



Hepatitis C National Inuit Strategic Planning Session

Focus Group Analysis prepared for the
*Hepatitis C Gaining the Tools to Make
Informed Decisions Project*

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Contents

Introduction.....	1
Methodology.....	2
▪ <i>Focus Group Sessions</i>	2
▪ <i>Focus Group Participants</i>	2
▪ <i>Facilitator’s Guide</i>	4
▪ <i>PowerPoint Presentation</i>	4
▪ <i>Methodological Limitations</i>	4
Knowledge, Attitudes, and Behaviours	5
▪ <i>Basic Knowledge of Hepatitis</i>	5
▪ <i>Knowledge of HCV Transmission</i>	5
▪ <i>Knowledge about HCV Infection, Testing, and Treatment</i>	6
▪ <i>Attitudes about HCV Infection</i>	9
▪ <i>Inuit-Specific Risk Behaviour</i>	11
▪ <i>Inuit-Specific Attitudes about HCV Testing</i>	12
▪ <i>Knowledge Transfer</i>	13
Session Wrap-Up	16
Discussion and Conclusions	16
▪ <i>Knowledge</i>	17
▪ <i>Attitudes</i>	17
▪ <i>Behaviour</i>	18
▪ <i>Health Literacy</i>	19

Introduction

In the past, Inuit did not consider diseases as contagious. When caring for someone who was sick, Inuit did not think that they could get sick, even if they were exposed to the sick person's spit and blood.

Those of us over the age of fifty don't really believe in wearing gloves. We were used to taking care of very sick people who were dying. It was only after the qallunaat came that there were contagious diseases.¹

Times have changed and Inuit populations across Canada have experienced a range of epidemics that have heightened their awareness about communicable diseases. Measles, tuberculosis, respiratory tract infections, and otitis media have left their mark on the health and minds of many Inuit. Today, concerns over influenza and HIV are widespread and Inuit have become more knowledgeable about how to protect themselves. However, despite a history of hepatitis A virus (HAV) and hepatitis B virus (HBV) epidemics,² general knowledge about hepatitis is limited among Inuit. This is especially true of hepatitis C virus (HCV). For example, Pauktuutit's research indicates the Twinrix television commercials for the HAV and HBV vaccine are widely viewed among Inuit but the distinction between the three main hepatitis viruses is lost and the dangers are often viewed as a risk only in southern or tropical climates.

Inuit and First Nations communities are at risk of hepatitis viruses because of poor health, low education levels, overcrowded housing, poor sanitation, high unemployment, regular involvement in certain high-risk activities, and their over-representation in the high-risk environment of Canada's prison system.³ Change can be instilled, however, with increased knowledge. The assumption is that education leads to greater awareness which, in turn, leads to changes in attitude and then to changes in behaviour. Information campaigns, however, are filtered through cultural lenses and these may limit the success of campaigns aimed at changing behaviour. With respect to HCV, it is important to undertake knowledge-attitude-behaviour (K-A-B) studies in order to identify Inuit-specific attitudes and behaviours. For example, many Inuit maintain a stigma against those who are HIV-positive and this seems to extend to those who may have HCV and other blood-borne illnesses. This stigma may discourage HCV testing.

The utility of health literacy as a component of clinical care and health promotion is gaining importance. Its relevance to community-based outreach and health communication is clear.

¹ Inuit Elder quoted in Therrien and Laugrand (eds.) (2001). *Interviewing Inuit Elders: Volume 5 – Health Practices*. Iqaluit: Nunavut Arctic College. p. 200.

² HAV and HBV occur at high and endemic rates in Arctic populations. For example, serosurveys suggest 50-70% of adults in Arctic populations have had previous exposure to HAV. There was a major HAV epidemic in northern Canada in 1991-92 in communities without running water and adequate sewage disposal. Among Canadian Inuit, serosurveys show HBV exposure rates of about 25% and chronic HBV infection of 5%. These rates far exceed those among other Canadians (Koch, A., M. Bruce, and P. Homøe (2008). Infectious Diseases, in *Health Transitions in Arctic Populations*, T.K. Young and P. Bjerregaard (eds.). Toronto, ON: University of Toronto Press. p. 272-4).

³ Minuk G.Y. and J. Uhanova (2003). Viral hepatitis in the Canadian Inuit and First Nations populations. *Can J Gastroenterol*. 2003 Dec; 17(12): 707-12.

There is a need, however, to focus on the skills and capacity of community members to exert greater control over their health and the factors that shape health. With respect to Inuit and HCV, there is a need to learn more about the associated knowledge, attitudes, and behaviour. This will contribute to the development of communication and learning tools that meet the capacity and skills of the audience and which are culturally and linguistically appropriate. Accordingly, Pauktuutit conducted a number of focus groups to facilitate the design and implementation of appropriate public health education strategies that will better support behavioural changes.

Methodology

Focus Group Sessions

In order to gain a cross-Canada sense of Inuit knowledge, attitudes, and behaviours about HCV, Pauktuutit undertook five focus group sessions involving a total of 43 individuals. The sessions took place in August and September 2011 in the communities of Inuvik, NWT (nine participants), Iqaluit, Nunavut (12 participants), Arviat, Nunavut (nine participants), Kuujuaq, Nunavik (three participants), and Goose Bay, Nunatsiavut (10 participants). Focus group participants were selected from the general Inuit public. Each participant signed a consent form, completed a brief registration form that garnered limited demographic data, and received a modest \$50 honorarium at the end of the session.

Focus groups provide an opportunity for a small number of people who share common interests or concerns to share their opinions on a given topic in a comfortable, non-coercive environment. The group format of the session promotes an atmosphere of disclosure in which people can exchange their ideas, experiences, and attitudes. Respondents can qualify responses or give contingent answers to questions. The researchers have an opportunity to interact directly with respondents, to seek clarifications, to ask follow-up questions, and to probe further for responses. As well, it is possible for researchers to observe non-verbal responses that can supplement verbal response. In all but the Inuvik session, a session facilitator and note taker managed the events. To facilitate the recording of the sessions, Pauktuutit used a ‘smartpen’ made by Livescribe that allowed the note taker to record everything that was heard and written.⁴

As part of other projects, Pauktuutit has conducted focus group sessions on such topics as communicable diseases, Fetal Alcohol Spectrum Disorder (FASD), and HIV/AIDS. Where relevant, the results of this research will be referenced in this report.

Focus Group Participants

For this project, there was concern that any focus group that included health professionals would result in these individuals dominating the sessions. Their knowledge and expertise would

⁴ Livescribe’s smartpen contains a high-speed digital camera and digital audio recorder. The camera records the handwritten notes and links them to the audio recording. Tapping the pen on the notes will replay the audio at the point when the note was written. Optionally, the notes and audio can be uploaded to a computer for playback and review. The pen frees the note taker from recording verbatim notes, allowing them to capture the sequence of discussions and non-verbal reactions instead. See Livescribe’s Internet site, URL: <http://www.livescribe.com>

influence the discussions, perhaps suppressing less informed commentary. Dominant and informed individuals may reduce the sharing of ideas, experiences, and attitudes on medically related topics. As such, health professionals were not included in the focus group sessions.

Overall, the male-female mix was almost equal among all participants (49% female and 51% male) though there was wide variation between sessions. All three participants in the Kuujjuaq session were female as were nine of the 10 participants in Goose Bay. In Arviat, however, eight of the nine participants were male (89%) as were eight of the 12 participants (67%) in Iqaluit. Only in Inuvik was the male-female mix fairly equal — four females (44%) and five males (56%).

In terms of age, almost 56% of the participants were under the age of 30 years. The age of the participants are summarized as follows:

Age Group	% of All Participants (n=43)
16 - 20 years	14%
21 - 30 years	42%
31 - 40 years	18%
41 - 50 years	18%
51 + years	7%

Overall, the age mix for the focus groups approached the makeup of Canada's Inuit population — according to the 2006 Census, 63% of the Inuit population was under 30 years and the median age was 22 years. As such, it was important to capture the views of younger Inuit. The views of older Inuit, however, should not be overlooked since many may hold a stronger sense of Inuit culture and history.

The focus group sessions were conducted in English though occasionally participants made comments in Inuktitut. About 84% of the participants indicated they spoke English at home; 37% indicated they spoke Inuktitut as well. Only 3% indicated they spoke French at home. Participants from Nunavut were the most likely to indicate they spoke Inuktitut at home which is an important consideration given that 84% of all Inuit living in Nunangat reside in that territory. None of the participants in Inuvik indicated they spoke Inuktitut at home and only 10% indicated as much in Goose Bay.⁵

Consistently, about one-third of participants in each session indicated they had attained at least a high school education which is about triple the rate reported in the 2006 Census for Inuit living in Inuit Nunangat. Thirty percent of participants indicated they had completed some form of college and 9% indicated they had completed university. Notably, almost 12% preferred not to answer the question, primarily those in Goose Bay. Overall, the level of education among the

⁵ According to the 2006 Census, almost all Inuit in Nunavik could speak Inuktitut in conversation and in Nunavut over 90% could do the same. In both Nunatsiavut and Inuvialuit, the rates were much lower, 27% and 20% respectively (Statistics Canada (2008). *Tables Report. 2006 Census Inuit Tables*. Catalogue no. 89-636-X no. 001. Ottawa, ON: Statistics Canada, Social and Aboriginal Statistics Division).

focus group participants exceeds the levels among Inuit recorded in the 2006 Census.⁶ Focus group participants from Iqaluit had the highest levels of education.

As part of the focus group registration, participants were asked to rank their knowledge or understanding of hepatitis using a five-point scale. The average rating was *fair*. Over 46% indicated they had a fair knowledge of the disease; less than 5% indicated a *very good* or *excellent* understanding. About a third ranked their knowledge as *poor*. In Inuvik, however, only 22% ranked their knowledge as *poor*.

When asked to rank whether hepatitis is a health problem in their community, participants generally *neither agreed nor disagreed* with the question (63%). However, those in Iqaluit and Arviat were more likely to agree that the disease is a problem (25% and 22% respectively). Education and larger communities may be a factor.

Facilitator's Guide

To ensure consistency between focus group sessions, a facilitator's guide was prepared to help direct the facilitator and note-taker through the events. The guide outlined the role of the facilitator and note taker, outlined the anticipated sequence of events for each focus group session, provided a sample introductory statement, provided guidelines about questions and topics, explained the post-session debriefing process, and provided a basic glossary of terms and concepts in anticipation of questions and issues that may be raised. The intent was to ensure a consistent and systematic approach to each session in order to garner consistent and comparable focus group results.

PowerPoint Presentation

To guide the focus group sessions, to promote participant dialogue, and to ensure consistency between sessions, a 15-slide PowerPoint presentation was prepared. Each slide was supplemented with notes to help the facilitator. The notes outline the purpose and intent of each slide (e.g., what is the goal or objective of the slide's discussion points; what kind of information is being sought?). The supplemental notes accompanying each slide also include possible questions to be asked, often in the form of a general question followed by more probing or specific questions. For some slides, additional clarifications were included in the accompanying notes in anticipation of possible questions that could be raised by focus group participants.

Methodological Limitations

The following limitations should be noted with respect to the execution of this project:

- The focus group session conducted in Kuujjuaq had only three participants and they were all women. As such, the session did not garnered as wide a range of view points as expected; and

⁶ *Ibid.* See Table 5.

- Technical difficulties prevented the use of the smartpen during the Inuvik session. The resulting recording — using alternate equipment — was of poorer quality, forcing the analysis to rely more upon the session’s notes.

Knowledge, Attitudes, and Behaviours

Basic Knowledge of Hepatitis

The focus group session began with a general discussion about hepatitis: the participants were simply asked: “What do you know about hepatitis infections?” The intent was to gauge general knowledge about the virus and to determine if participants are aware of HAV, HBV, and HCV and the differences. Interest was in whether participants recognize hepatitis as a viral infection that causes an inflammation of the liver. Typically, participants were first quiet and reluctant to talk. Some indicated they had no knowledge, others asked questions about its similarity to tuberculosis, its mode of transmission, whether greater hand washing as a result of people avoiding the flu had reduced the rate of hepatitis, or whether statistics about the disease among Inuit existed. In Iqaluit, Arviat, Kuujjuaq, and Goose Bay reference was made to the Twinrix TV commercial for the HAV and HBV vaccine – contaminated ice cubes was a common comment. Some informants knew hepatitis was a blood-borne disease but they were not always sure if it affected the liver or the kidneys. Those in Inuvik seemed more informed, recognizing the disease as treatable or curable but over time and requiring lifestyle changes. Those in Arviat appeared to be least informed.

Knowledge of HCV Transmission

I know people with Hep C but I don't know how they got it; I do not know how you can really spread it. I worry. But I know I would never know how I got it; I think there are... too many ways that it could have happened that I could never pin it down (Female participant in Iqaluit).

Through the course of the opening discussion topics, participants were informed about different hepatitis viruses and their modes of transmission. In part, this unfolded as the participants’ initial questions were answered. With this added knowledge, the participants were then asked to discuss how a person could become infected with HCV and how they would know. Interest was in general knowledge about transmission and risk behaviours and in identifying possible misconceptions. To stimulate discussion, the participants were presented hypothetical vectors for transmission of HCV and then were asked what they thought. Possible scenarios included coughing or sneezing, shaking hands and kissing, sharing food, eating contaminated food, insect bug bites, and sharing razors, toothbrushes, and needles for drugs or tattoos.

The topics of discussion varied between focus groups. Those in Iqaluit and Kuujjuaq tended to focus on blood-to-blood transmission with reference to blood transfusions and sharing needles and razors. However, there were also comments about insect bites in hot countries and mucous and saliva. In Goose Bay, participants discussed blood-borne transmission but also suggested ice cubes, physical contact, and contaminated food. Participants admitted they were not really sure.

One person wondered if a mother chewing food before giving it to her child might pass on the virus. Another wondered about breastfeeding, noting it was possible to transmit HIV/AIDS but they were unsure about HCV. When prompted, participants in Goose Bay and Inuvik identified sharing needles for drugs or tattoos and toothbrushes as modes of transmission. Those in Arviat also identified coughing, hand shaking, and contaminated food. Reference to the Twinrix TV commercial was repeated. In Inuvik, participants wondered about spreading the virus through shared food; what if a person were to cut himself or herself while eating raw caribou meat and then another person ate the meat? This issue was raised in Iqaluit in response to a different question. A participant noted Inuit eat together and that high-risk behaviour is part of Inuit. “Inuit cut themselves all the time.”

In general, the question about ways of becoming HCV infected initially elicited little response. Participants in Goose Bay and Arviat appeared to be the most engaged in the topic though neither group appeared more informed than any other. Some participants admitted they were not sure about how the virus was transmitted. When prompted with the PowerPoint presentation, some participants identified the full gamut of hypothetical possibilities. There is some confusion about vectors common to influenza and tuberculosis and those more specific to HCV and HIV/AIDS. As well, some participants failed to differentiate HCV from HAV and HBV. Participants failed to offer any statements about possible signs or symptoms of HCV infection. A few suggested the need to get tested but wondered how you would know to get tested.

Participants in Iqaluit expressed concern about how easy it is to contact HCV; they discussed HCV in the context of contracting tuberculosis versus HIV: “...if it as easy to get as TB then we are at high risk but then I am also thinking that if it is as hard to get as HIV then I think we would be OK.” Another responded, “...if it is as bad as TB then we are really in the dark.... I think we'll learn how easy it is to catch it and how very communicable it is.” Someone speculated that maybe HCV has been around for centuries “...and we just didn't know it.”

Tattoos seemed to be a point of concern in Iqaluit. Some participants expressed concern about their homemade tattoos and others tended to agree. This was also true among those in Goose Bay where participants noted there was lots of home tattoos and body piercing; “lots of tattoo artists who do not have shops here in Goose Bay.”

Participants also considered the risks associated with manicures. In Kuujuaq, there was reference to a TV commercial about hepatitis and manicures. In Goose Bay, discussion shifted to misinformation and TV commercials. Someone noted “...some may think they can get it from just touching something.” Another noted, “A lot of people are misinformed and they think they can get it this way and that way.” In general, there was not a strong link between engaging in possible risk behaviour as a reason to consider getting tested.

Knowledge about HCV Infection, Testing, and Treatment

The focus groups sought to gauge participant understanding of HCV symptoms. Of interest was any confusion between HAV, HBV, and/or HCV and participant recognition that symptoms are usually mild and gradual and that they may take years to appear. In all communities but Inuvik, at least one participant mentioned jaundice and/or discolouration of urine and stool. In Goose Bay, one female participant cautioned “yellowing of the skin does not mean hepatitis C; I was in

the hospital for five days with liver problems. That was “hep” because the doctor gave me the wrong medication....” A participant in Kuujjuaq note: “I know you get sick but I am not sure you get pale, or... lack of cells or something.” Gradual or more frequent illnesses and loss of appetite were mentioned in Iqaluit and Kuujjuaq. Other thoughts offered in the various sessions included concerns about excessive urination, abdominal pain, chronic alcohol consumption, flu-like symptoms, coughing, bleeding that will not stop, and symptoms similar to chickenpox. However, one female participant in Iqaluit simply stated she was unsure of the symptoms because she has never had HCV.

A persistent question posed by the focus group participants was how they would know they need to get tested, especially if the test is not routine, but something they should discuss with a medical professional. As some pointed out: Inuit will often ‘tough it out’ through an illness and will not seek medical attention. In Kuujjuaq, a participant commented that getting tested was a personal decision, “...that there are so many tests out there that you have to ask for it. Otherwise, you’d be in the hospital for days getting tested.”

Participants were asked what they would do if they thought they had symptoms for HCV. The question sought to determine participants’ knowledge about how and where to get tested, how they might feel or react (attitudes), and what they would do (behaviour). In most groups, people stated they would seek medical advice and testing. A male in Iqaluit quipped: “If you wake up with a tattoo and you don't remember, you should get tested.” Another commented:

[It] depends on what would give me that idea. If I'd been sick for a long time and it's a fever and seems systemic and serious, then I'd see a doctor. If it is minor, then I might just tough it out and think it is nothing. I might not mention it to anybody. So I do not really know how severe the symptoms are.

In Iqaluit, a woman thought peoples’ reactions would depend on their lifestyle.

If you are a drinker, maybe you do not want to be told not to drink. It's a reality. If you are a healthy person, you would not go and get tested. Personally, myself, I would never think to go and get tested for Hep C.

When asked about being too scared to go to the hospital, it was suggested that ‘older folks’ might be too scared to go to the hospital; they might assume it is just another sickness. One male suggested elders are afraid of needles.

In Kuujjuaq, there was agreement that people should get tested right away; “they should deal with it right away before it gets worse.” In Goose Bay, two women indicated they would talk to their partner and/or family first. This was echoed by a male in Arviat. Others said they would have a sense of panic or would feel embarrassed. There also was concern about ostracism. A woman in Iqaluit commented:

Look at society, before you say anything. People do not understand the disease so you might be ostracized, so you might be left out of the social circle, so I'd be pretty careful about approaching this or telling the public.

In Kuujjuaq, one person commented that if they tested positive, they would worry more about their health and less about embarrassment. Others agreed with the comment.

Primarily in Iqaluit, but also in Kuujjuaq and Goose Bay, discussions shifted to the availability and quality of medical care in the communities and the delays before receiving medical test results. Participants expressed concern about confidentiality and the long waiting period they normally expect for test results. In Kuujjuaq, it was noted that in small communities:

...they may be able to do some tests but maybe not that. So there are only two hospitals [in Nunavik], so they may have to wait to go to another community or down south. They may have to be shipped out.

A participant in Iqaluit expressed concern about communities that lack doctors: a patient's first contact would be the nurse in charge and an interpreter may be required. This raises heightened concerns about confidentiality. In small communities, medical interpreters are often from the area and are more likely to be related to, or know, a patient or a member of the patient's family. Potentially, this network acts as a barrier to voluntary testing for STIs, HIV, and HCV. Embarrassment and fear of ostracism are key concerns among Inuit. Even so, participants in Kuujjuaq and Arviat — both larger communities — agreed that it was better to get tested for HCV right away rather than wait and go to another community.

In terms of treatment, many participants were unsure. Some asked if it was curable. A participant in Arviat stated that HAV and HBV were treatable but not HCV, but he was not too sure. In Goose Bay, some one asked about the need to quarantine patients. In Kuujjuaq, one participant suggested medication, health care everyday, or that there is no treatment. She admitted she was guessing. "It lasts a year or more. I do not know." Someone else suggested a blood transfusion. Going to a doctor or hospital, following doctor's instructions, and taking pills were thoughts offered by participants in Goose Bay and Inuvik.

Importantly, participants recognized the need for lifestyle changes as part of HCV treatment. For some, this included relaxing, having a strong mind or changes in attitude. For an Arviat participant lifestyle changes meant staying away from school and being careful. In Goose Bay and Kuujjuaq, participants talked about diet and alcohol consumption and the effects of toxins on the liver and kidneys. There was discussion in Kuujjuaq whether the occasional glass of wine would be harmful. Participants also discussed how lifestyle changes would vary between patients — those taking drugs would need to stop and seek treatment. This was repeated in Goose Bay. In Iqaluit, there was reference to the benefits of country food.

Goose Bay participants discussed the responsibility of HCV patients to inform people of the risk, such as an accident involving blood. Those in Arviat offered advice that HCV patients should find out all they can about the spread of the disease and that they should look after themselves and others. In Inuvik, participants felt it was important for patients to have knowledge about the disease.

In Goose Bay, discussion turned to those who may not seek treatment. It was suggested that Inuit may avoid treatment because of shame or because they are scared. This was linked to traditional thinking: "...like going to a medicine man instead of a doctor." It was suggested that people may

just think they have the flu and will try to treat themselves using home remedies. Some may rely on the Internet for diagnosis and then will self-treat the condition. Others may convince themselves that they feel healthy and believe they are healthy.

Attitudes about HCV Infection

The focus group participants were asked what their reaction would be if they discovered they were HCV positive. The intent was to gain a greater understanding of Inuit attitudes and behaviour, and to gauge personal or emotional reactions to HCV and other communicable diseases. Generally, participants were willing to discuss the matter and they offered a range of comments. Participants from Iqaluit and Goose Bay expressed concern about the reputation and respect for the affected individual and their family. A male from Iqaluit noted “stigma is a pretty big deal; everybody knows everybody.” A woman stated she would be ashamed at first because of the stigma and that this might be a concern when seeking treatment. She said she would feel undesirable and would not want to share information. To avoid shame she may avoid treatment and seek ways to treat herself.

In Goose Bay, a female expressed concern about a person’s health and what others might say. She stated “... [I] don't want to walk around town with others saying whatever or whispering, or like don't take something from her or something like that...” Goose Bay’s participants had a general concern about other peoples’ reaction, about misinformed community members, and concern about the stigma associated with a HCV diagnosis. Even so, there was agreement that it was better to seek treatment than to worry about what others thought. This was echoed by participants in Kuujjuaq.

One participant in Kuujjuaq concluded that HCV was not as scary as HIV; “like with AIDS you would be really embarrassed or something to tell people.” There was speculation that “maybe with hepatitis C where people are not totally aware of it. They may not know or think it is a virus, so they may not be ashamed when people find out.” Another stated she would be “...more worried than anything until you knew all the risks involved.”

Fear, shame, embarrassment, and anger also were widely cited as possible reactions. For some it would be shock, surprise, or nervousness. A female in Goose Bay stated “I wouldn't know where I got it or where it came from; it would be like ‘why me kind of thing’.” In Inuvik, there was a comment about finding out who had given them the virus. In Arviat there were comments about guilt, self-blaming, being sad, and shocked. One participant thought they would be scared and “...embarrassed about myself for whatever I had done to get the disease. Also mad about wherever I got it from and mad with myself.”

A more traditional perspective was offered by a participant in Iqaluit:

Inuit have a way of, you know, it is what it is, you accept it right away without really thinking about it. You fight it the best way you know how... The ajurnarmat [‘it can't be helped’ or ‘it can't be fixed’] is one of the philosophies that might be one of the ways we approach things. We may keep it quiet because of our casting people so there might be a lot of elders out there who are familiar with it — we don't know. The old way of approaching stuff was to keep it quiet, deal with it in the family, but if it has to be told, you would go to each of the household heads and talk with them.

That was how it was spread by word. I do not know if they still do that. We try to do it anyways with our families but it still could be kept quiet as well because some people can't handle it... It depends on a case-by-case I guess.

To further gauge knowledge and attitudes about HCV, participants were asked if they were concerned about HCV in their community and about the communicable disease they thought was the biggest problem in the North. Though HCV infection rates are disproportionately higher in First Nations and Inuit populations in Canada — up to 5.5 times higher than in the non-Aboriginal population — it is unclear that Inuit perceive the disease as a problem. Additional interest is in whether Inuit understand the different risks associated with different communicable diseases.

In general, the concerns of the focus groups were linked to the level of media or health promotion associated with an illness. Accordingly, concern over HCV was not high. In Iqaluit, a participant stated “...I don't know. We don't care about it [HCV] in Resolute, Iqaluit, or Whale Cove.” In Kuujjuaq, a participant indicated that they don't really hear about it:

...you hear about it when you go for shots when vacationing in the south. You hear it advertised. You hear about people getting it down there; you don't hear about getting it up here. You get shots before you do.

This was echoed in Inuvik — that people are probably least knowledgeable about HCV. A participant expressed concern that this lack of knowledge means that there is greater potential for HCV to spread. In Goose Bay, there was heightened awareness about hepatitis because of a recent incidence of HAV in a Tim Hortons located in Labrador City. Underlying these comments is the fact that some focus group participants are not clear about the different types of hepatitis infections.

Initially, participants in Iqaluit, Goose Bay, and Kuujjuaq identified tuberculosis as the North's biggest health problem. However, a participant in Iqaluit stated “...I would say TB though we don't need to worry about TB anymore... First thing I think of is TB. And that was horrible. I hated the stigma of everybody knowing I had TB.”

Influenza also was widely cited. As a female in Iqaluit stated: [there are] so many flus going around that it is easy to panic. It depends on how Health and Social Services [Government of Nunavut] approaches it. With H1N1 there was a big panic. Media plays a role.” Others commented that the flu is airborne, and that “...even if you get the flu shot you still can get it.”

A great deal of concern was expressed in every group about HIV/AIDS. There were views that HIV/AIDS was on the rise, that there was no cure, and that it was expensive to stay alive. A participant in Kuujjuaq noted that the publicity for AIDS was “pretty strong.” For some in Arviat, the lifelong illness associated with both HIV/AIDS and HCV were points of concern.

In Goose Bay, more than one participant identified STIs as their biggest health concern. Participants also identified cancer as a problem as did participants in the Nunavut (Iqaluit and Arviat) sessions. One person noted that nobody talks about it in a focus group-type session. Those in Kuujjuaq spent time talking about diabetes as the number one health problem. Diabetes was identified as a major communicable disease in Nunavik by one participant. Another noted

that medical services are now better so tuberculosis and diabetes are less of a concern. In other focus groups, there was also passing reference to FASD, heart attacks, and strokes but there was little or no discussion on these topics.

Participants also were asked to prioritize tuberculosis, HIV, and HCV in terms of who should receive immediate medical attention. In all but Inuvik, the response was to give priority care to tuberculosis patients. It was perceived to be the most easy to diagnose, in the short-term more likely to be fatal, and the easiest to cure. A deciding factor in all sessions was how fast each disease progresses. HIV/AIDS and HCV were perceived as lifelong illnesses — diseases that are less urgent. In Goose Bay, participants considered the extent of each patient's illness. Though tuberculosis is a serious illness that deserves treatment, participants agreed "...a person with AIDS and the flu may require immediate attention." In Kuujjuaq, there was reference to the fact that tuberculosis is more common in the North, suggesting infection rates are a factor in how people prioritize illnesses for immediate attention.

Inuit-Specific Risk Behaviour

The focus group participants were asked to identify Inuit-specific behaviour that may lead to HCV infection. The effort was to gauge further Inuit understanding of typical risk behaviours as well as to identify unique examples that may be useful or relevant in future health promotion strategies. The participants offered a wide range of views and opinions. For many, there was a sense that everyday or common activities make them vulnerable to HCV. Some expressed concern about sharing ulus and the loss of traditional practices and values if such activities as hunting, fishing, carving, sewing, communal eating, and such Inuit games as mouth pulling and wrestling are deemed risk factors. In Iqaluit, there was discussion about the possible spread of HCV in the blood of raw seal meat when it is eaten communally. One woman described the stigma associated with country food following warnings about northern contaminants:

... [If] we start advertising various scenarios, there might be widespread panic... Like when they did research on PCBs there was widespread panic all over Nunavut and to a point where we lost a lot of our culture... because the young generations refused to eat seal meat any more. And this is another thing that might do that.

A male participant noted most Inuit are at high risk and automatically may be afraid of anything that leads to HCV infection. This point was echoed in Kuujjuaq where someone suggested even a bicycle accident or a cut finger may place a person at risk.

Overcrowding was discussed in Kuujjuaq, Arviat, and Goose Bay as social and physical circumstances that may contribute to the spread of HCV among Inuit. Close quarters may increase the prospect of sharing items for personal hygiene which, in turn, may lead to more frequent blood-to-blood contact.

In Goose Bay, participants talked about tattoos and the number of artists without shops. Discussion then turned to the consequences of the stigma and lack of knowledge about HCV among Inuit. It was suggested Inuit are at risk because of their lack of knowledge. When people find out they are sick it is already too late since they have passed on the virus to others. Alternatively, people may keep knowledge of their HCV infection to themselves to avoid negative responses and this could lead to HCV transmission. It was noted that people already

have a negative term or image in their head about HCV. In a related comment, someone in Iqaluit noted that information needs to be provided in a “truthful way” that fits the needs of the locals.

In Kuujuaq, there was some discussion about the idea that Inuit are reluctant to discuss the topic of HCV. However, participants agreed that it is something that should be talked about. One participant suggested that Inuit are not shy about the topic, “I think Inuit are more aware of it... that there is a lot of help that is here because it is a smaller community. I think they are more aware of it and not that shy to talk about it...”

There was also discussion about alcohol, bars, and drug use. It was noted that people are less careful and therefore at greater risk when they are under the influence of drugs or alcohol.

Inuit-Specific Attitudes about HCV Testing

When asked, the focus group participants agreed that HCV testing was important to stop the spread of the virus. However, there were a number of comments concerning Inuit attitudes about health and sickness that are relevant to the question of testing. A more traditional perspective was offered in Iqaluit. A female suggested Inuit hunters are strong and do not want to get tested so that is why there are a lot of late diagnoses. A male suggested, “...Inuit may think their bodies are too precious; they don't know they have it.” In Arviat, the suggestion was one of denial: “[an] attitude that it won't happen to me. Like Inuit attitudes about cancer and HIV...” A female participant in Goose Bay suggested Inuit are willing to live with the symptoms; that they will just go on and on and wait.

Being too scared to get tested was mentioned in Arviat, Goose Bay, and Inuvik. This fear was linked to a fear of needles and to issues of confidentiality and stigmatization. For example, a Goose Bay participant described her concerns about confidentiality in the context of two nurses discussing a patient's HIV tests in a hospital hallway where everyone could hear. She suggested this makes people paranoid. Another suggested Inuit keep knowledge of HCV secret to avoid negative responses and that this could lead to the spread of the disease.

The Goose Bay participants talked about how Inuit do not want to go to the hospital, that the wait times to see a doctor or nurse or to get test results, make people frustrated with the healthcare in the region. If it takes weeks to get test results, there is no prevention in the meantime. A participant wondered how long it would take to get HCV test results back. Focus group participants in Iqaluit also expressed concerns about health and social support services. One female participant suggested Inuit might not get tested if they do not know how they will be treated. There is concern — especially in the smaller communities — that they might have to leave their community or go to Ottawa for treatment. This is viewed as a hassle, especially if they are not sure of the treatment. It was suggested that age also might be a factor when it comes to taking pills and getting blood work. Basically, people do not want to leave Iqaluit. This concern about treatment also was echoed in Kuujuaq — Inuit may be afraid to get tested because they do not know what will happen to them if they test positive.

Discussion in Iqaluit shifted to the availability of support services. It was noted that even in Iqaluit there were not enough counsellors and homecare workers to support people. Participants

agreed with the statement made by one that “even if someone is suspicious [of having HCV], they don't bother [to get tested] because who is going to help you anyway?” A female participant advised that if you are going to talk to people in the communities about HCV you must tell them what the treatment entails and how their lifestyles are going to change. She stated “...they have to be that much informed and not just know if they have it.” A male participant added that Inuit need to know the risks of carrying it without knowing, that they need to know how it is affecting their family and people close to them.

In Goose Bay, the theme of knowing when to get tested was revisited. Participants asked why people are not automatically tested for HCV. Having to know what disease to get tested for made one female participant nervous. The discussion considered the dilemma of waiting for signs of the infection before getting tested and then finding out that there is nothing that can be done.

Knowledge Transfer

...it is hard to explain illnesses in our language because we are always pointing to certain spots on our body if we are ill.... Hepatitis C attacks the liver so trying to explain that sort of stuff is really really hard (Female participant in Iqaluit).

The focus group participants were asked about the availability of HCV information. They were also asked to consider how best to convey knowledge about the disease to Inuit. Notably, none had seen Pauktuutit's online HCV factsheet. Those in Iqaluit, Arviat, and Goose Bay indicated that there was little information available and that it is not something people talk about. They tended to focus on HAV and HBV in Goose Bay, referring to the Tim Hortons HAV scare in Labrador City or confusing HCV transmission with swimming in the Dominican Republic. Notably, a Goose Bay participant lamented that the Labrador Friendship Centre cut its HCV program, that it is not under the HIV file, and there is no worker who is distributing HCV information. In Kuujjuaq, it was mentioned that they only hear about HAV and HBV.

In Iqaluit, some participants posed questions about HCV testing — whether it was available in communities, whether communities can afford the tests, and whether someone could go to a nurse and be able to ask for the test. The implication was that this was information is important to the public.

A number of formats were suggested for raising awareness about HCV. These ranged from posters; videos and video games; workshops, discussion groups and/or talking circles; TV (CBC and APTN), radio, and/or print advertising; T-shirts; school visits; marches for HCV; toll free numbers; and such computer and smart phone formats as email, text messaging, Facebook, and YouTube. Suggestions on where to advertise were equally diverse. Some participants jokingly talked about advertising in bars and toilet stalls and getting bootleggers to advertise on their products. These comments were in reference to people being less careful while drinking. Even advertising on milk cartons was suggested. Schools were widely mentioned. Other suggestions included shelters, boarding homes, hotels, institutions, hamlet offices, arenas, newspapers, Reader's Digest, Spam email, and the Inuvialuit Regional Corporation's magazine. The idea of school events was discussed in detail in Kuujjuaq. Telling children in school about HCV and sending them home with notices would also get the information to parents. The idea of bring people with HCV into the classroom was mentioned. They also thought getting the message to

people while they were at work was important. In Goose Bay, it was suggested school events should include prizes to keep students from ‘fidgeting’.

One female in Iqaluit suggested working with elders because they have "...a beautiful way of explaining stuff" so people will listen. Another suggested having information available at Iqaluit's Tukisigiavik Centre, a community-based organization.⁷ In Kuujjuaq, the idea was that elders should be informed because they adopt little children. Those in Arviat thought elders should be informed through presentations at elder groups. In Kuujjuaq, the use of the radio was recommended, in part, because older people listen to it.

One Iqaluit participant noted that workshops "are great" until the weather is nice, then everyone wants to be outside. A suggestion in Inuvik was to "...keep advertising, and then have a feast or supper to bring people together." In Kuujjuaq, the sense was that workshops were "worth a try." They also talked about whether HCV Awareness Day (July 28) was recognized in Nunavik. TV also was recommended. The Goose Bay participants kept returning to the value of TV commercials even though their comments throughout the session suggest they tend to associate the Twinrix commercial with HCV. With respect to workshops and/or discussion groups, someone suggested people do not want to sit down and talk to you. They want [greater] interaction.

In terms of disseminating information, there was some reference to better targeting of audiences. In Arviat, it was suggested that public awareness announcements should be developed that target different groups. In Kuujjuaq, drug users were specifically identified. The idea was to include HCV as a topic during awareness events, discussions, or sessions that target drug users. In Iqaluit, there was some discussion that messaging should vary depending on location and the audience. For example, Iqaluit was viewed as different from other communities. A female noted that chronic abuse in the communities and chronic abuse among urban Inuit is different, and that the message needs to be adjusted accordingly. She stated "...it is important to differentiate substance abuse, chronic abuse, and how long people have been sick so it does not become a scare...." The participant expressed concern that the problems plaguing urban Inuit are being used to describe and guide messaging for all Inuit. She suggested the message could target those who need to get treated or those who should be tested.

The use of posters was widely discussed. In Iqaluit, one participant noted that they work if they are seen everyday — if they have lots of information they take a while to read. Another suggested they ‘should give a little scare’ about being cautious. In Kuujjuaq, the thought was that posters should be placed in hospital waiting rooms. In Goose Bay, it was suggested that posters should catch the eye and make you want to learn more, that they should not present too much information or “overload” the poster with information. Condom posters were identified as a good example. It was suggested a poster should catch a person’s attention, offer a few words, and then

⁷ The Tukisigiavik Centre offers practical support and assistance to individuals and families with personal and family issues, as well as health, healing, education, employment issues, etc. Two Inuit elder-advisors teach traditional skill development and give advice on Inuit values, customs, belief, and practices. Inuit Qaujimajatuqangit forms the basis for the services and programs offered by the centre.

direct people to web links for more information. Breastfeeding posters were offered as another good example.⁸

In Iqaluit, there was discussion about fact sheets. A male in Iqaluit admitted that if they were placed in the public health centre he might have seen it but was never interested in it.

Noting that some people are illiterate, one Iqaluit participant recommended approaching the matter of information dissemination in simple language:

...people just don't pick up a piece of paper and read about hepatitis C. That just will not happen... And when you mention about high risk practices, alarm bells went off... I thought this was going to be something like an epidemic. If you use language like that — like high risk behaviour, you're pointing fingers already and people will not want to come and get tested. What we should do... is get tested on our own initiative; it should be from our compassionate point of view, that you encourage people, give them hope if they get tested. So if you get tested, you feel better. More people would be inclined to get tested. If you approach it in a very researched sort of way there is no feeling there and nobody will care.

Some focus group participants identified the need to translate material into Inuktitut. A female in Iqaluit asked, “How do we make our elders understand? It is easier to understand when you are bilingual. How do unilingual people feel about it?” In Kuujuaq, all participants agreed HCV information should be translated. This was echoed in Goose Bay.

The focus groups clearly demonstrate a need for greater knowledge about HCV. A few of the sessions had individuals with a sound understanding of the disease and others who could offer practical insights into how best to transfer knowledge. The diversity of thoughts on disseminating HCV information makes it difficult to identify a single or common tool that will achieve success for all age groups in all regions. Targeted strategies that engage the audience — but not overload the audience — may prove the most acceptable. Rather than list the clinical dimensions of HCV when messaging, it may be better to engage Inuit in a desire to get tested. Participants want to know how and when to get tested. They want to know what testing involves. Rather than reinforce to stigma with information about high-risk behaviour and ‘finger pointing’ it may be better to encourage testing using more creative and compassionate means.

The focus group participants tended to agree that messaging for those who regularly engage in high-risk behaviour may not be best for those who are at risk under more casual or less frequent circumstances. Similarly, messages for youth will not meet the needs of older Inuit. The use of new media is now an important tool that many focus group participants identified. The young age of the Inuit population, the high rates of STIs among younger Inuit, the popularity of body piercing and tattooing, and the high use of the Internet and smart phones suggest new media is a potentially important avenue for distributing information.⁹

⁸ All but one focus group participant indicated they use the Internet. Seventy-nine percent indicated they use the Internet at home and almost 35 percent had access at work.

⁹ A good example of a high school produced HIV/AIDS YouTube video that targets Inuit was prepared by the students of the Angik School in Paulatuk, NWT. The idea could easily be adapted to HCV as a means of engaging

Session Wrap-Up

As the focus groups wrapped up, participants were offered the opportunity to pose further questions about HCV, the project in general, and about Pauktuutit. Some participants sought greater clarification about the different types of hepatitis and how they are transmitted. In Iqaluit, one person asked about explaining the differences between HAV, HBV, and HCV. "What kind of symptoms are you going to get with each of them? And what's the length, are they all chronic diseases? Can you get really sick from either one? Can you be cured?" Participants in the different sessions posed a number of questions and clarifications. The questions reveal some of the topics of concern and some of the misconceptions that require clarification. These inquiries included:

- Are HAV, HBV, and HCV different diseases?
- What are blood products?
- How can tattoos and ear piercing transmit HCV?
- How is food contaminated?
- Are vaccinations given to a child or can it be given later in life?
- Are vaccines available for hepatitis?
- Sometimes newborns have yellow skin and eyes. Is this HCV?
- What is the source or origin of the hepatitis virus? and
- Does treatment for the infection cure HAV, HBV, and HCV or control the illness only?

Other comments indicated that some participants felt more empowered after the session, considering the sessions informative and having reduced their fears about the disease. Some commented that they were going to get tested.

Discussion and Conclusions

The effort of this focus group analysis has been to identify factors that influence the behaviour of Inuit. Specifically, it is intended to identify Inuit-specific knowledge and values that can guide interventions intended to reduce Inuit exposure to HCV infection and to persuade Inuit to seek testing. General characteristics identified from this analysis include a limited understanding of the medical symptoms and consequences of HCV infection, confusion about HCV transmission, fear of stigmatization similar to how Inuit respond to HIV/AIDS and STIs, a reluctance to get tested based on denial of risk, a belief that treatment may require leaving their home community, and a lack of knowledge about testing and treatment procedures. The focus group participants expressed concern that elements of traditional Inuit culture may be considered high-risk activities. In terms of risk reduction, there is a recognized lack of information in most regions. A need for targeted messaging was suggested that is directed at urban and rural Inuit, those using drugs, and at different age groups. For younger audiences, the use of new media is an important

students in a learning exercise. The project was supported by the Status of Women Council of the NWT and Health Canada. See URL: <http://www.youtube.com/watch?v=AYNh2fJAgPY>

consideration. Messaging that promotes testing may be more successful than those that convey too many facts, are judgemental against drug use, tattoos, and other high-risk behaviours, or raise the spectre of a panic or epidemic.

Knowledge

The results of previous K-A-B studies conducted by Pauktuutit indicate that STIs are readily recognized as a problem in Inuit communities. Some recognize that there is a variety of diseases to be concerned about, that younger people are getting infected and that there is a failure among some Inuit to protect themselves. In past focus groups, participants expressed a need for more information. They indicated information on STIs was available, but they were concerned that the message was not getting out. During this HCV study, participants repeated the need for more information. An environmental scan undertaken by Pauktuutit uncovered little or no health promotion on the topic of HCV in Nunavut, Nunavik, and Nunatsiavut. Like Pauktuutit's earlier focus groups on communicable diseases, the participants from Inuvik seemed to know a more than those in the other Inuit regions. This may reflect the territorial government's health promotion efforts.

Themes and Conclusions

- Some participants in each HCV focus group were more informed than others. Those in Inuvik were somewhat more informed.
- In all of the focus group sessions, some participants knew the nature of HCV transmission and its symptom.
- Many participants admitted they knew very little about hepatitis or HCV.
- There were persistent misconceptions and confusion with HAV and HBV. References to the Twinrix TV commercials for the HAV/HBV vaccine were common.
- Knowledge about the symptoms of HCV infection and about how it spreads varied widely. Generally, there was limited knowledge, suggesting the focus group participants confused the transmission of tuberculosis, influenza, and HAV and HBV with possible HCV vectors.
- Participants in Inuvik and Iqaluit wondered about the risk of spreading HCV when communally eating raw country food.
- Knowledge about testing and treatment was limited and a topic of questions regularly posed by focus group participants.
- Discussion about high-risk drug use was limited — participants were either uncomfortable with the topic or unwilling to discuss their own activities. Some considered drug use more of an urban Inuit problem.

Attitudes

Previous research by Pauktuutit confirms that many Inuit fear being stigmatized by HIV/AIDS. This is a factor that limits testing, not just for HIV but for other STIs as well. In smaller communities, Inuit worry about a lack of confidentiality or anonymity — everybody knows everybody, including those working in the health centres. This stigmatization can extend to HCV, especially if it is linked too closely with HIV/AIDS and the drug culture. The HCV focus

group research indicates Inuit do not view HCV as a health priority. They are unsure of the similarities and differences with HIV/AIDS and are unsure of Inuit society's reaction to those who are infected. Currently, any stigma against HCV may be limited because Inuit know so little about the infection. There is limited information about HCV in most Inuit regions.

Themes and Conclusions

- According to the focus groups, the same stigma and fear associated with HIV/AIDS and STIs is relevant to Inuit attitudes about HCV.
- The stigma against HCV patients is not unanimous, in part because Inuit know less about the disease, thus there is less reason to be ashamed or fearful of community reactions.
- Focus group participants do not consider HCV a priority illness, ranking it below tuberculosis, HIV, and influenza. Given the historical legacy of tuberculosis within Inuit communities, recent campaigns to combat the spread of influenza, and the Inuit-specific HIV/AIDS campaigns that have been underway for many years, it is not surprising HCV is not a priority concern.
- Because there is a misconception that HCV cannot be cured, some participants reasoned that medical attention should focus on other treatable illnesses instead. Others identified the potentially life long illness as a reason for their concern.
- Some participants expressed reluctance to get tested, citing concerns of confidentiality or because they did not know what the test involved.
- Many participants expressed concern about their homemade tattoos.
- Some participants expressed concern about the loss of traditional practices and values if such activities as hunting, fishing, carving, sewing, communal eating, and such Inuit games as mouth pulling, knuckle hop, and wrestling are deemed HCV risk factors.
- Participants cited fear, shame, embarrassment, anger, guilt, self-blame, sadness, disbelief, and shock as possible responses to being diagnosed as HCV positive.
- It was suggested traditional Inuit accepted events and circumstances from the perspective that it cannot be helped (*ajurnarmat*). The old way was to keep things quiet, to deal with it in the family, or to go to the head of each household and talk. Fear of ostracism would compel Inuit to keep some things from public view.
- Participants suggested that some Inuit may endure through illnesses, try to tough it out, rather than go to see a nurse or doctor. Those suffering a long and gradual illness may try to cure themselves.

Behaviour

Access to health care professionals can be difficult in the North, thus illnesses may go undiagnosed and underreported. Northern adult Inuit are less likely to have had contact with a medical doctor than other adult Canadians (56 percent and 79 percent, respectively in 2005).¹⁰ Only a few Inuit communities have hospitals. The others are serviced by health centres staffed by

¹⁰ Tait, H (2008). *Aboriginal Peoples Survey, 2006: Inuit Health and Social Conditions*. Catalogue no. 89-637-X no. 001. Statistics Canada, Social and Aboriginal Statistics Division. Ottawa: Ministry of Industry.

nurses. It is estimated that only 31 percent of Inuit living in the North are within 50 kilometres of a hospital.¹¹ For treatment requiring physicians, appointments with specialists, and for some diagnostic testing, Inuit are often flown out to larger centres. As such, it is understandable that the HCV focus group participants expressed concerns about where to get tested, what the tests involve, and how long it takes to get test results. Efforts to promote testing will require more knowledge about the procedures and assurances that the blood samples can be taken locally. This will allay fears of having to leave a home community to get tested.

Themes and Conclusions

- Participants were not sure if they should get tested. The possible asymptomatic nature of HCV infections was a point of concern. Many participants asked how they would know they needed to get tested.
- In general, there was not a strong link between possible risk behaviour as a reason to consider getting tested. Participants wondered more about the link between HCV symptoms and testing.
- The uncertainty about testing is linked to the problem of knowing HCV symptoms. A strong link should be made to common risk behaviours such as tattoos — and to a lesser extent, drug use — as the rationale to get tested.
- Inuit may be afraid to get tested if they do not know what will happen to them if they test positive. There is a need to explain possible lifestyle changes and treatment procedures when someone tests positive for HCV.
- The need for lifestyle changes may be a limiting factor when deciding to get tested. Those engaged in high-risk behaviours may not want to be told they must change. Others may refrain from testing if they thought they must leave the community for treatment.
- Inuit appear to be disinclined to read fact sheets. Though few are available, the sense was that people do not read them anyway. Short, eye-catching posters that do not overload the viewer with information are preferred.

Health Literacy

According to the 2006 Census, the median age of the Inuit population in the four Inuit regions of Inuit Nunangat was 22 years. In comparison, the median age of Canada's non-Aboriginal population was 40 years. As much as 35 percent of the Inuit population is estimated to be below the age of 14 years. Further, 58 percent of Inuit living in Inuit Nunangat have achieved less than a high school education.¹² Independent of other risk factors, low literacy is often indirectly linked to poor socioeconomic circumstances, and this in turn is associated with low health status. Low literacy levels limit the use of available health information and services.¹³ Accordingly, there is both a literacy and generational divide whereby programmes that target the general Canadian population may not be relevant to the general Inuit population. Patient decision-making to

¹¹ McDonald J.T. and R. Trenholm (2010). Cancer-related health behaviours and health service use among Inuit and other residents of Canada's north. *Social Science & Medicine* 70(9): 1396-1403.

¹² Statistics Canada (2008). Op. cit.

¹³ Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science & Medicine*, 2008 Dec; 67(12): 2072-78.

participate in health and screening processes, to comply with prescribed medication use and health advice, and the capacity to self manage diseases are linked to health literacy.

The 43 participants in Pauktuutit's HCV focus group sessions tended to have a higher level of education than the general Inuit population. Even so, their knowledge and attitudes about HCV demonstrate the need to increase Inuit understanding of HCV and its risk factors, and to persuade the population to become more engaged in HCV screening and harm reduction. The youthfulness of the Inuit population and the low literacy levels demand innovative solutions. As an example, the focus group participants identified the Internet and new media as some of the tools with which to communicate health information.

Themes and Conclusions

- The need for targeted messaging was mentioned in most of the focus groups. Different messages and strategies should be used for urban and rural Inuit, those engaged in high-risk drug activities, those going to school and elders.
- Participants suggested Inuit are less interested in learning about the clinical dimensions of HCV infection and that they will more likely respond to eye-catching media that points to additional information.
- It was suggested a poster should catch a person's attention, offer a few words, and then direct the reader to web links for more information. Condom and breastfeeding posters were offered as good examples.
- The participants wanted to know what treatment for HCV entails and how their lifestyles are going to change if they test positive.
- Some participants thought Inuit should know about the consequences of not knowing they are HCV positive; Inuit need to know how an asymptomatic HCV infection can affect their family and people close to them.
- Concern was expressed by some participants about the accuracy of Inuktitut translations of information material. Other Pauktuutit focus groups have identified this issue in the context of STI and HIV/AIDS terminology.
- The value and utility of HCV school events and presentations was discussed in most focus group sessions.
- Some participants cautioned against advertising scenarios that might foster widespread panic. Reference was made to the northern contaminants research that discouraged the consumption of country foods.
- A wide range of suggestions were made on how best to communicate information about HCV. These ranged from posters; videos and video games; workshops, discussion groups and/or talking circles; TV, radio, and/or print advertising; T-shirts; school events; marches for HCV; toll free numbers; and such computer and smart phone formats as email, text messaging, Facebook, and YouTube.