studies or assessments and the sharing of Traditional Knowledge with researchers are best addressed openly at the beginning of a research project and highlighted through the informed consent process. Researchers conducting environmental health research with Aboriginal communities have a responsibility to be knowledgeable about, and adhere to, the CIHR Guidelines for Health Research Involving Aboriginal People (2007).

Across this environmental scan, core factors for promoting KTE, particularly of the transfer of scientific data to Aboriginal communities, were identified. The primary recommendations focused on developing communication strategies at the beginning of the project and integrating KTE strategies throughout the research project, particularly by involving local community members in the planning and conduct of the research. It is also essential for researchers to identify cultural brokers (individuals with knowledge of both

local community values and beliefs and the skills to interpret scientific data), to act as bridges between researchers and communities (Jezewski, 1990). Cultural brokers play pivotal roles in both assisting with the crafting of key messages and disseminating information to the community.

Given the complexity of the language of environmental health work, there is a specific need to translate the technical jargon of the studies into lay language. To increase the relevance of the data it is also important, when possible, to tailor the messages to the needs of the community and to highlight the local relevance of the findings. In regards to communication channels and dissemination strategies, it was recognized that strategies will need to be identified that are geared specifically to each community. However, the common elements of the recommendations included: 1) releasing results first to the community prior to disclosure to other target audiences; and 2) utilizing multiple approaches, including interactive face-to-face strategies supported by Internet or paper-based communication tools.

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Appendix A: Semi-Structured Interview Guide – Environmental Health Researchers

**As new concepts emerge the interview guide will be adapted for subsequent interviews to permit in-depth exploration of all key ideas and themes.

Participant ID: _____

Date of Interview: _____

Thank you for agreeing to participate in this interview with me today and for your willingness to share your expertise. The overall purpose of the interview today is to gain an understanding of the processes of knowledge uptake and utilization by researchers and stakeholders involved in either the creation of environmental health research or the uptake and utilization of this research to influence environmental health programs and policies impacting First Nations communities. I would like to confirm that all of the information you share today will remain confidential and no identifying information will be included in any of the final report documents. The interview will last for approximately 90 minutes.

1. Can you briefly describe your role in developing and conducting health research that includes an element of environment and your relationship to working with First Nations communities?
 - a. Confirm title of role, type of organization
 - b. Confirm area of environmental health expertise (eg. climate change, water quality, indoor environmental health)
 - c. Confirm type and level of relationships and interactions with First Nations communities.

For this project, we are broadly defining knowledge transfer and exchange as a collaborative and interactive process of knowledge exchange between researchers and decision-makers. In regards to the timing of knowledge transfer and exchange activities, we recognize that researchers may participate in either 1) end of grant activities; or 2) integrated KTE approaches with decision-maker partners through the lifespan of the project.

2. Can you briefly describe your current understanding of what such terms as knowledge translation or knowledge transfer and exchange mean? (Probe for their understanding of the terms).
 - a. What activities are included?
3. Please describe at least one environmental health research project that you have participated in that involved some aspects of knowledge transfer and exchange with First Nations decision-makers, communities or organizations. (If an

example is required, the interviewer might state “In this context “decision-makers” might be Community Health Representatives, Health professionals in the community, the Band Council, the Chief Medical Officer of Health or a local Health Committee for example.)

- a. Probe for timing of KTE activities e.g. integrated throughout process, end of grant activities only
 - b. Probe for how ‘key messages’ were developed e.g. how was it determined ‘what’ data would be shared with decision-maker partners.
 - c. Is there a process for identifying and then involving ‘indigenous’ knowledge with the research evidence findings?
 - d. Probe for process by which target audience is defined? E.g. To whom do you specifically transfer research knowledge? Is the KTE process in a project altered when multiple target audiences are identified? If so, how?
 - e. When working with First Nations decision-makers or organizations, who do you perceive is a credible ‘messenger’ to share research evidence with the decision-maker partners? Public?
4. How do you engage your target audience in the research process?
 - a. When are members of the target audience invited to participate in the research process e.g. at stage of question development, through study implementation, only at dissemination stage?
 - b. What dissemination strategies have you commonly used to transfer research knowledge?
 - c. What channels of communication have you used to transfer research knowledge? Probe: Do you use supporting infrastructures such as websites or newsletters to share research knowledge?
 - d. Can you describe what would be the most effective dissemination strategies (or are you wanting to inquire about channels?) for communicating scientific research evidence about environmental health issues to First Nations decision-makers? Probe for any current barriers to using what they would perceive as most ‘effective’ strategy
 - e. Ideally, what would be the most effective and appropriate channels of communication? Probe for any current barriers to what they would perceive as the most effective channels.
 5. Have you evaluated these knowledge translation activities? (yes/no)
 - a. How did you evaluate the activity?
 - b. What indicators of success did you use?
 - c. What strategies were successful?
 - d. What were the significant challenges faced?

6. What are your ideas for moving towards the goal of having both indigenous knowledge and research evidence inform environmental health policy impacting First Nations populations?
7. The development of relationships between researchers and decision-makers is encouraged throughout the research process to eventually facilitate the uptake and utilization of research evidence. What advice would you give to a researcher interested in establishing this type of relationship with a decision-maker in an organization or community concerned about environmental issues impacting First Nations populations?
8. What is unique about the process of knowledge translation and exchange within First Nations communities or organizations?
9. Will you be engaged in similar work in the future?

Semi-Structured Interview Guide – External/Internal Decision-Makers

**As new concepts emerge the interview guide will be adapted for subsequent interviews to permit in-depth exploration of all key ideas and themes.

Participant ID: _____

Date of Interview: _____

Thank you for agreeing to participate in this interview with me today and for your willingness to share your expertise. The overall purpose of the interview today is to gain an understanding of the processes of knowledge uptake and utilization by researchers and stakeholders involved in either the creation of environmental health research or the uptake and utilization of this research to influence environmental health programs and policies impacting First Nations communities. I would like to confirm that all of the information you share today will remain confidential and no identifying information will be included in any of the final report documents. The interview will last for approximately 90 minutes.

10. Can you briefly describe your role in either the development or utilization of environmental health research and your relationship to working with First Nations communities?
 - a. Confirm title of role, type of organization
 - b. Confirm area of environmental health expertise (eg. climate change, water quality, indoor environmental health)
 - c. Confirm type and level of relationships and interactions with First Nations communities.
 11. Can you discuss your experiences of how environmental health decisions or policies are made in First Nations communities?
 - a. Probe for who is involved in the decision-making process
 - b. Identify different types of evidence used to inform decisions
 - c. Identify factors that influence decision-making within organization
 12. What types of knowledge or 'evidence' is valued by decision-makers within your organization?
 - a. Probe if different levels of decision-makers value different types of knowledge
 - b. Probe for if there is a 'hierarchy' of evidence of if more value is placed on one type of evidence over another
 - c. What is the process of resolution, if information from different knowledge sources is in conflict?
 13. What are the sources for different types of evidence?
 - a. Probe for barriers and facilitators for accessing these different sources
 14. The process by which research evidence is shared and communicated with different audiences is an important step in the knowledge translation process. In your organization, how is information best shared and communicated?
 - a. Probe for both written and oral communication
 - b. Probe for who would be perceived as a credible key messenger
 - c. Probe for communication strategies that may not be effective within the organization
 - d. Introduce concept of knowledge brokers and explore participant's perceptions of the concept and role.
 - e. Discuss perceptions of communication channels, products and processes currently being developed by the National Collaborating Centre for Aboriginal Health and the First Nations Environmental Health Innovation Network
 15. What factors influence the utilization of research evidence within your organization?
 - a. Probe for individual, organizational, cultural and environmental factors.
 16. For researchers who produce research evidence relevant to environmental health decision-makers, how would you best advise them to share or disseminate their research findings to decision-makers in Aboriginal health care settings?
 17. What is the solution for moving towards the goal of having both indigenous knowledge and research evidence inform environmental health policy impacting First Nations populations?
 18. The development of relationships between researchers and decision-makers is encouraged throughout the research process to eventually facilitate the uptake and utilization of research evidence. What advice would you give to a researcher interested in establishing this type of relationship with a decision-maker in an organization or community concerned about environmental issues impacting First Nations populations?
 19. What is unique about the process of knowledge translation and exchange within First Nations communities or organizations?
- ### Additional Questions
- Based on responses from participants in earlier interviews, we are also interested in learning more about the following issues:
1. What can be done to facilitate the sharing of worldviews between researchers, decision makers and FN communities?
 - What type of knowledge exchange strategies would specifically help researchers to understand the concept of environmental health from the perspective of FN communities since they see it differently?
 - How can researchers better communicate their career objectives and academic obligations to FN communities?
 - When language or terminology is a barrier, what strategies need to be adopted to ensure that researchers, decision-makers and FN people understand each other?
 - How can the research process be designed to ensure both that FN ways of knowledge and working are respected and that academic or funding regulations are upheld?
 2. What impact has OCAP (Ownership, control, access and possession principles) had on the process of knowledge transfer and exchange? (see National Aboriginal Health Organization [NAHO] website www.naho.ca)
 3. How do you define indigenous knowledge?
 4. The process of gaining trust is complicated when outsiders enter a FN community.
 - How do FN people judge the credibility of a person?
 - What is the role of food during FN public communications?
 - Are there common social norms among FN communities that influence their communication with researchers and DM?
 5. What is the social calendar/time clock of the FN communities and how does it influence or impact knowledge exchange?
 - What are ways to facilitate the approval process for Band & Council that will limit the time it takes?

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