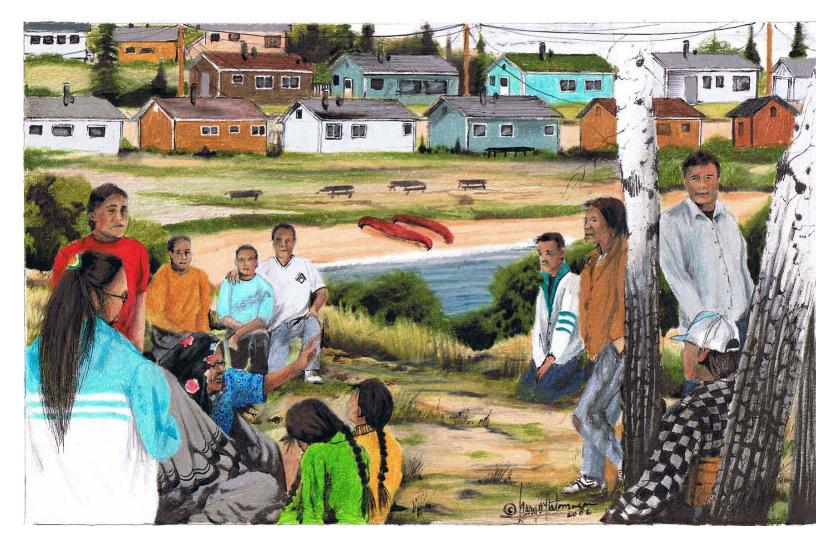
Northern Saskatchewan HIV/AIDS and HEPATITIS C Awareness Initiative: Research Project



Created by the Research Project Steering Committee 2006 Northern Saskatchewan HIV/AIDS and HEPATITIS C Awareness Initiative: Research Project

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Mayor Max Morin of Ile à la Crosse, SK, and member of the project Steering Committee, opened many of our discussions with a prayer and a few words of wisdom to guide us in our work together. Mayor Morin has shared the following to open this report.

PRAYER/WORDS OF WISDOM

Oh heavenly Father in Jesus' name we ask you to bless all the people that helped out with this very important work that was done over the last 3 years.

We ask for guidance to implement the recommendations. Give us wisdom to share this work with our fellow Leaders and People.

Open the ears and eyes of our People to see and understand this very important research project. We also ask for Blessing from God to protect our people from these illnesses, watch over our communities - our people. We also ask for Special Blessing to the people that have these illnesses, help them. Protect them and let them share with their fellow man some of the experiences and hardships they had to deal with and how to prevent others from getting these illnesses.

I hope this report helps Northern Saskatchewan Communities in educating their people. It's very important we do that to prevent people from getting HIV/AIDS or Hepatitis C. We have to take these illnesses seriously before it is too late. Let's prevent them now. Let's Educate our People.

ACKNOWLEDGMENTS

The Steering Committee would like to especially thank the community members and front line service providers for their participation in this project. Thanks also to our community-based project coordinator and the community research assistants who organized and conducted the interviews and focus groups. They handled a challenging topic with grace and sensitivity. Finally, thanks to the research assistants who worked on the analysis and drafted versions of this report.

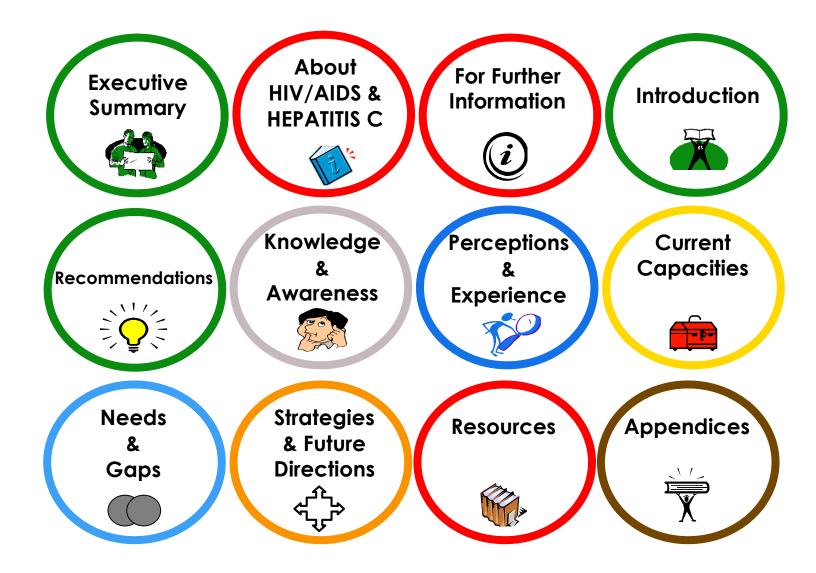
We would also like to offer a special thanks to Mr. Gary Natomagan¹ of the northern village of Pinehouse, who illustrated the cover of this report. Despite very short notice and against tight timelines, his artistic vision captured the collaborative and collective spirit the individuals and communities of northern Saskatchewan brought to this project.

This project is funded by the Canadian Institutes of Health Research, grant # 200203HHP-99410.

¹ Gary Natomagan's contact information can be obtained from Dr. Sylvia Abonyi, see page (i) of this document.

ORGANIZATION OF THE REPORT

Over 200 focus group and interview participants provided valuable insights into issues surrounding HIV/AIDS and hepatitis C in their communities. Their thoughts are organized into five topic areas: Knowledge & Awareness, Perceptions & Experiences, Current Capacities, Needs & Gaps, and Strategies & Future Directions. These topics, along with the work of the Steering Committee, are organized into the following colour and key coded sections for easy reference:





ΗIV

HIV is a short description for **H**uman Immunodeficiency **V**irus. People may not know if they are infected with this virus since initially there may be no signs or symptoms. It is not possible to tell just by looking at a person if they are infected with HIV. HIV infection status is confirmed by a positive HIV blood test.

AIDS

AIDS (**A**cquired Immuno**d**eficiency **S**yndrome) is a late stage of HIV infection when signs and symptoms of disease or illness are present.

Hepatitis C

Hepatitis C is an infectious disease caused by a virus that is carried in the blood and affects the liver. Initially there may be no signs or symptoms and infected individuals may not know they have the virus. It is not possible to tell just by looking at a person if they are infected with the hepatitis C virus. Hepatitis C infection is confirmed in a blood test.

Anonymous Testing for HIV¹

The person ordering the HIV test does not know the identity of the person being tested for HIV. The HIV test is carried out using a code. The person ordering the HIV test and the laboratory carrying out the testing on the blood sample do not

¹ From the Public Health Agency of Canada web site: http://www.phac-aspc.gc.ca/publicat/epiu-aepi/epi_update_may_04/3_e.html

know to whom the code belongs. Only the person being tested for HIV knows the unique, non-identifying code. Information such as age, gender, HIV-related risk factors and the ethnicity of the person being tested for HIV may be collected during anonymous testing, depending on the province or territory in which the test is ordered or on the test site. Test results are not recorded on the health care record of the person being tested. It is only the person being tested who may subsequently decide to give his or her name and include the HIV test result in the medical record. Tests are usually available at specialized clinics, organized and supported by public health departments, and by some health care providers.

Confidential Testing for HIV²

With confidential testing, you supply your name during the testing process, but your health provider, the health care system, and government health agencies are required by law to keep your testing information confidential – they can't let it become public information.

There are two types of confidential testing: <u>name-based</u> and <u>non-identifying</u> HIV testing. In <u>name-based HIV testing</u>, the person ordering the test knows the identity of the person being tested for HIV. The HIV test is ordered using the name of the person being tested. There is collection of patient information (such as age, gender, city of residence, name of diagnosing health care provider, country of birth); information detailing the HIV-related risk factors of the person being tested; and laboratory data. The amount of information collected is dependent upon the province/territory. If the HIV test result is positive, the person ordering the test is legally obligated to notify public health officials of the

² From the Public Health Agency of Canada web site: http://www.phac-aspc.gc.ca/publicat/epiu-aepi/epi_update_may_04/3_e.html

person being tested. <u>Non-identifying HIV testing</u> is quite similar to name-based HIV testing except the HIV test is ordered using a code or the initials of the person being tested (not the full or partial name).

Face to Face/ Individual Interviews

An approach whereby participants contributed their views on HIV/AIDS and hepatitis C via a discussion with only the interviewer present.

Focus Group/Discussion Group

An approach whereby participants contributed their views on HIV/AIDS and hepatitis C in a discussion that included 3-6 participants, an interviewer, and a note-taker.

Front Line Worker

Front Line Workers interviewed in this project included health, social, and education service providers, and spiritual leaders.

Participant

An individual who contributed their views and experiences of HIV/AIDS and hepatitis C in this project through one-on-one interviews or group discussions.



Overview

The idea to undertake this research project came from a partnership of northern health regions, an Aboriginal health organization, academic researchers, and the leadership of four participant communities, as they plan proactive responses to the emergence of HIV/AIDS in northern Saskatchewan. These organizations and communities were represented on a 10 member Steering Committee that directed all aspects of this project. Because hepatitis C comes to communities in many of the same ways as HIV and AIDS, the Steering Committee was also interested in better understanding the context of hepatitis C in northern Saskatchewan as well. This background information is being used to inform prevention, education, and management programs for northern Saskatchewan communities. Project activities took place between October 2002 and September 2005.

The Steering Committee began this project with the following objectives:

- 1. Determine community awareness, attitudes and knowledge of HIV/AIDS.
- 2. Document knowledge derived from local experiences of the challenges facing communities, families and individuals when someone with HIV/AIDS lives in the community.
- 3. Determine community awareness, attitudes, capacity and strategies for accepting and supporting individuals with HIV/AIDS.
- 4. Determine factors to increase capacity of communities to accept and support individuals with HIV/AIDS.
- 5. Determine appropriate and meaningful ways to talk about HIV/AIDS and to conduct primary prevention, education, care and surveillance.

How Were People's Views on HIV/AIDS and Hepatitis C Collected?

The four communities whose experiences and perceptions of HIV/AIDS and hepatitis C are reflected in this report participated because their leaders were among those who initiated this project because concerns about these diseases were being expressed there. Individual participants were recruited via a poster and newsletter campaign in each community asking those who were willing to share their views on HIV/AIDS or hepatitis C to contact their community research assistant. When the interview process began, word of mouth resulted in more participants coming forward. Interview and focus group discussion questions were designed by the Steering Committee in a collaborative exercise that built on questions asked in other projects that matched the objectives of this project. Over 200 individuals participated in interviews and group discussions between January and June 2004. Individual interviews were conducted with 136 community members and 16 Front Line Workers, and there were a total of 24 focus group discussions that included between 3 and 6 participants. Front Line Workers interviewed in this project included health, social and education service providers and spiritual leaders. One community member from each of the four participating communities (2 First Nation and 2 Métis) was hired as a research assistant to conduct interviews and group discussions in their home community. All research assistants attended a 2-day workshop for training in research ethics and interviewing techniques. They were also provided with some education on HIV/AIDS and hepatitis C.

Analysis and Interpretation

Transcripts and notes were analyzed using a "grounded theory" approach (Charmaz, 2000). In this way the results are grounded in the experiences of those being interviewed. This approach is especially useful in uncovering unanticipated themes and relationships. A second round of analysis that drew in themes from a review of the literature was then conducted. This level of analysis facilitates the placement of the project results in a larger context. A qualitative data analysis software package, *Atlas.ti* - was used to help manage the analysis. Other information was also considered in the analysis process, such as personal correspondence with the Project Coordinator and the Community Research Assistants, and field notes kept by the Community Research Assistants.

Main Findings

• Fear: Many participants had a good general understanding of HIV and AIDS but also expressed a strong desire for more knowledge. Younger people had more knowledge than middle age or older people. Many were fearful of HIV/AIDS, mainly due to perceptions of HIV/AIDS as a terminal illness or "death sentence." Simultaneous feelings of fear and anxiety were linked to concerns about the challenges of HIV in a northern context, such as access to services around prevention and

management, and what they felt was a lack of adequate education and awareness on HIV/AIDS.

- Hepatitis C knowledge: Some participants were more unfamiliar with hepatitis C than HIV/AIDS; a surprising finding given that hepatitis C is a more prevalent and immediate concern in some communities.
- Misconceptions: Misconceptions about HIV/AIDS and hepatitis C transmission/cause/vulnerability exist in each of the communities. These misconceptions influence the type and level of support participants feel they can offer affected community members.
- Level of support: Reactions to, and anticipated support for, people infected with HIV/AIDS differed based on the closeness of the relationship between the participant and the (potentially) affected person. All participants expressed a desire for themselves and their community as a whole to be supportive of all affected community members.
- **Confidentiality:** Confidentiality with respect to accessing information, testing, and treatment was an overriding concern.
- Geography: Long distances to appropriate services, and the remote location of some communities were issues discussed by participants. Mobility of clients was cited by service providers as affecting their ability to track and provide follow-up to clients.

- **Creativity:** Participants felt that education and awareness need to be increased using more creative strategies (e.g. going beyond pamphlets and workshops).
- **Consistency:** Participants would like to see programs/services offered on a more consistent basis.

Steering Committee Recommendations

The Steering Committee met to consider the comments and contributions of the individual project participants and communities as they are reflected in the pages of this report. In considering their recommendations, the Steering Committee felt strongly that an understanding of the diverse cultures, languages, geographies, histories, and jurisdictions and the complex manner in which these play out in a broad range of issues for northern Saskatchewan individuals and communities, forms the foundation for any initiatives specific to HIV and AIDS or hepatitis C. At the same time, the Steering Committee felt it was important that a northern Saskatchewan HIV/AIDS and hepatitis C strategy be framed as a collective initiative involving a broad range of stakeholders across agencies, regions, and sectors. In this spirit, the Steering Committee drafted the following four recommendations. Suggested actions for these recommendations were also discussed and are elaborated in the *Recommendations* section of the report.

Recommendation #1

The major recommendation of the project steering committee is to create a <u>regional</u> HIV/AIDS and hepatitis C strategy that will combine:

- a broad-based and holistic prevention approach, with
- consistent education and awareness messages, as well as
- support for diagnosis, management and treatment, with
- a community support initiative.

Recommendation #2

Increase Knowledge and Awareness of HIV/AIDS and hepatitis C in northern Saskatchewan.

- Provide a consistent awareness message
- Shift the focus from treatment to public education

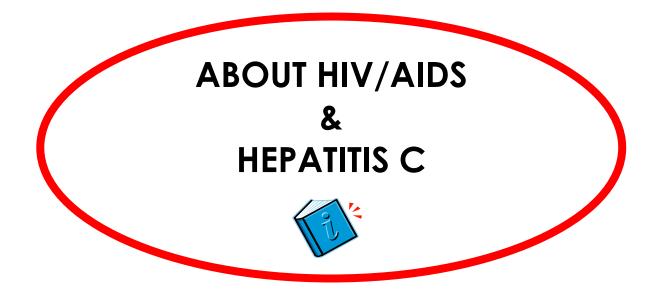
Recommendation #3

Improve awareness of the availability of HIV/AIDS and hepatitis C testing in the community, locally, and regionally. At the same time, it is also important to address misconceptions about anonymity and confidentiality in the testing process. An important approach to alleviating the apprehension around testing will be to normalize the testing process.

Recommendation #4

Improve community preparedness.

• Communities as a whole should be included in planning strategy; rather than focusing solely on the responsibilities of individual organizations within the community (e.g. schools, workplaces, health centres). Roles for organizations such as churches and Friendship centres, or local businesses, should also be included in holistic community preparedness strategy development.



HIV/AIDS

What are HIV and AIDS?

HIV is a short description for **H**uman Immunodeficiency **V**irus. People may not know if they are infected with this virus since initially there may be no signs or symptoms. It is not possible to tell just by looking at a person if they are infected with HIV. HIV infection status is confirmed by a positive HIV blood test, which is easy to get through your local health centre or away from your community.

HIV attacks the body's immune system, which is how the body defends itself from infections. The attack of the virus can weaken the immune system so that people living with HIV may get infections such as an unusual type of pneumonia, or develop skin cancer or other types of cancers. AIDS (**A**cquired Immuno**d**eficiency **S**yndrome) is a late stage of HIV infection in which signs and symptoms of illnesses and diseases like these start to appear.

There is a lot that can now be done to help manage HIV infection.

Who is at risk?

Anyone can get HIV. The most important thing to know is how you can get the virus.

How does someone get HIV?

The virus is spread through body fluids such as blood, semen, pre-semen, vaginal fluids, and breast milk.

To become infected with HIV, the virus must have a way into your body. This can occur during unprotected sex (vaginal, anal, oral) with an HIV-positive

individual, or when needles or other injecting (skin-piercing) equipment is shared with an HIV-positive individual. Sharing sex toys can also spread the virus from one partner to another, if one of the partners is HIV-positive.

Personal items, such as toothbrushes and razors can have small amounts of blood on them from bleeding gums and shaving cuts. So even though the risk is very low, sharing personal items like toothbrushes and razors with someone who is infected could spread the HIV virus.

Can I have children or breast feed if I have HIV?

HIV can be transmitted from an HIV-positive mother to her baby during pregnancy, at the time of birth, or afterwards during breastfeeding. That is why it is so important for any woman who is pregnant to be tested for HIV. Ask your doctor about HIV testing.

What are some of the myths about how HIV is spread?

HIV is not spread by everyday social contact. Touching, hugging and shaking hands with a person living with HIV/AIDS are all safe. You cannot get HIV from sweat, spit, tears, clothes, drinking fountains, phones, toilet seats, or through everyday things like sharing a meal. Insect bites, stings, and pets cannot spread HIV.

Some people worry that they can get HIV by donating blood in Canada, but this is not true. A new, sterile needle is used every time for every person who donates blood.

Donated blood in Canada is always checked for HIV so the chances of getting it from a blood transfusion are very, very low.

2.2

What are the symptoms of HIV infection?

It is not possible to tell just by looking at yourself or anyone else if either of you is infected with HIV. Initially there may be no signs or symptoms.

How can I tell if I have HIV? How can I tell if my partner has HIV?

A simple blood test of your blood, or your partner's blood, can tell if you or your partner has HIV. It is called the HIV antibody test.

If your blood test result is positive, that means you have HIV. If your test result is negative, that means that no antibodies to HIV were found in your blood at the time of testing.

If your partner's blood test is positive, that means that he or she has HIV. If your partner's test result is negative, that means that no antibodies to HIV were found in his/her blood at the time of testing.

How can I protect myself or others from HIV infection?

- abstinence is the only certain way to prevent sexually transmitted diseases like HIV
- engage in a long term faithful relationship with an HIV negative partner
- discuss HIV and other STIs (sexually transmitted infections) with your partner(s)
- have male partners consistently and correctly use a latex condom
- consider other things like caressing and touching instead of having sex
- ensure that both you and a new partner are tested for HIV before having sex with each other

• remember not to share items that could result in the exchange of blood, semen or vaginal fluids. This includes injection, piercing and tattooing equipment, sex toys, toothbrushes and razors.

What if I think I may be at risk or have already been exposed to HIV?

If you are worried that you might have HIV see your physician or a nurse at your local health care centre and discuss whether or not you should be tested. Ask about anonymous or confidential testing.

Learn the risks so that you can avoid exposure. Seek support, ask about needle exchange programs, have repeat testing done if exposure is difficult to avoid.

What happens if I test positive?

If you have become HIV-positive, then your sex partners, or others with whom you have shared items that could result in the exchange of blood, semen or vaginal fluids must be told that they also may have been in contact with the virus. They will have to decide if they wish to be tested for HIV.

You might want to tell them yourself, but if you are not comfortable, talk to your doctor or nurse – they can help. Contacts can be notified by your doctor or public health and advised to seek testing without revealing your identity.

Protect your partners from HIV.

How is HIV/AIDS treated?

Once infected, you have HIV for life. While there is no cure, HIV/AIDS can be managed. Several treatments have been developed that may slow the progress of HIV.

HEPATITIS C

What is hepatitis C?

Hepatitis C is the liver disease caused by the hepatitis C virus (HCV) which was first identified in 1989. Hepatitis C is spread by direct contact with the blood of an infected person. Although to a limited extent, hepatitis C can also be transmitted sexually and from an infected mother to her child. The virus can be identified through blood screening.

What are the differences between hepatitis A, hepatitis B and hepatitis C?

Hepatitis A is spread mostly through food and water contaminated by the stool of an infected carrier. Transmission may also occur through close personal contact. Hepatitis A is rarely spread through blood exposure. This is not a chronic infection. Hepatitis A causes a flu-like illness with skin or eyes turning yellow. At one time it was common but has become more rare because it and can be prevented through childhood immunization.

Hepatitis B is spread through blood and body fluids contaminated with blood. Other infectious body fluids include uterine/vaginal secretions and semen. One type of this virus (HBV) can also be found in saliva. Transmission may occur through a needle stick, blood transfusion, or sexual contact. It can also be spread from mother to baby in the uterus. This form of hepatitis leads to chronic liver disease and complications. As with hepatitis A, hepatitis B can be prevented through immunization. Immunization is provided free of charge to grade 6 students and to individuals at risk of hepatitis B or C.

Hepatitis C is spread through direct contact with the blood of an infected person. The most common means of transmission is injection drug use or through activities such as tattooing and body piercing performed without

sterile precautions. Newborn babies are at a moderate risk of infection by a hepatitis C-positive mother during birth, but not through breastfeeding unless nipples are cracked or bleeding. The risk of transmission through sexual contact, either homosexual or heterosexual, is considered to be low. This form of hepatitis leads to chronic liver disease and complications. So far, it cannot be prevented through immunization and there is no cure.

Who is at risk?

People at risk for hepatitis C include the following:

- blood transfusion recipients prior to 1990
- people who use injection drugs or share drug-related equipment
- people with tattoos and body piercing acquired with non-sterile equipment

How does someone get hepatitis C?

The most common means of transmission is through injection drug use, even if the drug use was many years ago or happened only once. Sharing needles of any drug-related equipment is enough to spread hepatitis C.

Another way of getting hepatitis C is through a blood transfusion from a donor who has hepatitis C – especially for those people who received a blood transfusion prior to 1990. The risk of getting HCV in this way is now extremely low because of the universal testing of all blood donors.

Activities such as tattooing and body piercing, which may be performed without sterile precautions, or sharing toothbrushes and razors with an infected person can also spread the hepatitis C virus. The risk of getting HCV infection through ordinary household or workplace interactions is extremely low.

Could I get hepatitis C from having unprotected sexual intercourse?

The rate of transmission by sexual contact – either heterosexual or homosexual – is considered to be very low.

In spite of the low risk, long-term monogamous couples must decide for themselves about routine condom use. They should however, avoid unprotected intercourse during menstrual periods if the woman is HCV-positive. People with multiple sexual partners should always practice safe sex, not only to decrease the small risk of hepatitis C transmission but to minimize the risk of acquiring other infections.

Can I have children or breastfeed if I have hepatitis C?

The risk of passing hepatitis C to your newborn is approximately 5%. Cesarean section is not recommended to prevent HCV infection. Breastfeeding does not appear to transmit hepatitis C unless nipples are cracked or bleeding.

How can I avoid getting hepatitis C?

If you use drugs, do not share needles or other drug-related equipment. Do not share razors or toothbrushes. Wear gloves if you have to touch anyone's blood. If you get a tattoo or body piercing, make sure it is done with clean tools. Although sexual transmission is rare, take appropriate precautions.

What are the symptoms of hepatitis C?

Most people with hepatitis C have no symptoms and may feel quite healthy. Others may develop fatigue, jaundice (yellowing of the eyes and skin), abdominal and joint pain, nausea and loss of appetite. There are few physical signs in the first 20 years as the disease progresses from mild to moderate.

How do I know if I have hepatitis C?

Most people with hepatitis C are unaware they have it and can carry it unknowingly for decades. Only a blood test can detect the hepatitis C virus infection. If you think you may have been exposed to the hepatitis C virus through high-risk behaviour, major surgery, a blood transfusion or blood products, and are concerned, you should see your physician and discuss whether or not you should be tested.

What happens if I test positive?

If you test positive for antibodies to HCV, your physician will advise follow-up blood tests to see whether actual viral material can be found in your blood, along with blood tests to check the state of your liver. Approximately 15-25% of people infected with HCV have a mild, brief disease and get rid of the virus completely. In this case, the antibodies to HCV usually remain detectable in the blood but the actual viral material does not.

However, most people who get hepatitis C will have HCV infection for a long time, and possibly for the rest of their lives. If this is the case, you will need to provide information on how you think you were exposed and the names of individuals who may have been exposed to the virus through you, so they may also be tested. You should learn about hepatitis C infection and be sure to receive follow-up care if advised by your physician.

How is hepatitis C treated?

Your family physician may refer you to a specialist to determine whether or not you require treatment. You may wish to contact the Canadian Liver Foundation to learn about support groups and education materials available through this organization.

What happens as the disease progresses?

Most people with chronic hepatitis C feel well for many years. In 10-20% of patients, chronic hepatitis C leads to cirrhosis – irreversible and potentially fatal scarring of the liver. In severe cases, hepatitis C may lead to liver cancer or liver failure. Hepatitis C is one of the most common reasons why people need to have liver transplants in Canada. The earlier you find out that you have hepatitis C, the more likely it is that treatment could be successful. Factors that may lead to a faster progression of disease include consuming more that 2-3 alcoholic drinks per day, co-infection with HIV or other infections (such as hepatitis A or B).

If I have hepatitis C, how can I protect others?

If you have been diagnosed with hepatitis C there is no need to become socially isolated, but there are common – sense precautions you should take to avoid spreading the virus:

- do not give blood
- do not share razors or toothbrushes
- if you use drugs, do not share needles or other drug-related equipment
- inform health professionals or others who care for you and may be exposed to your blood that you have hepatitis C
- although sexual transmission is rare, inform your sexual partner(s) that you have hepatitis C and take appropriate precautions

Sources for the Information about HIV/AIDS and hepatitis C:

"What You Need to Know About Sexually Transmitted Infections (STI)" - Health Canada, Minister of Public Works and Government Services Canada, 2002.

"Hepatitis C: A Liver Disease" - Canadian Liver Foundation, 2235 Sheppard Avenue E, Ste 1500, Toronto, Ontario M2J 5B5 "HIV" – Shirley Woods, NITHA, Presentation to Northern Saskatchewan, HIV/AIDS Awareness Research Assistant training workshop, Prince Albert, SK. Feb-Mar 2004.

"Epidemiology of hepatitis C in Canada" – Shirley Woods, NITHA, Presentation to Northern Saskatchewan, HIV/AIDS Awareness Research Assistant training workshop, Prince Albert, SK. Feb-Mar 2004.



LOCAL COMMUNITY RESOURCES

Counseling, Testing and Information

Northern Physician Clinics

Northern Community Health Centres

Anonymous Test Site (Prince Albert, Sexual Health Clinic)

Needle-Exchange Services in the North

lle à la Crosse	1 (866) 848-8299
La Loche	1 (888) 688-7087
La Ronge	1 (306) 425-4800
Meadow Lake	1 (306) 236-1570
Prince Albert	1 (306) 765-6540

Toll-Free #'s:

AIDS Saskatoon	1 (800) 667-6876
Health Line	1 (877) 800-0002

Counseling and Information:

Canoe Lake Health Centre - Phone: (306) 829-2140

Physician (Wednesdays) and Community Health Nurses

- confidential testing for HIV, hepatitis C and STI's
- professional health advice and information
- medical support

Director of Health

 information regarding health programs and support services (on and off reserve) from the Canoe Lake First Nation, M.L.T.C. and Keewatin Yatthe Regional Health Authority

Community Wellness Program - Phone: (306) 829-2140

- counseling and support
- referrals

Addictions Services - Phone: (306) 829-2140

- counseling and support
- referrals

Indian Child and Family Services - Phone: (306) 829-2210

- counseling and support
- referrals

Nearest Needle-Exchange Service:

Meadow Lake Public Health Office - Phone: (306) 236-1570

9 – 411 Centre Street, Meadow Lake, SK Hours: 8 am - 12 pm and 12:30 pm – 4:30 pm

lle à la Crosse Public Health Office - Phone: (306) 833-5503

Box 340, lle à la Crosse, SK Hours: 8 am - 12 pm and 1 pm – 5 pm

Public Health Nurse

Phone to see if she's in the office. She travels to other communities.

- professional health advice and information
- counseling and needle-exchange
- immunization for hepatitis A and B
- health promotion in the community: includes: working on material for radio spots and other media, organizing workshops and other activities, and helping people find resources for their educational activities.

Confidential HIV, Hepatitis C and other STI Testing:

Meadow Lake Associate Clinic - Phone: (306) 236-5661

- confidential testing for HIV, hepatitis C and STI's
- professional health advice and information
- medical support

Counseling and Information:

Jonah Sewap Memorial Nursing Station - Phone: (306) 632-2106 Hours: 8:30 am - 12 pm and 1 pm – 5 pm

Primary Health Care Nurses

- confidential testing for HIV, hepatitis C and STI's
- professional health advice and information
- medical support

Director of Health

 information regarding health programs and support services (on and off reserve) from the Peter Ballantyne Cree Nation Health Services

Holistic Health Coordinator

- counseling and support
- referrals

Nearest Needle-Exchange Service:

Sexual Health Clinic - Phone: (306) 765-6540

800 Central Avenue, 2nd Floor, McIntosh Mall, Prince Albert, SK Hours: 8:30 am – 4:30 pm (Appointments preferred)

- professional health advice and information
- counseling and needle-exchange
- anonymous testing for HIV, confidential testing for hepatitis C and other STI's

Confidential HIV, Hepatitis C and other STI Testing:

Jonah Sewap Memorial Nursing Station - Phone: (306) 632-2106

Hours: 8:30 am - 12 pm and 1 pm – 5 pm

Primary Health Care Nurses

- confidential testing for HIV, hepatitis C and STI's
- professional health advice and information
- medical support

Director of Health

 information regarding health programs and support services (on and off reserve) from the Peter Ballantyne Cree Nation Health Services

Holistic Health Coordinator

- counseling and support
- referrals

Counseling and Information:

lle à la Crosse Health Clinic - Phone: (306) 833-5503

Hours: 8 am - 12 pm and 1 pm – 5 pm

Public Health Nurse

Phone to see if she's in the office. She travels to other communities.

- professional health advice and information
- counseling and needle-exchange
- immunization for hepatitis A and B
- health promotion in the community: includes: working on material for radio spots and other media, organizing workshops and other activities, and helping people find resources for their educational activities

Natawihin Nakasuwenik Medical Clinic - Phone: (306) 833-2044

Physicians

- confidential testing for HIV, hepatitis C and STI's
- professional health advice and information
- medical support

Mental Health Therapist - Phone (306) 833–5505

- information
- counseling and support
- referrals

Addictions Services - Phone (306) 833–5502

- information
- counseling and support
- referrals

HIV/AIDS Support Worker - Friendship Centre - Phone (306) 833-2313

- information
- counseling and support

Nearest Needle-Exchange Service:

lle à la Crosse Health Clinic - Phone: (306) 833-5503

Hours: 8 am - 12 pm and 1 pm – 5 pm

Public Health Nurse

Phone to see if she's in the office. She travels to other communities.

- professional health advice and information
- counseling and needle-exchange
- immunization for hepatitis A and B
- health promotion in the community: includes: working on material for radio spots and other media, organizing workshops and other activities, and helping people find resources for their educational activities

Confidential HIV, Hepatitis C and other STI Testing:

Natawihin Nakasuwenik Medical Clinic - Phone: (306) 833-2044

Physicians

- confidential testing for HIV, hepatitis C and STI's
- professional health advice and information
- medical support

Pinehouse

Counseling and Information:

Pinehouse Health Centre - Phone: (306) 884-5670

Hours: 8 am - 12 pm and 1 pm – 5 pm

Physician or Primary Health Care Nurse

Mondays and some Wednesdays.

- professional health advice and information
- confidential testing for HIV, hepatitis C and STI's
- medical support

Public Health Nurse

Phone to see if she's in the office. She travels to other communities.

- professional health advice and information
- medical support
- health promotion in the community: includes: working on material for radio spots and other media, organizing workshops and other activities, and helping people find resources for their educational activities

Community Health Educator

- information
- counseling and support
- referrals
- health promotion in the community: includes: working on material for radio spots and other media, organizing workshops and other activities, and helping people find resources for their educational activities

Mental Health Worker/Social Worker

- information
- counseling and support
- referrals

Addictions Service

- information
- counseling and support
- referrals

Clinic Manager

- information
- counseling and support
- referrals

Principal – Minahik Waskahigan High School - Phone: (306) 884-4888

- information
- referrals

Mamewetan Churchill River Health Region Resource People:

Sexual Health Educator - Phone: (306) 425-4843 La Ronge Health Centre, La Ronge, SK

 developing grade specific school resources on sexual health for northern schools, has educational resources

Nearest Needle-Exchange Service:

Sexual Health Clinic - Phone: (306) 765-6540

800 Central Avenue, 2nd Floor, McIntosh Mall, Prince Albert, SK Hours: 8:30 am – 4:30 pm (Appointments preferred)

- professional health advice and information
- counseling and needle-exchange
- anonymous testing for HIV, confidential testing for hepatitis C and other STI's

lle à la Crosse Health Clinic - Phone: (306) 833-5503

Hours: 8 am - 12 pm and 1 pm – 5 pm

Public Health Nurse

Phone to see if she's in the office. She travels to other communities.

- professional health advice and information
- counseling and needle-exchange
- immunization for hepatitis A and B
- health promotion in the community: includes: working on material for radio spots and other media, organizing workshops and other activities, and helping people find resources for their educational activities

La Ronge Medical Clinic - Phone: (306) 425-2174

Hours: 9 am – 12 pm and 1 pm – 5 pm

- professional health advice and information
- counseling and needle-exchange
- confidential testing for HIV, hepatitis C and other STI's

Confidential HIV, Hepatitis C and other STI Testing:

La Ronge Medical Clinic - Phone: (306) 425-2174

Hours: 9 am – 12 pm and 1 pm – 5 pm

- professional health advice and information
- counseling and needle-exchange
- confidential testing for HIV, hepatitis C and other STI's

REGIONAL RESOURCES

(*i*) Anonymous HIV Testing Clinics and Needle Exchange Service

Sexual Health Clinic - Phone: (306) 765-6540

800 Central Avenue, 2nd Floor, McIntosh Mall, Prince Albert, SK Hours: 8:30 am – 4:30 pm (Appointments preferred)

- professional health advice and information
- counseling and needle-exchange
- anonymous testing for HIV, confidential testing for hepatitis C and other STI's

Public Health Services - Phone: (306) 655-4642

100-310 Idylwyld Drive North, Saskatoon, SK Hours: 1:00 – 4:00 pm (Appointments preferred) Needle exchange hours: Monday – Friday (9 am – 12 pm and 1-4 pm) on clinic days.

- professional health advice and information
- counseling and needle-exchange
- anonymous testing for HIV, confidential testing for hepatitis C and other STI's

🥑 24 Hour Health Line

Health Line - Toll-Free Phone: 1 (877) 800-0002

Health Line is a confidential 24-hour health advice telephone line staffed by registered nurses. They can provide you with immediate professional health advice or information, and direct you to the most appropriate care. Health Line can help you decide whether you should treat your own symptoms, go to a clinic, wait to see your doctor, or go to a hospital emergency room. Cree or Dene translation available when requested.

Counseling, Peer-Support, Information

AIDS Saskatoon – Toll-Free Phone: 1 (800) 667-6876

130A Idylwyld Drive North, Saskatoon, SK Hours: 9 am – 5 pm

- drop in center
- counseling and support
- referrals
- needle distribution
- prevention education and support for those infected and affected by HIV/AIDS
- advocacy, resource library, videos, pamphlets, booklets on AIDS, hepatitis C, research documents, HIV/AIDS related curriculum resources
- offers workshops and presentations

AIDS Program South Saskatchewan – Toll-Free Phone: 1 (877) 210-7623

1504 B Albert Street, Scotia bank Building, Regina, SK Website: http://www.aidsresourcesask.ca/

Promote the health of our communities by working together to share HIV/AIDS knowledge and resources, and to provide support to those with high-risk behaviors.

- counseling and support
- referrals
- needle exchange

- advocacy, library (videos, CD-ROMs, books, pamphlets, and HIV/AIDS related curriculum resources)
- offers workshops and presentations

All Nations Hope AIDS Network – Toll-Free Phone: 1 (877) 210-7622

1504 B Albert Street, Scotia bank Building, Regina, SK Hours: Monday – Friday (9 am – 12 pm and 1:30 pm – 5 pm) Website: http://www.allnationshope.ca/

- counseling
- advocacy, library (books and videos), publications
- offers workshops and presentations
- needle exchange

PLWA (Persons Living With AIDS) Network of Saskatchewan Toll-Free Phone: 1 (800) 226-1944

1504 B Albert Street, Scotia bank Building, Regina, SK Hours: Monday – Friday (9 am – 12 pm and 1:30 pm – 5 pm) Email: plwa@dlwest.com

• support and services for persons with HIV/AIDS (families, friends

and partners)

Planned Parenthood Saskatoon Centre - Phone: (306) 244-7989

314 – 220 3rd Avenue S, Saskatoon, SK Youth Sexual & Reproductive Health Drop in: Hours: Wednesday 7 – 9 pm Website: http://www.saskatoon.ppfc.info/ Gay and Lesbian Health Services of Saskatoon

203–220 3rd Ave South , Saskatoon, SK Toll-Free Phone: 1 (800) 358-1833 Hours: Monday – Friday (10 am – 10 pm), Saturday (12 – 6 pm) Website: http://www.glhs.ca/

- services for persons with HIV/AIDS (families, friends and partners)
- referrals to health services
- peer counseling
- informed, confidential support
- lending library (books and magazines focused on sexual orientation issues), fundraising boutique
- information about safer sex

(*i*) Medical Health Officers in the North

Dr. James Irvine

Northern Regional Health Authorities KYRHA, MCRRHA, AHA Population Health Unit, La Ronge, SK

 consultation and support for northern public health programs including hepatitis C & HIV / AIDS prevention, communicable disease control programs and harm reduction programs for the northern regional health authorities. Provides local authority functions for the Public Health Act.

Dr. Mandiangu Nsungu

Northern Inter-Tribal Health Authority 2300 - 10th Avenue West, Cottage 11 Prince Albert, SK, S6V 5N6

NATIONAL RESOURCES

Online Resources for Information on HIV and AIDS and Hepatitis C

HIV and AIDS - General Information:

AIDS Vancouver

http://www.aidsvancouver.org/

AIDS Committee of Toronto

http://www.actoronto.org/

AVERT

A focus on information about education to prevent infection with HIV,

information for HIV-positive people, the latest news and statistics.

http://www.avert.org/

Canadian AIDS Society

http://www.cdnaids.ca/

Canadian HIV/AIDS Information Centre - Resources

http://www.aidssida.cpha.ca/english/res_e/index.htm

CDC National Center for HIV, STD and TB Prevention

General information on HIV and AIDS, cause, the virus, transmission,

opportunistic infections, testing for HIV, treatment and care, prevention of

HIV, populations at risk, vaccine

http://www.cdc.gov/hiv/general.htm

Health Canada AIDS

http://www.hc-sc.gc.ca/english/diseases/aids.html

Health Canada Sexual Health and Sexually Transmitted Infections:

http://www.hc-sc.gc.ca/pphb-dgspsp/std-mts/faq_e.html

Sexualityandu.ca

Your link to sexual well-being administered by: the Society of Obstetricians and Gynecologists of Canada

http://www.sexualityandu.ca/

THE BODY - An AIDS and HIV information resource

http://www.thebody.com/index.shtml

Toronto General Hospital University Health Network

http://www.tthhivclinic.com/

Hepatitis C - General Information

Health Canada / Hepatitis C

http://www.phac-aspc.gc.ca/hepc/hepatitis_c/index.html

HCV Advocate

Hepatitis C Newsletter (American)

http://www.hcvadvocate.org/

HEPNET

The hepatitis information network (Canadian) Source for accurate and up-to-date information on all forms of hepatitis. http://www.hepnet.com/hepc.html

HIV and AIDS or Hepatitis C: Special Interest Groups:

<u>Women</u>

Amnesty International - Women's Rights http://www.amnestyusa.org/women/index.do Planned Parenthood Federation of Canada Provides information on sexual health issues, linked to local community affiliates. http://www.ppfc.ca/ Positive Women's Network

http://www.pwn.bc.ca/resources.html

Prairie Women's Health Centre of Excellence

http://www.pwhce.ca/

Motherisk

HIV in women and pregnancy

http://www.motherisk.org/

The British Columbia Centre of Excellence for Women's Health

http://www.bccewh.bc.ca/

WORLD

An information and support network by, for and about women with HIV/AIDS

http://www.womenhiv.org/

Voices of Positive Women

http://www.vopw.org/voicesweb/index.htm

<u>Youth</u>

AVERT

Young people's section of Avert.org . AVERT is an international $\ensuremath{\mathsf{HIV}}$

and AIDS charity. AVERTing HIV and AIDS.

http://www.avert.org/youngflash.htm

Coalition for Positive Sexuality

http://www.positive.org/Home/index.html

HIV Women and Youth

http://www.ppfc.ca/HIV/e/welcome_e.html

Live Positive Website

Developed by a partnership between Positive Youth Outreach

(PYO), The Hospital for Sick Children Divisions of Adolescent

Medicine & Infectious Disease, Canadian AIDS Treatment

Information Exchange (CATIE), and TeenNet at the University of Toronto in collaboration with youth and youth serving agencies across Canada Resource for Canadian students and their teachers about living with HIV/AIDS.

http://www.livepositive.ca/

Planned Parenthood Federation of America

http://www.teenwire.com/index.asp

YouthCO

A non-profit organization working to involve youth ages 15 – 29 from all communities in addressing HIV/AIDS, hepatitis C and related issues. Website is under expansion. Expected launch April 1, 2004. http://www.youthco.org/

Gay, Lesbian, and Bisexual

Gay and Lesbian Health Services of Saskatoon Advocates, celebrates and affirms sexual and gender diversity. http://www.glhs.ca/

<u>Aboriginal</u>

All Nations Hope AIDS Network – Regina http://www.allnationshope.ca/ B.C. Aboriginal HIV/AIDS Society http://www.healingourspirit.org/ Canadian Aboriginal AIDS Network http://www.caan.ca/

<u>Prisoners</u>

Correctional Services Canada http://www.csc-scc.gc.ca/text/home_e.shtml PASAN - Prisoner's HIV/AIDS Support Action Network

Toll-Free Phone: 1 (866) 224-9978

Only organization in Canada with a website exclusively providing HIV/AIDS education, support and advocacy to prisoners, ex-prisoners, young offenders and their families. The toll-free number is a service for those who are HIV-positive and who have been incarcerated. It is manned by volunteers who are knowledgeable about HIV/AIDS, but most of whom have not been incarcerated.

http://www.pasan.org/

<u>Miscellaneous</u>

Needle Exchange

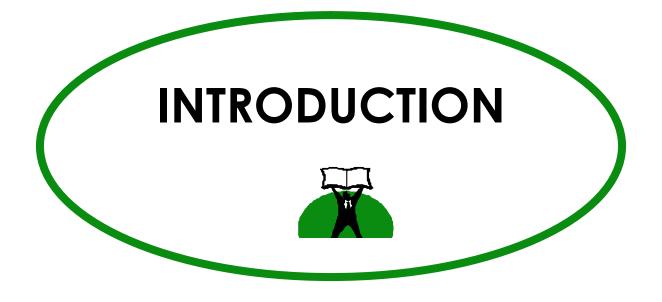
The Canadian Harm Reduction Network http://www.canadianharmreduction.com/

Research on HIV or AIDS

HIV Community-Based Research Network http://www.hiv-cbr.net/index.php?newlang=english Health Canada - Division of HIV/AIDS Epidemiology and Surveillance http://www.hc-sc.gc.ca/pphb-dgspsp/hast-vsmt/

International Resources on HIV or AIDS

AIDS Education Global Information System http://www.aegis.com/
UNAID - United Nations AIDS
The main advocate for global action on HIV/AIDS, UNAIDS leads, strengthens and support an expanded response to the epidemic http://www.unaids.org/en/default.asp



This section of the report provides some background information on this project, some detail around the research questions and objectives, the design of the data collection strategy, and the analytical approach. Major findings are summarized. The section that follows lists the project recommendations and suggested actions associated with them. For those who wish to read a more detailed presentation of the results, these are presented according to theme area following the recommendations.

Background

The 1996 Royal Commission Report on Aboriginal Peoples commented on the dearth of information regarding HIV/AIDS among Aboriginal¹ people in Canada, conjecturing that HIV/AIDS in these populations is a problem in the making (Royal Commission on Aboriginal Peoples, 1996). At the same time, the Canadian HIV/AIDS Legal Network (1999) has demonstrated that management of HIV in Indigenous communities needs different approaches than are predominant in more mainstream milieus. Because few people in isolated communities have as yet become HIV-infected, there is little experience on which to build. Not much information is available about the determinants of HIV/AIDS in isolated or reserve communities, nor about the special needs of Aboriginal people and their families living with HIV/AIDS in these areas (Health Canada 1999). The Steering Committee on this project wanted to fill this gap in knowledge with a research initiative.

Why a Need for Research in Northern Saskatchewan Now?

Epidemiological and other data suggest that HIV/AIDS is an emerging concern in northern Saskatchewan First Nation and Métis communities. In 2003, Aboriginal people comprised 50% of HIV cases in Saskatchewan. This is a marked increase from 18% in 1991 (Saskatchewan Health, 2004). The Northern Saskatchewan region also has high rates of other diseases transmitted through high risk behaviours, such as hepatitis C, particularly among those aged 15-24. According to Saskatchewan Health (2004: 3), four of six Aboriginal women diagnosed with HIV in 2003 were in the 15-24 year age group, while the majority

¹ The term 'Aboriginal' is understood broadly as all those people who identify with being of Aboriginal ancestry, and in Canada includes Inuit, status and non-status Indians, and Métis. They represent diverse groups with unique cultural systems, historical experiences, and a range of formalized relations with provincial and federal governments. 'First Nation' is used to describe people who are status or registered Indians as defined by the Indian Act. 'Métis' people are of mixed Aboriginal and European heritage.

of the 14 Aboriginal male cases were in the 20-34 year age group and 35-49 year age group.

Northern Saskatchewan Aboriginal community leaders and health professionals identify HIV/AIDS as just emerging as an increasing issue of concern. In light of the high rate of other sexually transmitted diseases and the high prevalence of hepatitis C and associated risk behaviours (e.g. injection drug use), however, the potential for HIV/AIDS to become a major problem is of considerable concern.

What Do We Already Know About Doing Research On:

HIV/AIDS in Aboriginal Communities

Several issues must be kept in mind when examining the experiences of HIV/AIDS in Aboriginal communities. Approaches to HIV/AIDS must be grounded in an understanding not only of local circumstances of life as shaped by historical contingency and contemporary conditions of education, employment, housing, and quality of life, but also by an awareness of local experiences and perspectives of the origins and course of HIV/AIDS (Health Canada 1999). Northern Saskatchewan communities are also small and remote, presenting their own unique challenges for HIV/AIDS prevention, treatment and surveillance. Another factor to consider is how HIV is introduced into communities and who is most vulnerable. Several studies report on the different perspectives and experiences of HIV in northern and remote First Nations communities. Myers and colleagues (1993), for example, presented survey findings that indicate 45% of Aboriginal respondents in northern Ontario had never heard of HIV.

HIV/AIDS in Isolated and Reserve Communities

Other issues such as geographic distances and resource limitations are also important to consider. Factors such as these result in greater reliance on community members and informal social networking for support rather than on formal structures. Anonymous or confidential HIV testing, particularly for high risk individuals are cited as a common concern in rural/remote contexts (Tseng, 1996). The literature suggests more information is required to understand issues fundamental to rural and remote contexts.

The Importance of Community Capacity in Addressing HIV/AIDS

Most agree that the best method of impacting the social response to HIV/AIDS, no matter what the context, is to implement strategies that facilitate community organization, ownership, participation, and empowerment (Shaw 1988; Nelson 1993). Using culturally sensitive, community-centered methods, will enable Indigenous communities to take more effective and sustainable action upon the health priorities most meaningful to them (Smith et al, 2001). Community capacity building may become an important "bridge" between action and positive long-term health outcomes for aboriginal communities.

Implications for HIV/AIDS Research in Northern Saskatchewan

Over time it has become clear that HIV/AIDS is a long-term development issue requiring a long-term multi-sectoral response that must include capacity building among communities, local organizations and networks (Kotellos et al 1998). With a diverse literature that implicates external intervention and control of Indigenous communities in their current disadvantaged position and poor health (Dacks & Coates, 1988; Waldram, Herring and Young 1995; Young 1994 and 1988; and Lee, 1992), a capacity building and proactive approach is imperative to tackling the potential problem of HIV/AIDS.

Northern Saskatchewan community leaders, members, and health organizations identified a concern for the emergence of HIV/AIDS as a health priority and recognize that there is benefit to control proactive initiatives. Tackling the issue of HIV/AIDS in northern Saskatchewan at this stage facilitates a capacity building rather than crisis intervention approach.

The primary objective of this project was to understand the context of HIV/AIDS in four northern Saskatchewan communities who came forward with concerns about HIV/AIDS and hepatitis C to inform the design and orientations of effective and appropriate prevention, education, and management initiatives, potentially across northern Saskatchewan. A more general objective was to contribute to the currently limited literature on HIV/AIDS in rural and remote Aboriginal communities and Reserves in Canada.

Research Objectives

- 1. Determine community awareness, attitudes and knowledge of HIV/AIDS.
- 2. Document knowledge derived from local experiences of the challenges facing communities, families and individuals when someone with HIV/AIDS lives in the community.
- 3. Determine community awareness, attitudes, capacity and strategies for accepting and supporting individuals with HIV/AIDS.
- 4. Determine factors to increase capacity of communities to accept and support individuals with HIV/AIDS.
- 5. Determine appropriate and meaningful ways to talk about HIV/AIDS and to conduct primary prevention, education, care and surveillance.

Anticipated Outcomes

The outcomes of this project contribute to filling gaps in knowledge identified by Health Canada (1999) and will also have direct effects on policy and practice in northern Saskatchewan by:

- Enabling First Nation and Métis communities to discuss and prepare for the potential need for supporting a community member with HIV/AIDS.
- Increasing the capacity of communities to accept and support individuals with HIV/AIDS.
- Enabling these communities to develop strategies for supportive care and management for individuals with HIV/AIDS in northern Saskatchewan communities.
- Increasing acceptance of testing for HIV/AIDS in northern Saskatchewan.
- Facilitating access to community services that can provide support to HIV-affected individuals and families, as well as addressing HIV/AIDS related questions on prevention, or needs of all community members.

The Decision to Include an examination of hepatitis C

We began this project with the idea of focusing on HIV/AIDS. As the Steering Committee met to consider the specific questions we wanted to ask people, it became clear that hepatitis C in particular is a current concern with some of the same transmission risk behaviours associated with it as HIV/AIDS. We therefore decided to ask the same questions about both infections.

Community and Participant Recruitment

The four communities whose experiences and perceptions of HIV/AIDS and hepatitis C are reflected in this report participated because their leaders were among those who initiated this project because concerns about these diseases were being expressed there. Individual participants were recruited via a poster and newsletter campaign in each community asking those who were willing to share their views on HIV/AIDS or hepatitis C to contact their community research assistant. When the interview process began, word of mouth resulted in more participants coming forward.

Design of Interview and Focus Group Questions

The Steering Committee played a key role in determining the specific questions to be asked, and in identifying cohorts of participants. We began with a broad survey of the academic literature and reports produced in other projects to pull out questions participants were asked in those projects. We focused our attention on what we could find specific to Aboriginal peoples, but also broadened the scope to vulnerable populations, or other population groups that shared some characteristics with northern Saskatchewan (e.g. geographic isolates). The questions were grouped according to our objectives, allowing us to both build on what others had found worked for them and identify gaps in topic areas specific to the northern Saskatchewan context. Some 200+ possibilities were generated across the 5 objectives. In an iterative process that included teleconferences and a face-to-face meeting, the Steering Committee created interview schedules appropriate to their communities and appropriate to the groups of potential participants identified (Appendices A, B, and C). They were: young adults (18-29); adults (30-54); and Elders (55+). Front Line Workers included health care providers, social workers, teachers, school principals, and spiritual leaders; anyone in the different communities the Steering Committee thought people might turn to for help and guidance with respect to HIV/AIDS and hepatitis C. The questions were pilot tested in a northern Saskatchewan community not participating in this project.

Data Collection

Over 200 individuals participated in interviews and group discussions between January and June 2004. They included community members as well as health, social, and education service providers, and spiritual leaders ("Front Line Workers"). One community member from each of the four participating communities (2 First Nation and 2 Métis) was hired as a research assistant to conduct interviews in their home community. All research assistants attended a 2-day workshop for training in research ethics and interviewing techniques. They were also provided with some education on HIV/AIDS and hepatitis C.

While not included as part of the analysis, we also asked participants about their experience of participating in this project, so that we would have an indication of any concerns emerging in different communities about the effect of the project itself (e.g. initiating rumour and gossip about particular individuals or communities), and could be proactive in managing them. Participant responses are summarized in Appendix D. We also had a regular debriefing strategy with community research assistants through the project coordinator and the community representative on the Steering Committee to identify and handle concerns about the potential for negative impacts of this project.

Analysis and Interpretation

Interview transcripts were analyzed using a "grounded theory" approach (Charmaz, 2000); which simply means that we approached the first level of analysis with no preconceived ideas about what people might say about the topics of HIV/AIDS and hepatitis C. This approach is especially useful in uncovering unanticipated themes and relationships. A second round of analysis that drew in themes from a review of the literature was then conducted. This level of analysis allowed us to also consider what other people in other projects on HIV/AIDS and hepatitis C had to say compares with the responses of the

4.7

participants in this project. A qualitative data analysis software package, *Atlas.ti*, was used to help manage the analysis. Other information was also considered in the analysis process, such as personal correspondence with the Project Coordinator and the Community Research Assistants, and field notes kept by the Community Research Assistants. The process was led by a research analyst, with results presented back to the Steering Committee at regular intervals (4 interim reports were produced) for discussion and direction.

Main Findings

- Fear: Many participants had a good general understanding of HIV and AIDS but also expressed a strong desire for more knowledge. Younger people had more knowledge than middle age or older people. Many were fearful of HIV/AIDS, mainly due to perceptions of HIV/AIDS as a terminal illness or "death sentence". Simultaneous feelings of fear and anxiety were linked to concerns about the challenges of HIV in a northern context, such as access to services around prevention and management, and what they felt was a lack of adequate education and awareness on HIV/AIDS.
- Hepatitis C knowledge: Some participants were more unfamiliar with hepatitis C than HIV/AIDS; a surprising finding given that hepatitis C is a more prevalent and immediate concern in some communities.
- Misconceptions: Misconceptions about HIV/AIDS and hepatitis C transmission/cause/vulnerability exist in each of the communities. These misconceptions influence the type and level of support participants feel they can offer affected community members.

- Level of support: Reactions to, and anticipated support for, people infected with HIV/AIDS differed based on the closeness of the relationship between the participant and the (potentially) affected person. All participants expressed a desire for themselves and their community as whole to be supportive of all affected community members.
- **Confidentiality:** Confidentiality with respect to accessing information, testing, and treatment was an overriding concern.
- Geography: Long distances to appropriate services, and the remote location of some communities were issues discussed by participants. Mobility of clients was cited by service providers as affecting their ability to track and provide follow-up to clients.
- **Creativity:** Participants felt that education and awareness need to be increased using more creative strategies (e.g. going beyond pamphlets and workshops).
- **Consistency:** Participants would like to see programs/services offered on a more consistent basis.

More Detailed Results

We have organized participants' discussions under five main themes presented in more detail following the recommendations section:

- Knowledge & Awareness
- Perceptions & Experiences
- Current Capacities
- Needs & Gaps
- Strategies & Future Directions

The thematic presentation of results is followed by a detailed list of resources identified as part of our preparation to engage in this research and as the project unfolded. These include opportunities for funding research and programming, resources on HIV/AIDS and hepatitis C specific to Aboriginal peoples, more general resources about HIV/AIDS and hepatitis C, educational materials in the form of videos, multimedia, and games, and academic theses. The appendices include:

- A. General Interview Schedule
- B. Front Line Worker Interview Schedule
- C. Focus Group Discussion Schedules
- D. Interview Consent & Confidentiality Forms
- E. Participant Comments on the Interview Experience and on Participating in this Project



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"There needs to be more done as there seems to be no feeling of urgency amongst our communities to address it. Whether they feel it's not a problem. But I feel we should be educated about it before it becomes an epidemic or problem."

The sentiments summarized above by a Front Line Worker are echoed in the comments of many of the other participants in this project. This project Steering Committee, which includes leadership from these communities and representatives of health authorities (First Nations and Health Regions) with broad stakeholder ties, does feel an increasing sense of urgency about the issues of HIV/AIDS and hepatitis C. At the same time Steering Committee members feel they are at a stage where there is an opportunity to work towards proactive HIV/AIDS and hepatitis C strategies for the region. Their first step -this project – was to collect baseline information on the perceptions, experiences, needs, and capacities of their communities. The Steering Committee met to consider the comments and contributions of the project participants as they are reflected in the pages of this report. This section represents the recommendations of the Steering Committee that arose from their consideration of the contributions of project participants. Following a discussion of the recommendations, the recommendations and suggested actions are presented in worksheet format. The worksheets are provided as a guide to planning actions at many different levels. The who, what, when and how will vary for each individual, community, agency, health authority, or inter-sectoral partnership who is planning to implement the recommendations.

RECOMMENDATIONS

The Northern Saskatchewan Context

The people and communities of northern Saskatchewan are culturally, linguistically, and socially diverse; representing Cree, Dene, Métis, and non-Aboriginal backgrounds and histories. A majority experienced the negative consequences of colonial policies that systematically devalued traditional values, beliefs, and language and disrupted social and familial networks and relationships. Therefore, participants note the importance of incorporating traditional knowledge, practices, beliefs and values in HIV/AIDS and hepatitis C strategies for northern Saskatchewan. These include a consideration of spiritual, physical, emotional, and mental dimensions of healthy people and communities. Collective responsibility and capacity, as well as sharing and compassion were cited as important values. At the same time, people recognize that reclaiming and vitalizing cultural identity is a diverse, dynamic, and sometimes contested process as individuals and communities work in different ways towards determining the healthiest approaches for themselves. These include not only some of the traditional values and beliefs outlined here, but also various combinations and integrations of Eurowestern beliefs and ideologies.

This is taking place in a geographic context where many communities with relatively small populations are located in remote and rural locations with a variety of different capacities and needs, dealing with multiple and different health and social issues in addition to hepatitis C and HIV. Jurisdiction over service delivery is also complex with services organized, funded and delivered as part of provincial or federal responsibility, or a combination of both, through

5.1

regional First Nations and non-First Nations organizations, and directly in individual communities.

Many of the participants in this project, and the Steering Committee members expressed the importance of understanding and incorporating this diversity and complexity in HIV/AIDS and hepatitis C education, prevention, support, and treatment strategies recognizing too that effective management of these and other challenges lies in inter-sectoral and cross-jurisdictional coordination of the diverse capacities represented in the north both to address gaps and avoid overlap.

The Recommendations and Actions

The following recommendations and suggested actions for a northern Saskatchewan HIV/AIDS and hepatitis C strategy have been offered by the project Steering Committee, taking into consideration the results of this project and the context described above. Following their discussion below, these recommendations are presented in a worksheet format that will facilitate discussions about who should lead various action items at the individual, community, regional, or inter-sectoral levels, what resources might be needed to implement specific actions, and an estimate of timelines to implementation.

Recommendation #1

The major recommendation of the project steering committee is to create a regional HIV/AIDS and hepatitis C strategy that will combine:

- a broad-based and holistic prevention approach, with
- consistent education and awareness messages, as well as
- support for diagnosis, management and treatment, with
- a community support initiative

This is not a new idea for northern Saskatchewan; a Northern Communities Partnership Agreement that includes regional health authorities, First Nations, and recreation has successfully coordinated around the issue diabetes.

<u>Action</u>

Given the complex context described above, a regional coordinator position should be created to manage/coordinate this comprehensive approach and link regional, local, and individual human and structural resources and capacities. This dedicated position would work across jurisdictions to build a north-wide approach that combines existing resources and lobbies as a whole for additional resources.

Recommendation #2

Increase Knowledge and Awareness of HIV/AIDS and hepatitis C in northern Saskatchewan.

- Provide a consistent awareness message
 - Include the message that HIV- and Hepatitis C-positive status in individuals is not an immediate death sentence focusing on the ongoing contributions affected individuals can make to their communities
- Shift the focus from treatment to public education
 - Focus messages on the potentially preventable nature of HIV and Hepatitis C infection with a holistic approach that includes highlighting linkages between determinants and circumstances of infection such as alcohol and drug use.
 - o Use positive role modeling

<u>Actions</u>

- A. In addition to incidence and prevalence data (which is already provided), provide information to communities on emerging issues (determinants and circumstances increasing vulnerability) around HIV, AIDS, and hepatitis C in northern Saskatchewan. Information may include the reality that available data may only represent the tip of the iceberg and can highlight the challenges with surveillance of these diseases.
- B. Create an environment for families to learn together, including children at a young age, but also providing some education focus for Elders. Consider new and innovative approaches to knowledge and awareness messages in a multilingual format (Cree, Dene, Michif, English), such as drama groups, phone-ins, radio, or the development of humorous slogans to get messages into homes.
- C. Provide education to front service line workers, and some experience with potential situations via scenario discussions.
 Consistency and frequency of education is an important consideration in light of high turnover in some positions.
- D. Offer skills development programming in the community, workplace, and schools on assertiveness, healthy relationships, recreation, and arts as potential preventive measures.
- E. Encourage role modeling among leadership with regard to the ongoing contribution of HIV- and hepatitis C-positive individuals to community, and their normalized inclusion in community life. This must be framed so that affected individuals do not feel they are being leveraged for resources.

Recommendation #3

While many participants raised the issue of access to testing as a concern, testing is broadly available (see the "further information" section of this binder). Thus the recommendation is to improve awareness of the availability of HIV/AIDS and hepatitis C testing in the community, locally, and regionally. At the same time it is also important to address misconceptions about anonymity and confidentiality in the testing process. An important approach to alleviating the apprehension around testing will be to normalize the testing process.

Actions

- A. Encourage prenatal testing for all women, not just women considered to be at risk.
- B. Encourage testing at the time of counseling for any sexually transmitted infections (STIs) especially individuals with multiple STIs or multiple episodes of STIs, injection drug users, individuals undergoing STI treatment, and individuals with multiple partners. The definition for 'multiple partners' should include simultaneous/ polygamous relationships as well as serially monogamous relationships.
 - a. In the event of positive test results, social network analysis¹ of affected individuals should be considered as a strategy to identify other potentially affected individuals.

¹ See Christley, R.M. et. al. (2005) Infection in Social Networks: Using Network Analysis to Identify High-Risk Individuals. *American Journal of Epidemiology* 162:1024-1031 for a description.

Recommendation #4

Improve community preparedness

• Communities as a whole should be included in planning strategy rather than focusing solely on the responsibilities of individual organizations within the community (e.g. schools, workplaces, health centres). Roles for organizations such as churches and Friendship centres, or local businesses, should also be included in holistic community preparedness strategy development.

<u>Actions</u>

- A. Health authorities <u>should</u> revisit their blood borne pathogen infection control protocols for labs, hospitals, and clinics, particularly with regard to the ongoing orientation and training of new staff in light of the high turnover of staff in northern Saskatchewan
- B. Schools and workplaces should review their policies taking a wellness approach that includes:
 - Universal precautions for every day activities, sport, and playground
 - Support for affected children/ workers
 - Curriculum development around HIV/AIDS and hepatitis C knowledge and awareness in schools and workplaces that builds on current initiatives already underway
 - o Include parents and Elders
 - o Provide recreation strategy
 - Include assertiveness training and healthy relationship building skills

- C. Encourage leadership to become aware of HIV/AIDS and hepatitis C risk factors and provide support to community members with strategies such as:
 - Scenario-response discussions
 - Role modeling
 - Hosting presentations to band/town council focused in the areas of awareness and harm reduction strategies
- Increase community education and exposure to people with HIV by:
 - Inviting HIV or hepatitis C-positive individuals to give public presentations
 - Adding toll free phone numbers for HIV/AIDS and hepatitis C information sources, as well as the toll free Provincial Health Line phone number, to the back of needle exchange information cards that are already being distributed
 - Implementing strategies under the second recommendation
- E. Provide education to front line service workers about HIV/AIDS and hepatitis C specific to their roles in the community, looking at:
 - Handling potentially infectious materials
 - Management of HIV/AIDS and hepatitis C
 - Developing/ expanding harm reduction strategies
 - These strategies (e.g. needle exchange) should be developed in discussions that include health regions and authorities, MHOs, interagency committees, community leadership and should include an expansion of the prevention component in harm reduction

- Providing tools for families to act as support mechanisms through a case conferencing approach that
 - Identifies the needs and wants of affected individuals and families
 - Provides clinical support and follow-up
 - Ensures access to further information, education, and services (e.g. toll free numbers)
 - Includes the knowledge of Elders
- Managing anonymity and confidentiality of affected individuals by:
 - o Encouraging support mechanisms
 - Encouraging all service workers to maintain confidentiality, but:
 - Putting a problem strategy in place in consultation with MHO with community role for mitigating the dangers and harm of rumour and gossip

Worksheets

The following worksheets are provided as a guide to planning actions at many different levels. The who, what, when and how will vary for each individual, community, agency, health authority, or inter-sectoral partnership who is planning to implement the recommendations.

		Worksheet for individu	al, community, regio	nal, or inter-so	ectoral levels	5	
Re	commendation	Acti	ons	Lead Agency/ Organization/	Supporting Agency/ Organization/	Resource Needs and Sources	Timeline
		Major Action	Supporting Actions	or Individual	or Individual		
RECOMMENDATION #1	Create a regional HIV/AIDS and hepatitis C strategy that will combine a broad- based and holistic prevention approach with consistent education and awareness messages, as well as support for diagnosis, management and treatment with a community support initiative	A regional program coordinator position should be created to manage/coordinate this comprehensive approach and link regional, local, and individual human and structural resources and capacities.					

		Worksheet for individuo	al, community, regio	onal, or inter-se	ectoral levels	;	
Re	commendation	Actio	ns	Lead Agency/ Organization/	Supporting Agency/ Organization/	Resource Needs and Sources	Timeline
		Major Action	Supporting Actions	or Individual	or Individual		
IDATION #2	Increase knowledge and awareness of HIV/AIDS and hepatitis C in northern Saskatchewan by	Provide information to communities on emerging issues (determinants and circumstances increasing vulnerability) around HIV, AIDS, and hepatitis C in northern Saskatchewan. Information may include the reality that available data may only represent the tip of the iceberg and can highlight the challenges with surveillance of these diseases.					
RECOMMENDATION	providing a consistent awareness message and shifting the focus from treatment to public education	Create an environment for families to learn together, including children at a young age, but also providing some education focus for Elders. Consider new and innovative approaches to knowledge and awareness messages in a multilingual format (Cree, Dene, Michif, English), such as drama groups, phone- ins, radio, or the development of humorous slogans to get messages into homes.					

		Worksheet for individuo	al, community, regio	onal, or inter-se	ectoral levels	5	
Re	commendation	Actio	ns	Lead Agency/ Organization/	Supporting Agency/ Organization/	Resource Needs and Sources	Timeline
	1	Major Action	Supporting Actions	or Individual	or Individual		
RECOMMENDATION #2	Increase Knowledge and Awareness of HIV/AIDS and hepatitis C in northern Saskatchewan by providing a consistent awareness message and shifting the focus from treatment to public education	Provide education to front service line workers, and some experience with potential situations via scenario discussions. Consistency and frequency of education is an important consideration in light of high turnover in some positions. Offer skills development programming in the community, workplace, and schools on assertiveness, healthy relationships, recreation, and arts as potential preventive measures. Encourage role modeling among leadership with regard to the ongoing contribution of HIV- and hepatitis C-positive individuals to community, and their normalized inclusion in community life. This must be framed so that affected individuals do not feel they are being leveraged for resources.					

		Worksheet for individue	al, community, regio	onal, or inter-se	ectoral levels	5	
Re	commendation	Actio		Lead Agency/ Organization/	Supporting Agency/ Organization/	Resource Needs and Sources	Timeline
		Major Action	Supporting Actions	or Individual	or Individual		
3		Encourage prenatal testing for all women, not just women considered to be at risk.					
RECOMMENDATION #3	Improve awareness of the availability of HIV/AIDS and hepatitis C testing in the community, locally and regionally and address misconceptions about anonymity and confidentiality in the testing process.	Encourage testing at the time of counseling for any sexually transmitted infections (STIs); including especially individuals with multiple STIs or multiple episodes of STIs, injection drug users, individuals undergoing STI treatment, and individuals with multiple partners. The definition for 'multiple partners' should include simultaneous/ polygamous relationships as well as serially monogamous relationships. In the event of positive test results, social network analysis of affected individuals should be considered as a strategy to identify other potentially affected individuals.					

		Worksheet for individu	ual, community, regior	nal, or inter-so	ectoral levels	5	
Re	commendation	Actions		Lead Agency/ Organization/	Supporting Agency/ Organization/	Resource Needs and	Timeline
	1	Major Action	Supporting Actions	or Individual	or Individual	Sources	
ON #4	Improve community preparedness. Communities as a whole should be included in planning strategy; rather than focusing solely on the responsibilities of individual organizations within the community (e.g. schools, workplaces, health	Health authorities revisit their blood borne pathogen infection control protocols for labs, hospitals, and clinics, particularly with regard to the ongoing orientation and training of new staff in light of the high turnover of staff in northern Saskatchewan					
RECOMMENDATION			Universal precautions for every day activities, sport, and playground Support for affected children/ workers				
RECON	centres). Roles for organizations such as churches and Friendship centres, or local businesses, should also be included in holistic community preparedness strategy development.	Schools and workplaces should review their policies taking a wellness approach	Curriculum development around HIV/AIDS and hepatitis C knowledge and awareness in schools and workplaces * Include parents and Elders * Provide recreation strategy * Include assertiveness training and healthy relationship building skills				

		Worksheet for individu	Jal, community, regior	nal, or inter-se	ectoral levels	5	
Re	commendation	Act	ions	Lead Agency/ Organization/	Supporting Agency/ Organization/	Resource Needs and Sources	Timeline
		Major Action	Supporting Actions	or Individual	or Individual	3001063	
	Improve community preparedness.	Encourage leadership to	Scenario-response discussions				
N #4	Communities as a whole should be	become aware of HIV/AIDS and hepatitis C risk factors and provide support to community	Role modeling				
	 included in planning strategy; rather than focusing solely on the responsibilities of individual organizations within the community (e.g. schools, workplaces, health centres). Roles for organizations such as churches and Friendship centres, or local businesses, should also be included in holistic community 	members with strategies	Presentations to band/town council				
VDATIO		Increase community education and exposure to people with HIV	Inviting HIV or hepatitis C- positive individuals to give public presentations				
RECOMMEN			Adding toll free phone numbers for HIV/AIDS and hepatitis C information sources, as well as toll free Provincial Health Line phone number, to the back of the needle exchange information cards.				
	strategy development.		Implementing strategies under the second recommendation.				

	Worksheet for individual, community, regional, or inter-sectoral levels								
R	ecommendation	Act	ions	Lead Agency/ Organization/	Supporting Agency/ Organization/	Resource Needs and	Timeline		
		Major Action	Supporting Actions	or Individual	or Individual	Sources			
	Improve community		Handling potentially infectious materials						
a O	preparedness. Communities as a whole should be		Management of HIV/AIDS and hepatitis C						
RECOMMENDATION #4	included in planning strategy; rather than focusing solely on the responsibilities of individual organizations within the community (e.g. schools, workplaces, health centres). Roles for organizations such as churches and Friendship centres, or local businesses, should also be included in holistic community preparedness strategy development.	Provide education to Front Line Workers about HIV/AIDS and hepatitis C specific to their roles in the community	Developing/ expanding harm reduction strategies. These strategies (e.g. needle exchange) should be developed in discussions that include health regions and authorities, MHOs, interagency committees, community leadership; and should include an expansion of the prevention component in harm reduction.						

		Worksheet for individu	ual, community, regior	al, or inter-se	ectoral levels	5	
R	ecommendation	Acti	ions	Lead Agency/ Organization/	Supporting Agency/ Organization	Resource Needs and	Timeline
	1	Major Action	Major Action Supporting Actions		/ or Individual	Sources	
RECOMMENDATION #4	Improve community preparedness. Communities as a whole should be included in planning strategy; rather than focusing solely on the responsibilities of individual organizations within the community (e.g. schools, workplaces, health centres). Roles for organizations such as churches and Friendship centres, or local businesses, should also be included in holistic community preparedness strategy development.	Provide education to Front Line Workers about HIV/AIDS and hepatitis C specific to their roles in the community	Providing tools for families to act as support mechanisms through a case conferencing approach that identifies the needs and wants of affected individuals and families, provides clinical support and follow-up, ensures access to further information, education, and services (e.g. toll free numbers) and includes the knowledge of Elders. Managing anonymity and confidentiality of affected individuals by encouraging support mechanisms, encouraging all service workers to maintain confidentiality, but putting a problem strategy in place in consultation with MHO; with community role for mitigating the dangers and harm of rumour and gossip.				

	Worksheet for individual, community, regional, or inter-sectoral levels									
Recommendation		Actions	Lead Agency/ Organization/	Supporting Agency/ Organization	Resource Needs and	Timeline				
	Major Action	Supporting Actions	or Individual	/ or Individual	Sources					

	Worksheet for indiv	idual, community, regi	onal, or inter-se	ectoral levels	5	
Recommendation		Actions	Lead Agency/ Organization/	Supporting Agency/ Organization	Resource Needs and	Timeline
	Major Action	Supporting Actions	or Individual	/ or Individual	Sources	

	Worksheet for indivi	idual, community, regi	onal, or inter-se	ectoral levels	5	
Recommendation	4	Actions	Lead Agency/ Organization/	Supporting Agency/ Organization	Resource Needs and	Timeline
	Major Action Supporting Action		or Individual	/ or Individual	Sources	

	Worksheet for indiv	idual, community, regi	onal, or inter-se	ectoral levels	S	
Recommendation		Actions	Lead Agency/ Organization/	Supporting Agency/ Organization	Resource Needs and	Timeline
	Major Action	Supporting Actions	or Individual	/ or Individual	Sources	



This section discusses participants':

- Knowledge of HIV/AIDS and hepatitis C (for example, how these diseases are transmitted, which groups are more vulnerable).
- Awareness of the current and future significance of HIV/AIDS and hepatitis C and the seriousness of these diseases.
- Other issues such as sharing and generational perceptions.



KNOWLEDGE

Covered under the following topic area:

- Direct and Indirect Transmission
- Sharing
- Populations at Risk



• **Summary:** Participants knew that both HIV/AIDS and hepatitis C were caused¹ by drugs/needles, sexual activities, blood and unprotected sex. The sharing of personal items was discussed as linked with getting HIV/AIDS, but not with hepatitis C. Table 1 presents a summary of the most common responses to the questions, "How do you think people get HIV? hepatitis C?"

¹ The distinction between the definitions of "cause", "transmission" and "vulnerability" was too fine for participants to treat as separate concepts. Therefore the words "cause", "transmission" and "vulnerability" are treated as general terms – not clinical – in this report, 'defined' as: "How do you get HIV/AIDS or Hepatitis C?"



Table 1: How do you think people get HIV? hepatitis C?

Theme	Most Common Responses	HIV/AIDS	hepatitis C
Body fluids & Sexual activities	Drug/needles	\checkmark	\checkmark
	Sexual activities	\checkmark	\checkmark
	Blood	\checkmark	\checkmark
	Unprotected sex	\checkmark	\checkmark
Sharing	Sharing personal items 🗸		
Unsure	Unsure how to respond		\checkmark

• Direct and indirect causes: Participants discussed indirect and direct methods of contracting HIV/AIDS and hepatitis C. Indirect causes participants suggested ranged from young people partying and peer pressure, to lack of education and boredom related to unemployment as factors leading to situations or circumstances in which people may become vulnerable to infection. This contrasts with other, more direct, methods of transmission people described, such as coming into contact with infected blood (e.g. through sharing needles) or blood products (medical procedures).

Below are some of the comments made about how people get HIV/AIDS and hepatitis C.

"Through what I see, and what I read about it [HIV], they say it's through either needles or through sex and when they're, they're drunk, they don't, they're not knowing what they're doing but mostly I think it's transmitted by sex and those needles that they use [...]." – Woman, Age 55+

"Maybe because they don't know anything about, about that, that sickness and if they know more about it then they'll be careful." – Woman, Age 55+



"They can face peer pressure with all the drugs they have around you know. All the things that people do by sharing." – Female Youth Focus Group

"When people get drunk and high on drugs they don't know what the hell they're up to and who they sleep or share needles with." – Female Youth Focus Group

"Yah. They could have parties and then there's a big scrap that breaks out. They fight and start bleeding all over and everything." – Female Youth Focus Group

With respect to hepatitis C in particular, there is some confusion about the differences between hepatitis A, B, and C. (**Note**: The differences are described in the information section at the beginning of this report)

"I know less about, I mean, I don't know a whole lot about [HIV/AIDS and hepatitis C] but I, I'm not always clear, you know this is hep C and this is hep A, I'm not always clear about the differences even though it's posted and you can, there's lots of information, but sometimes, unless it touches you directly, it's not so easy for me to compartmentalize the A and the hep C, you'd have to tell me." – Elder Women Focus Group





• Sharing personal items (e.g. cups, toothbrushes) was seen, to a small degree, as one way of transmitting HIV/AIDS or hepatitis C. Aside from sharing needles for drug use, some participants felt that a person can become infected with either one of these diseases by sharing personal items such as cups or toothbrushes:

"Talk to kids about (hepatitis C) that they would not share anything like toothbrushes, cups, etc." – Female Youth Focus Group

"Love them and show them that you'll care for them no matter what, as long as you keep on reminding that person to keep their cup to themselves and don't pass it around 'cause they can give it to other people and that person can give it to other people and then from that person it keeps on going." - Man, Age 18-29

• **Misconceptions exist:** Responses suggests that while the majority of participants are aware of the major causes of HIV/AIDS and hepatitis C, there are still misconceptions that need to be clarified. As the information about HIV/AIDS and hepatitis C in the first section of this report suggests, there is a low risk of transmission if toothbrushes are shared, but you don't get it from sharing cups or cigarettes.



🔊 Populations at Risk

- **HIV/AIDS risk:** Overall, participants noted that basically any group could be affected by HIV/AIDS, but noted that specific groups such as African/African-Americans, drug users or younger people, have also been affected as a group by HIV/AIDS.
 - Other affected groups who were sometimes mentioned included Aboriginal people, alcoholics, people living in cities, poor people, and homosexual individuals.
- Hepatitis C risk: When asked which groups of people are most affected by hepatitis C, many participants were unsure or could not think of which groups of people were most affected by hepatitis C, but also noted that younger people could also be affected.

The most common responses for both HIV/AIDS and hepatitis C are summarized in Table 2.

Table 2: Which groups of people have been most affected by HIV/AIDS? (probes – around the world, in Canada – ethnicity, age, sex). hepatitis C?

Most Common Responses	HIV/AIDS	hepatitis C
African-Americans/Africans	\checkmark	
Drug users	\checkmark	
Teenagers/young people	\checkmark	\checkmark
Any group	\checkmark	
Unsure		\checkmark



AWARENESS

Covered under the following topic area:

- Current Importance Compared to Other Issues
- "HIV/AIDS is Not a Problem... Yet"
- Views of HIV/AIDS as a Terminal Illness
- Generation Perspectives

Current Importance Compared to Other Issues

• HIV/AIDS less important than other issues: Currently, HIV/AIDS is not specifically discussed as a widespread issue in northern Saskatchewan. Participants felt that both HIV/AIDS and hepatitis C were not currently large problems in their communities, so neither disease is given very much attention, compared to other concerns which may range from housing and unemployment to more general concerns about HIV/AIDS and hepatitis C risk behaviours such as drug abuse. People do, however, recognize the potential for HIV/AIDS and hepatitis C to emerge as significant issues in the future (see next section).

"You know [this is] the first time I heard about this Hep C [...]. I focused more on other subjects" – Elder Men Focus Group



"Both of our kids are fairly grown up and they've had their information through education in the school and that kind of thing and we probably talk more about bingo than about AIDS." – Elder Men Focus Group

"Crystal meth is coming in now and we gotta deal with Hep C, HIV, AIDS and trying to teach our kids about rubbers and all the dangers of smoking now. There's so many bad things with smoking where it was OK before this. So many things you have to deal with in trying to tell your family ...a) variety of everything eh. It's no wonder some of them just take it and throw it away." – Adult Men Focus Group

"I haven't, heard any [of any needs for people with HIV/AIDS or hepatitis C], but again, I don't know, I mean I'm not around people who have talked about it, it's not a, it's not something that we discuss over coffee." – Elder Women Focus Group



Comments from Community Members

• **Future issue:** Many participants thought that HIV/AIDS and hepatitis C were not large issues in their communities, but qualified their perceptions of HIV/AIDS by adding "not yet" – indicating that participants believe that HIV/AIDS may be inevitable or become a problem in the future.



• **Personal touch:** Participants also commented that until HIV/AIDS affects their community or themselves in a personal way, HIV/AIDS will not be given much attention. This perception may create challenges in developing and implementing successful education and prevention strategies (see *Perceptions & Experience* section for more discussion on this theme).

"It's a kinda scary thought that one of these days it [HIV/AIDS] will get into the community but now, as for now, there's none." – Women, Age 55+

"Um, I feel that both of them [HIV/AIDS and hepatitis C] are not a problem unless it starts to affect our community in a personal way, as in if somebody [coming] to the community that's when it would start affecting us but right now, people just brush it off, I don't think it really affects us right now." – Man, Age 18-29

"Not bad now, but it's [HIV/AIDS] going to be worse. Maybe in the future, not soon." – Man, 18-29

"I haven't heard much but, like I've heard some but, it's, like it [HIV/AIDS] started out small but it's getting bigger now like I've heard bigger problems and, I've heard problems about hepatitis and I think it's getting to be a big problem here,..." – Woman, Age 18-29

" Maybe in the future or something [I'd like to be part of an advisory board]. If it [HIV/AIDS or hepatitis C] becomes a problem or something in our community. – Woman, Age 30-54



"Now [HIV/AIDS is] no problem; in the future we might have a problem." – Woman, Age 30-54

• **Proactive approach:** Some participants said that they knew someone with HIV/AIDS and thought that HIV/AIDS will eventually become an issue in their community in the future, indicating that proactive measures should be undertaken before HIV/AIDS becomes a major issue in their community:

"Well, you can't stop, like that's the thing I don't understand, you can't stop the disease [HIV/AIDS] from coming here 'cause obviously it's everywhere around the world, so it's gonna come here, you can't prevent it but you can educate the public about It. Like I said before, education is the key thing [...]." – Woman, Age 18-29

"I, I don't think it's [HIV/AIDS] a big problem, but I think we have to stay on top of it and we have to educate the kids basically keep, keep pamphlets out there making people aware that there is, could, be a problem if we didn't stay on top of it." – Woman, Age 18-29

" [...] there's gonna be a lot of people with HIV so we gotta start the process now to help the ones in the future [...]." – Adult Men Focus Group

"We need to know more about what's coming in the future and I hope, I believe this is what this project is trying to do." – Elder Men Focus Group



Front Line Worker Comments

- Shared perceptions: Front Line Workers shared the same view as community members. HIV/AIDS was not perceived by Front Line Workers as a large issue currently facing northern Saskatchewan, but it could become an issue in the future.
- Lack of education and awareness: Front Line Workers and community members also feel that one of the main issues is the need for more HIV/AIDS and hepatitis C education and awareness. Front Line Workers point especially to education about aspects such as transmission and how to cope with knowing someone with the disease.
- **Denial:** Front Line Workers also felt that some community members believe that they are not vulnerable to HIV/AIDS or hepatitis C. This might reflect participants' perceptions that these diseases are not very visible in northern communities. The limited visibility may also play a role in the fear expressed by some about HIV/AIDS and hepatitis C.

Table 3: What do you think are some of the issues relating to HIV or AIDS in Aboriginal communities? hepatitis C?

Theme	Most Common Responses
	Lack of community education
	Lack of community awareness
Education &	Fear of disease
Awareness	Denial that they can get HIV/AIDS
	Drug use
	Lack of visibility of the disease in the community
Health Service Issues	No time for health workers to focus on HIV/AIDS
	Lack of formal supports



"The HIV and AIDS, I don't think its made a significant impact on the northern communities as of yet. I think that if one looks at the rate of spread of STDs in northern communities then it could have a significant impact when it does become more prevalent in the northern communities." – Front Line Worker

"Certainly a lack of awareness and attitude that "it's [HIV/AIDS] not going to happen to me", that it's going to happen in another community, but not here, and also, I think, there's an attitude that it's somebody else's disease, I'm not going to get it. And I think also, it doesn't seem particularly real because nobody here's got it that we know of (laugh)." – Front Line Worker

"I think one of the most important issues in Aboriginal communities is denial. A lot of people think it can never happen to them, but I have seen it happen and it is too late for them to do anything for themselves, that they become too scared to talk about it." – Front Line Worker

• Other Issues: A range of other issues related to HIV/AIDS and hepatitis C in Aboriginal communities were also identified by individual community members and front line health workers. One individual suggested that there is a lack of information among Elders about HIV/AIDS and hepatitis C. This is perhaps identified as significant because of the important role Elders play in knowledge transmission and education of younger generations. A general level of discomfort in discussing sensitive topics was also identified as playing a role in the level of awareness about HIV/AIDS and hepatitis C.



Views of HIV/AIDS as a Terminal Illness

• Some participants felt that HIV/AIDS is a death sentence or terminal illness. A positive HIV test result in particular was seen as devastating news, and some also felt the same way about a positive hepatitis C result.

"Fear of results. Stress goes high, for their life would be torn apart if [a person] was tested positive [for HIV/AIDS or hepatitis C]." – Man, Age 18-29

• Feelings of sadness: Some participants were asked how they would feel if a community member became HIV-positive. Many expressed sadness because of the direct link they make between a positive test result and imminent death of the affected individual.

"Sad knowing they're gonna die." – Woman, Age 30-54

"Same thing [sad] 'cause there's no cure." – Woman, Age 30-54

"Um... sad I guess 'cause knowing that HIV leads to AIDS and AIDS leads to death so I'd probably feel really sad about it." – Woman, Age 18-29

"I'd probably feel hurt and sad because there's nothing you could do to prevent it ..." – Woman, Age 18-29



"Because once you got the disease it's like signing a contract to your death." – Woman, Age 18-29

• Hepatitis C 'more manageable': Some participants thought that living with hepatitis C was more manageable compared to living with HIV/AIDS – hepatitis C was thought to be less serious or terminal compared to living with HIV/AIDS.

"Well actually um, hepatitis C doesn't seem as much as a big shocker as HIV/AIDS eh, because they seem like two different things. hepatitis C seems like an illness and AIDS just seems like you're gonna die right away from that stuff, they're just like stereotyped differently." – Man, Age 18-29

Respondent: "It's, it's [hepatitis C] serious but in my perspective, maybe (laughs)..."

Interviewer: "Not as, not as serious as HIV?"

Respondent: "Yea, yes."

– Man, Age 18-29

"I'd still be shocked [to hear of a hepatitis C family infection] but something like that I'd maybe a little easier to deal with [compared to HIV/AIDS]." – Man, Age 30-54

KNOWLEDGE & AWARENESS

• Level of concern and age: One focus group participant thought that older people would be less concerned about contracting HIV/AIDS or hepatitis C because the time they have left to live is shorter. The following participants are referring to a question they asked their workplace leader about taking hepatitis C safety precautions:

Participant: Do you know what [our workplace leader] said, 'I don't really care. I'm 60 years old. I'm gonna die pretty soon anyway, so why should I care.' And that's coming from one of the leaders.

Participant: But the people in that meeting took it in as a joke. They all started laughing, you know. They couldn't confront it as it was, you know. They should have opened their eyes and looked at this guy but no, they all started laughing. So, you can't understand the real impact of what's going to happen, you know, [...].

Participant: [...] we turn a lot of things into a joke right. It's part of our way of dealing with it.

-Adult Men Focus Group

Generation Perspectives

• **Exposure:** Several Elder focus group participants discussed how younger generations may be more aware of HIV/AIDS and hepatitis C because they have had more exposure to issues surrounding these diseases (e.g. through the school system, their friends, or other information sources). HIV/AIDS was never heard of or talked about when the Elder participants in this study were young people.



"I don't really know much about these diseases. I wouldn't probably think anything of it because I'm not a young guy. We weren't taught about it." – Elder Men Focus Group

"I talk, uh, I didn't hardly talk about [HIV/AIDS to] the children, but now I will be talking to my grandchildren 'cause I was never taught anything, I never."

- Elder Women focus group

• Gap within age group: In this project, 'Elder' participants were classified as people 55 years and older. The following focus group discussion, however, highlights a perceived knowledge gap within this Elder age group. Participants who were closer in age to 55 years old felt that 'older Elders' (e.g. 70+) would have more challenges in understanding HIV/AIDS and hepatitis C-related issues:

Participant: Do you think most people would understand [about HIV/AIDS and/or hepatitis C]?

Participant: Not for the Elders no.

Participant: No, not for the Elders.

Participant: Not for the Elders, I think it would be hard for them to.

Interviewer: And why would that be?

Participant: Because they never seen that when they were young.

Participant: They never heard of it.

- Elder Female Focus Group



• **Role reversal:** One focus group participant noted that information roles were often reversed in their household, with children informing their parents of safe sex practices rather than parents informing their children about safer sex practices:

"[...] and then I think that young people are in tune to it [HIV/AIDS]. I just gotta go back to my son and he's the one that's telling me that. Always use condoms." –Adult Men Focus Group

KNOWLEDGE & AWARENESS



MISCONCEPTIONS

Responses to some questions indicated that while people know a lot about HIV in particular, they are still unsure about how people get HIV /AIDS or hepatitis C, and the extent of the issues surrounding them. Some of the comments show worries about ways of becoming infected with HIV and hepatitis C that are not true. While it is important for prevention purposes to know the risks, it is also important for community members to know which day-to-day activities will <u>not</u> put them at risk, such as shaking hands and hugging, so that affected individuals and their families are not isolated or denied the social and informal supports that will include them in community life. Please read the first section of this report 'About HIV and hepatitis C', for the facts about HIV and hepatitis C. We have also included a second section with contact information if you want to know more.

YOUR THOUGHTS



This section discusses:

- The first thoughts to come to mind if participants were to hear that someone in their community had HIV/AIDS or hepatitis C.
- Thoughts about how a community or individual would respond to a community or family member infected with HIV/AIDS or hepatitis C.
- Level of comfort participants would feel in being with HIV/AIDS or hepatitis C-infected people in certain scenarios.
- Connection between a lack of information on these diseases and reactions of fear.



FIRST THOUGHTS

In individual interviews, participants expressed the following thoughts about hearing someone from their community had tested positive for HIV or hepatitis C (summarized in Table 4).

- HIV/AIDS first thoughts Range of emotions: Participants expressed a range of emotions towards news of HIV/AIDS, such as: fear, concerns for personal safety, avoidance of infected individuals and a desire to support affected individuals.
- Hepatitis C first thoughts Range of emotions: Participants expressed a range of emotions towards news of hepatitis C, such as: desiring more information on the disease and feeling sorry for the infected person.
- HIV/AIDS and hepatitis C first thoughts Unsure what would come to mind: Many participants were unsure what would come to mind if they heard that someone in their community was infected with HIV/AIDS or hepatitis C.

Table 4: What would be the first thing to come to your mind if you heard that someone in your community had HIV or AIDS? hepatitis C?

Theme	Most Common Responses	HIV/AIDS	hepatitis C
Eagr & Parsanglessfoty	Scared/afraid	\checkmark	
Fear & Personal safety	Personal safety	\checkmark	
Supportive Supportive		\checkmark	
Negative reactions Avoidance		\checkmark	
	Nothing	\checkmark	
Other	Unsure how to respond	\checkmark	\checkmark
Oniei	Desire more information		\checkmark
	Sorry	\checkmark	



There were some differences in the first thoughts Elder, adult, and youth focus group participants would have if they were told someone from their community had tested positive for HIV or hepatitis C. These are summarized in Table 5, below.

Table 5: First Thought to Come to Mind if a Community Member was HIV/AIDS-positive?

	FOCUS GROUP TYPE		YPE
	Elder	Adult	Youth
Avoidance/Ostracize Infected Person			\checkmark
Concern for Infected Person and/or Effect on		\checkmark	
Community			
Disbelief			\checkmark
Not a Death Sentence	\checkmark		
Not Surprised to Hear the News	\checkmark		\checkmark
Personal Safety or Child's Safety (i.e. participant	\checkmark	\checkmark	
does not want to become infected)			
Reveal Identity of Infected Person		\checkmark	\checkmark
Sadness	\checkmark		
Scared/afraid		\checkmark	\checkmark
Supportive			\checkmark
Treat the Infected Person the Same			\checkmark
Unsure how to Respond to Question	\checkmark		
Wonder about the Extent of the Disease in the			\checkmark
Community			
Wonder how the Community Member Became		\checkmark	
Infected			

"I'd like to help them, support them, tell them [...], I'll be your friend and help you out no matter what, I won't judge them and say, look oh you're infected [with HIV/AIDS]. I'd want to support them." – Woman, Age 18-39



"Um... same thing, how to protect yourself and how to not try and get infected with it[HIV/AIDS] as well." – Woman, Age 18-29

"Um, I wouldn't want to be around them (laugh)... This disease scares me and um, I wouldn't mind to talk to them and all but it just scares me to go around with people that have that disease. ...AIDS is just something that scares me." – Woman, Age 18-29

• Implication of a wide range of emotions: The wide range of answers indicates that more information may be needed by community members on not only how HIV/AIDS is caused/transmitted but also how to manage the news that there is an infected person in the community and how to support an infected community member and their family. This highlights the need for education on both the medical and social/emotional aspects of dealing with HIV/AIDS in the community.



COMMUNITY & PERSONAL REACTION

Covered under the following topic area:

- Community Reactions
- Community Reactions Compared to Personal Reactions
- Reaction to a Family Member Infection

Community Reactions

Some participants were asked to speculate on how they feel their community as a whole might react to the presence of an HIV/AIDS or hepatitis C-positive person in the community.

Overall Discussion

• Shared HIV/AIDS and hepatitis C reactions: Most participants talked about fear at the community level of someone infected with HIV/AIDS or hepatitis C coming among them. The first reaction might be to ostracize the affected individual. While these were the predominant responses (summarized in Table 6), a few participants felt that this first reaction would give way to a desire to pull together as a community and provide support.



Table 6: How do you think [an HIV/AIDS or hepatitis C-positive person in the community] would affect the community?

Theme	Most Common Responses	HIV/AIDS	hepatitis C
Negative	Increased gossip and talking	\checkmark	
Negative reactions	Scared/afraid	\checkmark	\checkmark
reactions	Ostracize	\checkmark	

"[HIV/AIDS] would get around really fast, everybody would be gossiping and people wouldn't know what to think, just stay away from that person." – Woman, Age 18-29

"I think most of the people at first would react in fear but then, later on, I think they would pull together and help that person [infected with HIV/AIDS] or those people as best as they could." – Woman, Age 30-54

"It'd probably be a lot of talk, a lot of, how do I put it, a lot of gossip and putdowns and all kinds of ways that people would try to get rid of that person or something, like there's just no communications in, in our community about HIV and all that so I think it would be a lot of, a lot of gossip and people would wanna get that person away from here and, you know, try to harm that person just to get away from here." – Woman, Age 18-29



"Maybe they'd be scared that [HIV/AIDS] would spread more to the young people and then their children after that, they have kids. It'd be, they'd be kind of worried, scared about it." – Woman, Age 55+

- **Reactions to HIV/AIDS:** In addition to fear, many participants thought that there would be a lot of gossip about an HIV/AIDS-positive person in the community and that community members might ostracize (avoid) an HIV/AIDS-positive person.
 - Some participants thought that having someone with HIV/AIDS in the community might have a positive effect by increasing awareness of HIV/AIDS or prompting community members to ask more questions about HIV/AIDS.
- **Reactions to hepatitis C:** Many participants thought that the community would be scared or fearful of someone infected with hepatitis C in the community.
- **Range of community reactions:** Responses from the face-to-face interviews and focus groups covered a wide spectrum, ranging from fear, increasing awareness, to being unsure how to react. Overall, participants' responses suggest that community reactions to a rumour can directly affect a rumoured person's experience in the community.

As Table 7, below, indicates, there were some differences between the Elder, adult, and youth focus groups with regard to how each would react to the news or rumour of someone in the community with HIV or AIDS. While everyone would be afraid, only the youth indicated a concern for their personal safety, and the adults in particular expressed they would feel at once devastated and ignorant.



Table 7: Community Reaction to Rumour of HIV/AIDS Infection

	FOCUS GROUP TYPE		YPE
	Elder	Adult	Youth
Avoid/Ostracize Infected Person		\checkmark	\checkmark
Community Gossip			\checkmark
Community Gossip Would Taper Off		\checkmark	
Community Gossip Would Hurt Rumoured Person		\checkmark	
Concern for Personal Safety			\checkmark
Devastated		\checkmark	
Ignorance		\checkmark	
Increase Community Awareness of Disease/Ask		✓	\checkmark
more Questions			
Scared/Afraid	\checkmark	\checkmark	\checkmark
Unsure how to Respond to Question			\checkmark

Community Reactions Compared to Personal Reactions

• Individual and community comparisons: Participants were asked not only how they would feel their community would react, but also how they would feel personally if they either heard a rumour or learned that someone among them was HIV- or hepatitis C-positive. Some felt that the community as a whole would not be as supportive compared to individual expressions of support.

"I think our community would shun them. I think, I think a majority of the people don't know enough about [HIV/AIDS] to understand just how, how it would affect them, their perception would be well, something that they just, I'd better stay away you know, because of, because of the lack of information that has been given to them." – Man, Age 30-54



"Like if I was the one that had [HIV/AIDS] and I was to go to a community supper or something and the people would just look at me and, you know, and say what is she doing here, you know. Stay away from her kind of thing. Like they'd ignore me kind of thing. That would really hurt a person. Like, why can't I go? You know, what's wrong with me, kind of thing? Like I'm still the same person but it's just 'cause I have this I'm not gonna hurt them. Like I'm not gonna do it physically or anything. Maybe emotionally but I'm not gonna hurt them." – Woman, Age 18-29

• **Type of relationship:** A participant's reaction to an infected community member usually depended on the level of relationship: whether the participant knew them on an individual level, a family level, or on a community level.

"I've had numerous friends and [...] my best friend died from AIDS and so it impacted my life. It carved a row in my life to make myself a better person and be more careful and I don't have HIV today and I don't ever plan on getting it or Hep C." – Adult Men Focus Group

"We always tend to be reactive, [...] the only time we react is when it's happening to others I think a lot of people don't know [about HIV/AIDS] unless their family member has it or somebody close to them off reserve had it, probably those, probably those are the only ones that are aware of it." – Adult Men Focus Group



"[News of HIV/AIDS] would probably, maybe some people would, would hate the family or hate that person. [...] But what if [...] I had it or my husband has it, or my grandson, or my grandchild, my daughter, you know, I would want people to, to be supportive of our, my family." – Woman, Age 55+

"[...] It's [HIV/AIDS] hitting close to home so you would wanna be there to provide support." – Man, Age 30-54

- Range of emotions: Participants who did not know someone infected with HIV/AIDS (which were most participants), expressed a variety of concerns and emotions, usually stemming from their lack of knowledge about the disease. At the same time, many expressed a desire to be supportive. Also, while many felt that reaction in a small community would include gossip and ostracism, some thought that for an HIV- or hepatitis C-positive individual that a small community could provide a more supportive environment.
 - This indicates that while participants may not be fully informed about these diseases, they recognize that an increase in education or exposure to these diseases will positively change the way they or their community might react/feel.

"Like, I imagine if you live in Edmonton and your neighborhood finds out you have AIDS, it would be just as difficult as living here, maybe even more so because strangers tend to be meaner. Like in our community, we know these people. We're not gonna be so harsh to them, I don't think." – Woman, Age 30-54



• **Community Reputation:** Several comments were made about the effect of an HIV/AIDS-positive person living in the community on a community's reputation. There was some concern that people from other communities might avoid their community because of the presence of an individual or individuals with HIV/AIDS.

"Mmm, that'd be a big, actually if [news of HIV/AIDS] got out to other communities, people would actually try to avoid this place for stuff." – Man, Age 18-29

"Well, usually at first, if, my, my thinking is that a person would try to conceal their defect [HIV/AIDS] by going to a different centre to get diagnosed before coming out publicly saying that they are sick with this disease. So at first it would, it would be a blow to their image, to their ego, to their family and lastly, of course, to the community." – Man, Age 30-54

Preaction to a Family Member Infection

• Range of emotions: While most participants emphasized that they would be supportive of an HIV/AIDS or hepatitis C-infected family member, many also discussed other emotions, such as: being afraid, feeling sad or feeling unsure how to react. As Table 8, below, summarizes, predominant feelings were the same, whether a family member had HIV, AIDS, or hepatitis C.



 Feelings such as devastation, disappointment and disbelief were associated with a family member with HIV or AIDS, but not with hepatitis C. In discussing their feelings about hepatitis C in a family member, participants did not specifically mention feeling worried, fearful for their personal safety, or angry, as they did for HIV/AIDS. Rather, and similar to HIV/AIDS in a family member, feeling hurt and shock were some of the reactions suggested.

Table 8: How would you feel if one of your family members has [had?] HIV or AIDS? hepatitis C?

Theme	Most Common Responses	HIV/AIDS	hepatitis C
	Scared/afraid	\checkmark	\checkmark
Various	Sad	\checkmark	\checkmark
emotions	Feel bad	\checkmark	\checkmark
	Supportive	\checkmark	\checkmark
Unsure	Unsure how to respond	\checkmark	\checkmark

"Same thing, I would support, I would support them as much as I can and ask about [HIV/AIDS] and what not." – Man, Age 18-29

"Oh, very, very scared I guess, scared and you know, I'd be scared and... probably won't know what to do you know, for sure I would have to try and find out what is the best possible way to handle [HIV/AIDS] you know." – Man, Age 55+



REACTION TO DIFFERENT SCENARIOS

Covered under the following topic area:

- Reaction to Three Infection Scenarios
- Participation in Public Activities

Presention to Three Infection Scenarios

- **Overall comments:** Participants were asked about their reactions to an HIV-positive individual according to different infection scenarios. The scenarios and predominant reactions (summarized in Table 9) included:
 - Blood transfusion: lack of trust in the medical system, angry, afraid, supportive, unsure
 - o Drug abuse: angry, ostracize (avoid), deserved it, unsure
 - o Homosexual activity: ostracize, unsure
- Question comfort level: Not surprisingly, some of the scenarios were difficult to discuss, both for the interviewers and the participants. The homosexual activity scenario was not consistently raised by all interviewers, and even when it was, few participants chose to directly discuss this scenario.



- **Personal choices:** Participating in drug use and homosexual activities were thought to be personal choices, whereas HIV/AIDS infection from a blood infusion was seen as "not their fault."
 - Given that many people perceive HIV/AIDS infection as the result of negative personal lifestyle choice(s), and that the infection scenario does make a difference in how they would react, this may make it challenging for people to support an HIV/AIDS-infected person.

Table 9: How would the community respond if it was known that someone had HIV from a blood transfusion? Injection drug use? Homosexual activity? (probes – Same? Differently? Why?)

		INFECTION SCENARIO		
		Blood transfu- sion	Drug use	Homo- sexual activity
Theme	Most Common Responses			
Lack of trust	Lack of trust in medical system	\checkmark		
Negative	Angry/mad/upset	\checkmark	\checkmark	
responses	Deserved it/foolish behaviour		\checkmark	
responses	Ostracize		\checkmark	\checkmark
	Supportive	\checkmark		
Other	Unsure	\checkmark	\checkmark	\checkmark
	Scared/afraid	\checkmark		



Participation in Public Activities

Participants were asked a series of questions about their feelings towards allowing HIV/AIDS or hepatitis C-positive people to attend/ participate in various public activities. Participants were asked if they would feel comfortable allowing an infected person to:

- Attend community suppers (or other social gatherings)
- Be allowed to work with food in a restaurant
- Attend or teach school
- Participate in church (or other spiritual activities)
- Be in public areas (e.g. the band office, health clinic waiting room)

Their responses are summarized in Table 10 with regard to HIV/AIDS and Table 12 with regard to hepatitis C. Some of the main responses include:

• Overall results: Most participants felt there was no problem in allowing an HIV/AIDS or hepatitis C-infected person to attend community suppers, attend or teach school, attend church or religious ceremonies, or be in public areas. Most participants felt that HIV/AIDS and hepatitis C were not very contagious in these contexts (especially if precautions were taken) and that infected people should still be treated like any other person. In particular, the highest support for a public activity that HIV- or hepatitis C- positive people should be permitted to attend is church or other spiritual places. As the quotes in Tables 11 and 13 illustrate, these are seen as important sources of healing and support for affected individuals.



- **Exceptional scenario:** Approximately half of the participants said they would not be comfortable in allowing an HIV/AIDS or hepatitis C-infected person work with food in a restaurant. Participants thought that HIV/AIDS or hepatitis C were much more contagious in this context, pointing to opportunities for food to come into contact with body fluids, such as blood from a cut. People seemed somewhat more cautious about hepatitis C individuals attending community gatherings and attending/teaching school.
 - Of those that felt it was O.K. for hepatitis C-positive people to work with food in a restaurant, many felt that the infected person must take safety precautions, such as wearing rubber/plastic gloves.

Table 10: Participation in Public Activities (HIV/AIDS)

Should people with HIV or AIDS be allowed to:

(a) attend community suppers or other social gatherings?

(b) be allowed to work with food in a restaurant?

(c) attend/teach school?

- (d) participate in church or other spiritual congregation?
- (e) be in public areas?

	RESPONSE %			
SCENARIO	Yes	No	Yes/ No (mixed response)	Don't know
Attend community gatherings? (n = 131)	85	8	1	5
Work with food in restaurant? (n =128)	33	48	7	11
Attend/teach school? (n = 125)	73	11	6	10
Attend church/spiritual places? (n = 129)	93	0	0	7
Be in public areas? (n = 125)	85	4	2	8



• **Response context:** Table 11 gives examples of various participants' thoughts on allowing an HIV/AIDS or hepatitis C-positive person attend various public functions. Participants' quotes highlight some of the misconceptions that still exist surrounding the transmission of HIV/AIDS, but also highlight supportive community comments as well.

Table 11: Comments on Participation in Public Activities (HIV/AIDS)

CONTEXT	PARTICIPANTS' COMMENTS
Community suppers/gatherings	"Because, um, they are not gonna get it by touching a person or having contact with them." – Woman, Age 30-54 "Well there's information out there, you can't get it through touching and sharing stuff and, you know, it's just, there's no other way that, to get it I guess." – Man, Age 30-54 "They're still people, can't treat them differently just 'cause they're dying." – Man, Age 18-29
Work with food in a restaurant	"They might cough or something on the food and pass it on to somebody." – Woman, Age 18-29 "Umm, I guess if they take the proper precautions, wear the proper gloves on their hand and like, just take the proper procedures like everybody should take, and be more cautious around, be more cautious around like serving, and if they have to cut up the food be more cautious about that too." – Woman, Age 18-29 "Because I've gotta eat that food. I wouldn't want anybody infected touching that food or even breathing same air I breathe. [] Especially if there's spit involved." – Man, Age 30-54

PERCEPTIONS & EXPERIENCES

CONTEXT	PARTICIPANTS' COMMENTS
Attend or teach school	"Well, yeah. It can't really be passed on while they're in school. They can talk about it in class or something." – Man, Age 18-29 "There's nothing wrong with them. They are still human." – Woman, Age 18-29 "I think so because, the same thing, they wouldn't, they just wouldn't get it by a teacher having it. Like, they wouldn't spread it around. In the meantime they would learn from this person." – Woman, Age 55+
Participate church/spiritual activities	"Mmmm, there's nothing wrong with that, there's no risk factor or nothing, it's just sitting in church." – Man, Age 18-29 "So they could feel better about themselves and kinda live longer []" – Man, Age 18-29 "I just don't like to call the shot right now and say no or yes till I know what, how the outcome would be." – Man, Age 55+
Be in public areas (e.g. band office, clinic waiting room)	"They won't spread it in any way, they're just standing there." – Woman, Age 18-29 "Ya, because they're still human. It doesn't matter what disease you have, you're still alive, you're human, you still have feelings." – Woman, Age 30-54 "I'd say so, it's, a public place and they're from the public" – Woman, Age 18-29



• Similar to the discussion above, the following table summarizes participants' responses to a series of questions about their feelings towards allowing a hepatitis C-positive person to attend various public activities.

Table 12: Participation in Public Activities (hepatitis C)

Work with food in restaurant?

Attend church/spiritual places?

Attend/teach school?

Be in public areas?

(n =128)

(n = 125)

(n = 129)

(n = 125)

Should people with hepatitis C be allowed to:				
 (a) attend community suppers or other social gatherings? (b) be allowed to work with food in a restaurant? (c) attend/teach school? (d) participate in church or other spiritual congregation? (e) be in public areas? 				
		RESPO	NSE %	
SCENARIO Yes No (mixed Don't l response)		Don't know		
Attend community gatherings? (n = 131)	76	11	0	13

28

69

91

82

50

11

1

3

5

3

0

3

15

16

8

11



• **Response context:** In order to put some of the numerical results in context, the following table contains examples of various participants' thoughts on allowing an HIV/AIDS or hepatitis C-positive person attend various public functions. Participants' quotes highlight some of the misconceptions that still exist surrounding the transmission of hepatitis C, but also highlight supportive community comments as well.

CONTEXT	PARTICIPANTS' COMMENTS
Community	"Because they're regular people too, if they can, if they can, how do I say it, if they can protect themselves from us it's okay, I say that as in, they know how it can be transferred and they know more about it than we do so if they can keep it away from us then it's fine with me." – Man, Age 18-29
suppers/gatherings	"Yes. [You] only get it through sex, needles." – Woman, Age 55+
	"[] I'm not too sure about that one. Like I said, that there's so much talk about HIV and AIDS and all that but not very much about hepatitis C. Like for myself, I don't know what that means. So I wouldn't know." – Woman, Age 18-29
	"Yes, as long as they, they have protection in their hands and in their mouth." – Woman, Age 55+
Work with food in a restaurant	"Because in a restaurant there's knives and stuff and they get cut." – Woman, Age 18-29
	"I don't know about those people with Hep C. I don't know if it's the same as HIV or AIDS. I know those people can't work with them. I'm not sure about that." – Man, Age 18-29

PERCEPTIONS & EXPERIENCES

1

CONTEXT	PARTICIPANTS' COMMENTS
Attend or teach school	"Because they're just working, they're not really working with sharp objects of anything like that." – Man, Age 30-54 "Yep. Since hepatitis C is not passed on through touching or talking to them I think it would be okay for them to teach." – Woman, Age 30-54 "That's again there, education, you know I have to get educated on all this before I can make any kind of decision." – Man, Age 55+
Participate church/spiritual activities	 "[] you can't really deny an individual or person who wants to exercise their patronage or, or coming to Mass. It, it would be like reliving the dark ages where the people with leprosy were segregated []" – Man, Age 30-54 "Yep, 'cause they need the help too eh, lots of people there to help them, keep positive, you know what I mean." – Man, Age 18-29 "[] Absolutely, of course, that's where they go to get their health too." – Man, Age 30-54
Be in public areas (e.g. band office, clinic waiting room)	"Yes. Equal rights." – Man, Age 18-29 "Uhhh, yea maybe in some places they won't let them come? And they shouldn't if they're not allowed to go, depends what, what kind of a, what kind of rules they make, then they should be respected and not go." – Woman, Age 55+ "Can hepatitis C be passed on easy? It can be kept a secret. They don't have to tell people about it." – Man, Age 19-29



FEAR & LACK OF INFORMATION

Overall Comments

• Participants clearly link their fears of someone with HIV/AIDS or hepatitis C to what they identify as their lack of knowledge about HIV/AIDS and hepatitis C; and point to this lack of knowledge as a barrier to providing the kind of support they would like to.

"[..] fear 'cause I guess that's the first reaction when you're not informed about anything um, people are scared and then people would feel sorry for him and feel sorry his family." – Woman, Age 30-54

> "If I knew more about these things. I'd be there for them." – Woman, Age 30-54

"If somebody had AIDS here it would probably be hard, everybody talking about you and people being scared of you like 'cause they don't really know what it is." – Man, Age 18-29

"You don't interact with them because of the fear of not knowing the extent of [HIV/AIDS] or how it can be transferred from one person to another." – Man, Age 30-54

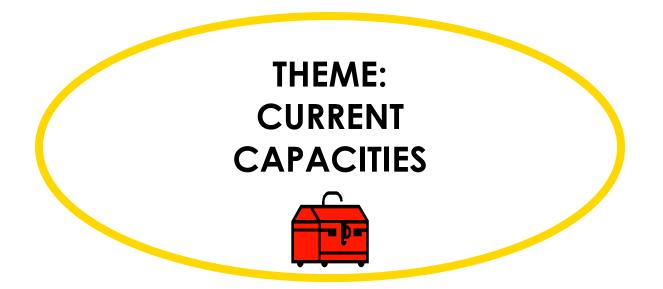
"I think people would be, they'd kind of hesitate at first but then after they found out a little bit more about [HIV/AIDS], then they'd be more relaxed." – Man, Age 30-54



MISCONCEPTIONS

Responses to some questions indicated that while people know a lot about HIV in particular, they are still unsure about how people get HIV /AIDS or hepatitis C, and the extent of the issues surrounding them. Some of the comments show worries about ways of becoming infected with HIV and hepatitis C that are not true. While it is important for prevention purposes to know the risks, it is also important for community members to know which day-to-day activities will <u>not</u> put them at risk, such as shaking hands and hugging, so that affected individuals and their families are not isolated or denied the social and informal supports that will include them in community life. Please read the first section of this report 'About HIV and hepatitis C', for the facts about HIV and hepatitis C. We have also included a second section with contact information if you want to know more.





This section discusses:

- Different ways that service providers increase awareness of their services.
- Participants' awareness of HIV/AIDS and hepatitis C testing locations.
- Awareness of where to get information on HIV/AIDS and hepatitis C.
- Support sources for people with HIV/AIDS or hepatitis C.



SERVICE AWARENESS

Covered under the following topic area:

- Service Awareness Activities
- Awareness of Testing Locations

Service Awareness Activities

- Awareness strategies: Community members found out about a Front Line Worker's services through a wide variety of media (listed in Table 14). Many Front Line Workers relied on the following to get their message and services across:
 - o Posters
 - o Referrals
 - o Radio
 - o Word of mouth
 - Presentations to schools (or general presentations)



• Front Line Workers, which include a range of people such as social workers, teachers, spiritual leaders, in addition to health professionals, also mentioned that community members may find out about their services from doctors and nurses, clinic staff, or from health centre open houses.

Theme	Most Common Responses	
Dan ar Madia	Newsletter	
Paper Media	Posters/advertisements	
	Radio	
Oral Communication	School system	
Oral Communication	Presentations	
	Other people/word of mouth	
Personal Initiative	Personal awareness/By asking a health worker	
Other	Referrals	

Table 14: How do your clients usually find out about your services?

"... usually through education. I do go to the rehab centre to do presentations and let them know what kind of services I provide at our clinic. ...also through referrals from the doctors. And referrals through the hospital. And word of mouth. And we advertise for our needle exchange program. And newsletters and posters so that people are aware of the service." – Front Line Worker



"Hep C... I don't know. We do some advertising. I guess for our follow-up clinics for hep C, people are just referred by the physician or other nurses in the local communities. For our educational sessions, like our phone-in radio show we've had advertisements on the radio and posters up about those. And things like... the community information meetings we've had." – Front Line Worker

• Informal networks: In addition to the familiar methods of communication about services, some Front Line Workers suggest that this is augmented through informal networks:

"Well, everybody that lives on the reserve knows that the clinic, where the clinic is, knows what kind of services they can get here. And I imagine if new people come here, and other people will tell them that they can come to the clinic for care. And, we try and help everybody out as best as we can." – Front Line Worker

Awareness of Testing Locations

- When participants were asked where they would seek HIV/AIDS or hepatitis C testing (Table 15), most participants would seek testing at places such as:
 - o The clinic
 - o Health centre
 - o Doctor
 - Another village/town/city (for confidentiality reasons)



 Other places/ people that were mentioned included the hospital for HIV or hepatitis C testing and nurses for HIV (but not mentioned for hepatitis C). The health centre was not frequently mentioned as a source for hepatitis C testing. A few participants expressed that they were unsure where to go for testing for either HIV or hepatitis C.

Table 15: Where would someone from your village go to find out if they have HIV or AIDS [and hepatitis C]?

Theme	More Emphasized Response	HIV/AIDS	hepatitis C
Madiaal	Clinic/lab	\checkmark	\checkmark
Medical	Doctor	\checkmark	\checkmark
sources	Health/medical centre	\checkmark	
Other	Larger/other city	\checkmark	\checkmark

"Mmm, for myself personally I submitted a blood test in [another town] and I was given a phone number I could call to find out the test results and that's the only way I've found out myself. [...] And it gives me some confidentiality too, and I'm not getting a blood sample taken from [someone that I] know personally [...]. There's some that have a little bit of vanity and there are others that, you know, have an ego to protect, but in actuality you're just trying to take care of yourself for the long term and that's something to be proud of instead of trying to hide."

– Man, Age 30-54



INFORMATION SOURCES

HIV/AIDS Information Sources (Table 16)

- When asked to specify where they would obtain HIV/AIDS information, most participants noted that they could obtain HIV/AIDS information in a medical or health setting, such as:
 - o health centre
 - o doctor
 - o hospital
 - o nurse
 - o clinic
 - o larger city
- Not specifically mentioned sources of information for HIV/AIDS included workshops, pamphlets, and the internet.

Hepatitis C Information Sources (Table 16)

- Most participants cited the same information sources as HIV/AIDS, with the exception that nurses, hospitals, and traveling to larger centres were not noted by many participants as sources of hepatitis C information. A few participants mentioned workshops, pamphlets, and the internet as sources of information about hepatitis C.
- Some participants felt unsure of where they would obtain information about HIV/AIDS or hepatitis C.



Table 16: Where would someone from your village go to find out informationabout HIV or AIDS [and hepatitis C]?

Theme	More Emphasized Response	HIV/AIDS	hepatitis C
	Doctor	\checkmark	\checkmark
Madiaal	Hospital	\checkmark	
Medical	Nurse	\checkmark	
sources	Clinic	\checkmark	\checkmark
	Health/medical centre	\checkmark	\checkmark
Other	Larger city	\checkmark	

• Participants' also offered suggestions for other information sources that could be considered:

- o alcoholic Anonymous meetings
- o the internet
- o library
- o radio
- o T.V.
- o video
- o workshops
- o a person living with the disease
- brief "education sessions" could be broadcast in between bingo calling on the radio

"Yea [bingo] intermission, we'll have a little ah, little education session. Cause you know there's a good audience, captive audience, during what else is there, that's really popular... auctions and a message from Dr. [...]." – Elder Women Focus Group



• Other participants noted:

"They all can go on the computer and look [HIV/AIDS] up, there's lots of information in the computer with new technology nowadays, that would be the same thing with hep C." – Man, Age 30-54

"Research, going to different resources... there's a resource centre, I can't remember where is it, North Battleford, Saskatoon, finding out, getting, you know, making sure you go to the doctor to, getting him to refer you to further education on it, you know what can you do to take care of yourself, basically outside resources because we don't have much on it here and I know that if we did, we wouldn't be so scared of [HIV/AIDS] (laughs)". – Woman, Age 18-29



SOURCES OF SUPPORT

• Most participants could not name a specific local program that addressed HIV/AIDS or hepatitis C. Many of the communities are small and there are no programs specific to HIV/AIDS or hepatitis C.

"Uhh, I just, I just have really no idea [what problems HIV/AIDS- positive people in the North face] 'cause like, um, like most, the majority of the community, I'm not really informed about that, I don't know... um, I don't even know what services are out there for people who are sick with those illnesses so... I have, I just don't know what to say." – Woman, Age 30-54

• Informal and formal supports: There was a range of responses regarding support for HIV/AIDS or hepatitis C that ranged from health professionals/personnel, supportive family members or friends, to spiritual leaders such as a priest (Table 17). Others discussed turning to Elders, holistic workers, or other community members for support:

"Uh, their, their parents I guess, family members 'cause nobody else in their community would listen to you if you had hepatitis C." – Man, Age 18-29

"Well probably some, one of the community, a doctor, friend or family member if they're trusting and understanding." – Woman, Age 18-29



"I think everybody, the pastors, and the leaders, you know, and the doctors and their friends." – Woman, Age 55+

Table 17: Who would [a person with either one of these diseases in the community] speak to for support?

Theme	Most Common Responses	
	Family	
Social	Friends	
300101	Trusting/comfortable person	
	Counselor (general response)	
Medical	Nurse	
Medical	Doctor	
Spiritual	Priest/spiritual person	
Unsure	Unsure who to turn to	

Some commented on the importance of supporting HIV- or hepatitis C-positive individuals, not only to help them cope with their illnesses, but also recognizing that they can continue to make contributions to community.

"If it was a family member I, I'd probably just, well I'd still think it's sad but you'd wonder how did they get it and... just the life that could be wasted but not necessarily so because even if, even if you have HIV you can live a, for a long time and make, continue to make contributions to your community and to, and to people around you."

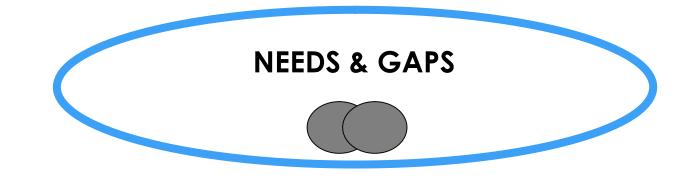
- Elder Women Focus Group

YOUR THOUGHTS



This section includes:

- A discussion of service provider-specific issues (for example, the ability to meet client needs, desired information).
- A discussion of service delivery challenges.
- A discussion of prevention/education, screening, and treatment issues and challenges (for example, perceived confidentiality of services).
- A visual summary of why available HIV/AIDS and hepatitis C information/services may not always be used.



SERVICE PROVISION ISSUES

Covered under the following topic area:

- Ability to Meet Client Needs
- Issues Identified by Front Line Workers
- Service Delivery Barriers
- Needs Identified by Front Line Workers

Ability to Meet Client Needs

- Most service providers interviewed stated that they could not or could only sometimes adequately address the needs of their clients with respect to HIV/AIDS and hepatitis C (Table 18).
 - Availability & relevance: While HIV/AIDS or hepatitis C programs may be available (or programs that address HIV/AIDS and hepatitis C are available), the quality or relevance of those services may not always be appropriate/adequate.

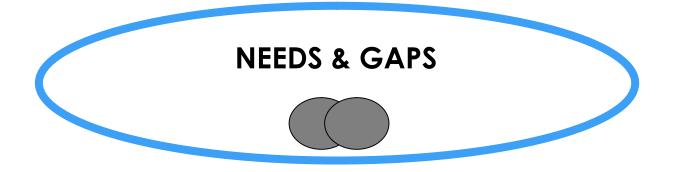


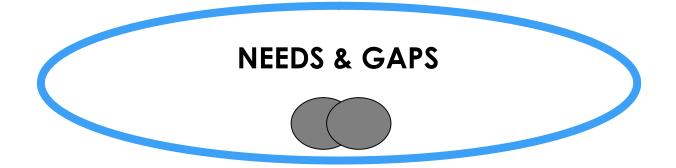
Table 18: Do you feel that you are able to adequately address the needs of your clients specific to HIV or AIDS?

	Percentage %	
	HIV/AIDS n=13	hepatitis C n=12
Yes, I can meet the needs of my clients	23	25
No, I cannot meet the needs of my clients	46	50
Sometimes I am able to meet the needs of my clients	30	25

"I would most definitely respond to [HIV/AIDS] but I could sure use a lot more information." – Front Line Worker

"Yes and no, I guess. To a certain point I'd probably be able to address their needs but, like I said before, I don't have the education on HIV and AIDS and Hep C, so that would be a big part of, and then, again, I'd have to go back to what I said before, that I'd have to refer them to an agency, an outside agency, that does have the service." – Front Line Worker

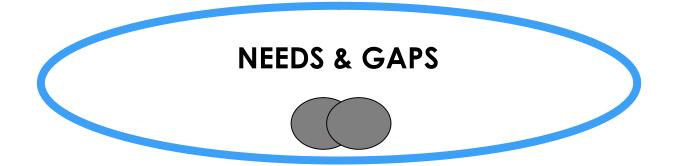
• Service provider awareness: In the quotation below, one Front Line Worker can only "hope" that the agency that they refer their client to can help. This may indicate that, not only is there a lack of information about these diseases among certain health and social service providers, but that there may also be a lack of awareness among health and social services providers concerning the types of services carried out by other agencies:



"Well, well that's not my area of expertise. So I do refer them on to the health district. And I'm hoping that somebody there can help them. Whether it be a doctor or a community service worker or something else. That's all that I, I'm able to do. And that's due to the lack of resources too." – Front Line Worker

Issues Identified by Front Line Workers

- The issues most commonly discussed by Front Line Workers included (Tables 19 and 20):
 - Increasing health provider education on HIV/AIDS and hepatitis C
 - o Increasing community education on HIV/AIDS and hepatitis C
 - Difficulty in keeping track of, and following up on, patients over large distances or patients who move around a lot
- Other issues identified by Front Line Workers included:
 - Need for universal safety precautions, stemming from some uncertainty about their role and approach to HIV and hepatitis Cpositive clients
 - Recognition by some that hepatitis C is already a large issue to deal with, and that current HIV-positive stats in the north may only represent "the tip of the iceberg"
 - Making required documentation easier to carry out to minimize the potential for errors in reporting
 - Finding extra time to be up-to-date on HIV/AIDS and hepatitis C



"Um, and then also issues of how we maintain follow-up with people that are in treatment for hep C, because we're quite a large geographic area, so if we're going to follow someone who's [...] a two hour drive away from here, it's hard to keep close tabs on them, whether they're getting all their blood work done regularly. Um, whether they're going to come and see us and follow-up on appointments. So, geographically, it's just hard to follow those people as well." – Front Line Worker

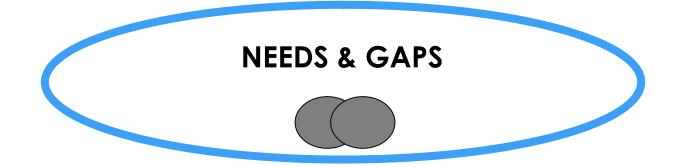
"Well, like I said, it's just like ..., more and more people I guess are asking [...] for more information and like I said if there was more time, you know, there would be more time spent on, you know, health prevention and more on education." – Front Line Worker

Table 19: What are some of the issues that come up for you as a service provider specific to HIV/AIDS?

Theme	Most Common Responses
Education	Lack of health worker education
Education	Lack of community member education

Table 20: What are some of the issues that come up for you as a service provider specific to hepatitis C?

Theme	Most Common Responses	
	Lack of health worker education	
	Treating addicts	
Single Themes	Open and effective communication strategies	
	Follow-up issues: keeping track of patients and overcoming	
	distance barriers	

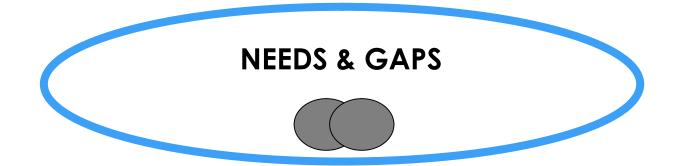


• Viewpoint on client management: The following is an interesting view from a community member regarding actions of their community's health professionals. The participant discussed an incident where a person with a disease (not specific) was sent out of town for treatment. The participant perceived this action as "rude", or perhaps insensitive on behalf of the health professionals, while in reality it may have simply been a case of lack of specialized services to treat that person in the community. This points to a need for broader or more open communication about treatment strategies at a community level:

"[...] the professionals in our community reacted in a rude way [...], you know, people I'm thinking of were admitted into and sent away because of their disease so the professional people need to be educated more than the regular citizens, I think." – Woman, Age 30-54

Service Delivery Barriers

- Main service delivery barriers identified by Front Line Workers or community members with respect to HIV/AIDS (Table 21) and hepatitis C (Table 22 included):
 - Lack of resources either health worker education, appropriate education or information materials for clients, or up-to-date information
 - o Embarrassment/lack of comfort in seeking services
 - Fear of both HIV/AIDS and hepatitis C by community members



- Other service delivery barriers mentioned either by community members or Front Line Workers related to both HIV/AIDS and hepatitis C included
 - Lack of program funding
 - Lack of education about HIV/AIDS and hepatitis C among some Front Line Workers
 - Communication challenges stemming from language barriers, travel distances to some services, and mobility of community members
 - Patients/clients missing their appointments (which may be related to the communications challenges identified above, travel distances, and mobility)

"Also, these workshops, presentations of those diseases should be both in English and Cree language as some community people don't speak English or understand it." – Front Line Worker

Table 21: What are some of the major barriers you experience when attempting to deliver HIV or AIDS services to this geographic area?

Theme	Most Common Responses	
Lack of education/up-to-date information		
Resources	Lack of time to devote to specific HIV/AIDS issues Lack of education and information resource materials	
	Lack of participation	
Community Issues	Community fear towards the disease	
	Comfort/less embarrassment in taking advantage of information opportunities	

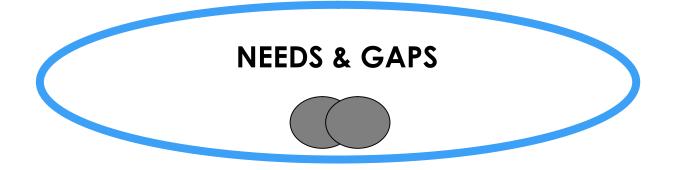


Table 22: What are some of the major barriers you experience when attempting to deliver hepatitis C services to this geographic area?

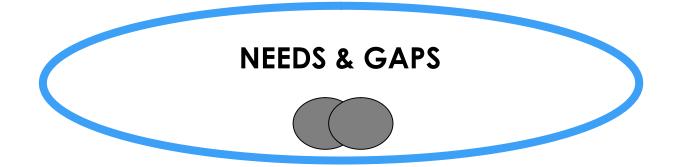
Theme	Most Common Responses	
Resources	Lack of time to increase health worker education Lack of education/up-to-date information Lack of education/ information materials	
Community Issues	Comfort/less embarrassment in taking advantage of information opportunities	

Needs Identified by Front Line Workers (Table 23)

Overall, Front Line Workers discussed a need for the following:

- More specific HIV/AIDS and hepatitis C information for health providers
- Data on the extent of these diseases in the north
- Availability of bilingual information (Cree/English)
- Access to a program coordinator who would focus on HIV/AIDS and hepatitis C programs and services
- Community-based solutions

"I guess I would welcome any information from any addictions specialists that have had good sort of community-based solutions to some of these intravenous drug use problems, that have worked elsewhere." – Front Line Worker

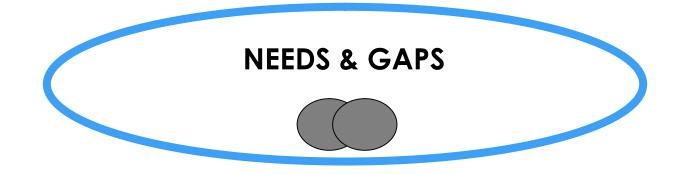


"I would like to have a person come in and teach the staff, or maybe, you know go to a conference on AIDS, HIV... hepatitis C, something like that [...]." – Front Line Worker

"Information that I would like to have is Cree language videos on what HIV/AIDS and Hep C is all about." – Front Line Worker

Table 23: What information would you like to have that would tell you more about the issues relating to HIV or AIDS in Northern Saskatchewan communities? hepatitis C?

Theme	Most Common Responses	HIV/AIDS	hepatitis C
	Bilingual information (Cree/English)	\checkmark	\checkmark
Services &	Community solutions	\checkmark	\checkmark
Solutions	Disease-specific coordinator or	\checkmark	\checkmark
	program		
Specific	Specialist information for health	\checkmark	\checkmark
Specific Information	workers		
information	Extent of disease in the north	\checkmark	\checkmark



EDUCATION/PREVENTION, SCREENING & TREATMENT ISSUES

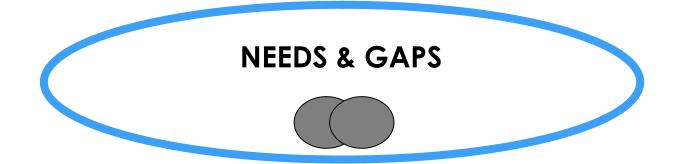
Covered under the following topic area:

- Education/Prevention Issues Identified by Front Line Workers
- Screening/Testing Issues Identified by Front Line Workers
- Barriers Common to Education & Testing Services Identified by **Community Members**
- Confidentiality
- Treatment Issues Identified by Front Line Workers



Education/Prevention Issues Identified by Front Line Workers (Table 24)

- Front Line Workers discussed HIV/AIDS and hepatitis C as sharing many of the same prevention and education issues, such as:
 - Program support
 - o Program availability
 - Program consistency



 Others discussed concerns such as confusion stemming from differences in the information available from different sources, the general level of discomfort among community members in discussing HIV/AIDS or hepatitis C even on a general level, and the challenges Front Line Workers face in reaching vulnerable populations with education/prevention messages (e.g. I.V.. drug users)

"I guess just having the availability of programs having programs and being able to attend to that program. You know, maybe if there was a person specifically targeted to that part of the education program, know where the person would just solely be responsible for that education for HIV/hep C, then maybe because, like I said before, it's just like lack of time and there's not enough time in the day for us to do that education part of it." – Front Line Worker

"Maybe that we don't teach it consistently enough. Maybe because it's not taught often enough. It's not enough to teach it once and once and once (laugh, in which every grade it's taught ah, that's not enough. It has to be repeated over and over and over. You don't teach kids to learn grade one and leave them alone. And we can't just teach about HIV or hepatitis C and just leave it alone for the next twelve years. It has to be done consistently and by everybody." – Front Line Worker

"I think that the level of awareness of HIV and AIDS is relatively fine. I think that the programs that are out there on the television and public health are relatively good. I think that the greatest challenge faced in the north is that there's still a belief that it couldn't happen to me." – Front Line Worker

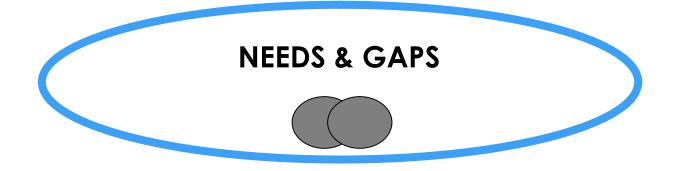


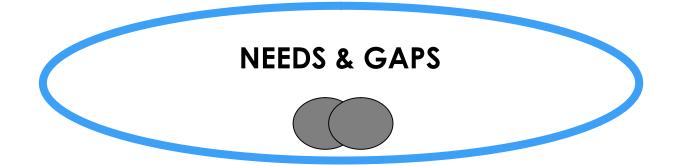
Table 24: (Front Line Worker question) What kinds of issues do you feel that your clients, or anyone in the community, are facing in relation to HIV education and prevention?

Theme	Most Common Responses
Program Support and Availability	Consistency in programming/education Need for an HIV/AIDS coordinator Lack of program availability
Denial	Denial they can't get HIV/AIDS/it won't affect them Lack of motivation to learn about HIV/AIDS



Screening/Testing Issues Identified by Front Line Workers (Table 25)

- Front Line Workers discussed screening issues such as: •
 - o Providing confidential services
 - o Increasing a community's trust in the confidentiality of services



 With regard to both HIV/AIDS and hepatitis C, some Front Line Workers felt that the perception some community members hold that receiving a positive test result is like receiving a death sentence may prevent them from coming forward. Other feelings Front Line Workers associate with a reluctance to be screened/tested for HIV/AIDS or hepatitis C include guilt, fear of losing friends, shame, stigma associated with a diagnosis, denial of vulnerability to infection, and religious/spiritual beliefs.

"[...] whenever we get involved with a family, that it's really positive, they're willing to do what we ask of them ah, 'cause they can see the benefit. So, I would feel if it was approached respectfully that people would have no problem. A lot of times it's based on the person or the agency who... are comfortable they are with the subject and discussing it with the people. Ah, of course, other people won't want to go to be checked out for it. But I think it's the approach."

– Front Line Worker

"I think the most important, or concern that I've heard, is confidentiality, confidentiality, and that's what, you know, their main concern is. And then once that they're reassured, then everything is, you know, that everything is confidential, then they, you know, they seem to be at ease with that." – Front Line Worker

Participants also commented that some people would just rather not know about their infection status:

"I think when it comes to screening for HIV/AIDS and hepatitis C testing, I find everybody has the same issue and that is the thought of having a positive result." – Front Line Worker

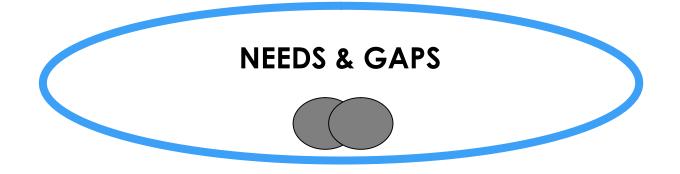


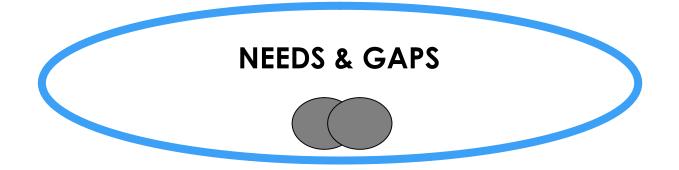
Table 25: (Front Line Worker Question) What kinds of issues do you feel that your clients, or anyone in the community, are facing in relation to HIV/AIDS and hepatitis C screening?

Theme	Most Common Responses	
Education About	Lack of education on the screening process	
Screening	Fearing results	
Confidentiality	Real and perceived confidentiality of screening	
Confidentiality	Increase comfort in seeking screening	
Other Issue	Unsure how to respond	



Barriers Common to Education & Testing Services Identified by Community Members (Table 26)

- When asked to describe barriers a person might face in obtaining • HIV/AIDS information or seeking testing for HIV/AIDS, most community members noted:
 - Confidentiality/trust (in service providers, testing procedures, etc...)
 - Scared/afraid (e.g. fear of getting a positive result)
 - Shy/embarrassed to get tested
 - o Unsure of any barriers

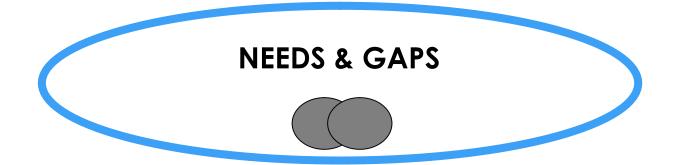


• Other community members also noted practical issues such as the lack of financial resources community members may have to travel to service locations for either education or testing. Common to both education and testing is also concern about being the subject of community gossip or teasing, a potential lack of family support, and a general feeling of shame associated with both HIV/AIDS and hepatitis C.

"Just the fact that there's other people sitting there and waiting for a test result in a room full of people that are there for different illness is not the best thing and I guess going into a HIV or AIDS clinic isn't the best thing either but, just I guess sitting around waiting would be the hardest part." – Woman, Age 18-29

"Well it would be hard because they want total secrecy and that might not be available because there's tons of people in the clinic and information can get out easily, be talked about and it would be, it would be hard for them because they don't want people knowing and it'd be hard for them because they'd be scared for anybody to know [...] people do talk." – Man, Age 18-29

"And then, not everybody here [clinic] has confidentiality, if they're not confidential. I'm not saying that the people in the [health service location], but I'm not saying that they don't either. I would never take the chance. I don't even get my blood work done here. [...] I will never get my blood work done here. For some chance I accidentally get it, I don't want them to know." – Adult Men Focus Group



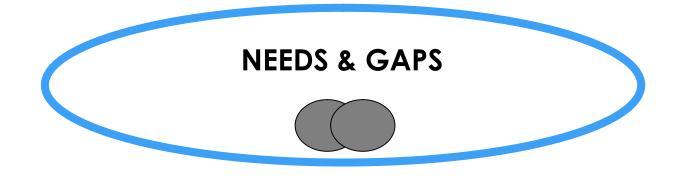
"I don't know how people would feel about that though [HIV/AIDS testing at the community health centre], because everybody knows everybody out here, even the nurses know everybody. Like, it's not like, like this, you don't even know who you can trust about things. [...] I think people would wanna go away where people don't know them." – Youth Women Focus Group

"I think the biggest fear would be within themselves, finding out that they have [HIV/AIDS or hepatitis C]. And then some people are better off just living their life without knowing if they have it or not, and it's the high risk people, like the people that are out there drinking and sleeping with different people and using drugs and, those are the people that, that need to be, be explained more about this situation, about it's easy to get a test, it's all confidential and stuff like that, eh."

– Man, Age 30-54

Table 26: What might make it harder for people to go to these places [for information and testing for HIV/AIDS and hepatitis C]? Easier? (Question 9c to community members)

Theme	Most Common Responses
Barriers	Confidentiality/trust
	Scared/afraid
	Shy/embarrassed
	Unsure
Easier Access	Increase confidentiality and trust



Confidentiality

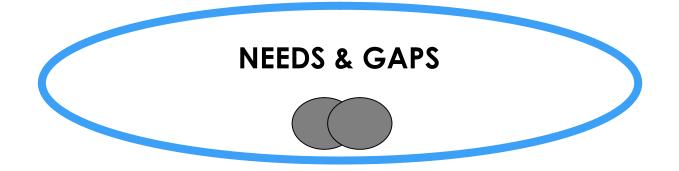
By far the most significant issue discussed by Front Line Workers, as well as by community members in both individual interviews and focus groups was that of confidentiality; even at the level of simply accessing information about HIV/AIDS and hepatitis C.

Confidentiality of Information Access

- **Sensitive issues:** The sensitivity of these diseases plays a role in informing communities about these diseases.
 - For example, holding a public meeting or increasing the number/types of pamphlets available may not always be the best methods given that some participants stated that they do not seek information at their community health centre/clinic because they are afraid that other community members will think they have HIV/AIDS because they are seen picking up/asking for information. People would like access to information and services, but are unsure of the best method of managing this locally:

I think have more of an open door policy for HIV and hep C. You know, make people aware that there's some support services in the clinic. But then you don't really wanna go waving flags and banners around saying that there are no support services because then, well actually it is, there's two sides to that. It would be good to have those support services in the public eye, but then everybody in the general public are going to start asking 'well just how many people are affected here?' [...] Well yea, like, you want to be careful of people's perceptions on how they view the services that you're trying to offer but then you don't want them to shun it away too, you want them to accept that the services are here."

– Man, Age 30-54



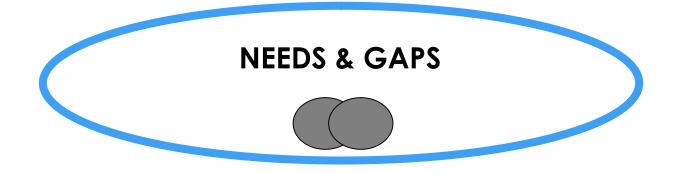
• Several community members noted the benefit of having home-tohome visits as one way to address confidentiality or comfort issues:

"Go out there. Talk to them. Go from house to house and talk to them. That's the only way that they know, or radio." – Man, Age 30-54

"More programs to educate youth, parents, Elders - workshops, conferences, school presentations, deliver pamphlets home-to-home and make them aware." – Woman, Age 30-54

"Conferences, workshops, presentations, home visits - deliver pamphlets, talk to parents." – Man, Age 18-29

"[...] I think somebody should go around to every home and talk about educate, educating people but I don't, I don't know how it could affect the person they go, go and see. [...] If you went to a home that nobody knew English they'd have to talk Cree." – Woman, Age 30-54



Confidentiality of Testing & Services

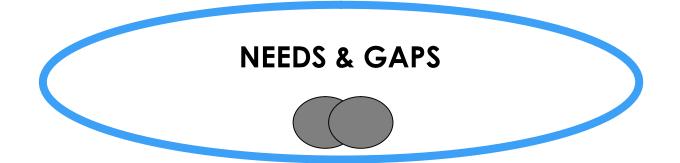
Concerns about confidentiality in the testing process are even more acute than accessing information. Members from these small communities, as well as the Front Line Workers that serve them, feel people are afraid:

- that results will leak out into the community (issues of living in a small community)
- of the reactions from family or the community to the testing process, much less a positive test result
- of a positive test result. Some participants thought that some people would rather not get tested and live without knowing if they have HIV/AIDS because getting a positive result is very scary news.

"The clinic is the best place or go, if you want to keep it confidential like you don't want to worry about it not being confidential just go out of town, [...]" – Woman, Age 18-29

"Because it is a small community, there's lot of people from the community that are working at the health clinic. Um, you know, individuals may not feel comfortable going to the [health centre]...." – Front Line Worker

"Um, well the one thing, in the city, they can go and have a test done anonymously. Here they can't do that. So I think that's a big drawback. I think if they could go have anonymous testing then they'd have more people being tested and willing to get tested." – Front Line Worker



"Um, I think another barrier is, to treatment, is issues of confidentiality, the small towns, people don't want to come forward for treatment or see a clinic regarding [HIV/AIDS] because of the perception that other people in the town will find out very quickly they have it and they'll be ostracized. I mean, we've had problems with that in the past, years ago, that I've seen in the community." – Front Line Worker

"Fear, embarrassment, trust. It's how I felt. It's just like everything went out the window. Like my blood's out there and I don't know where." – Woman, Age 30-54

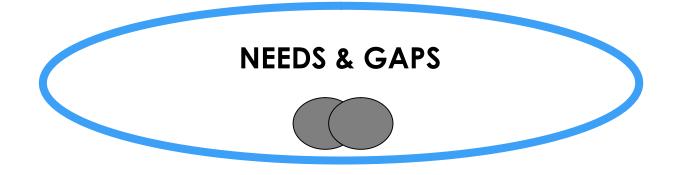
• Concerns about confidentiality extend not only to accessing information and testing services, but also to participating in prevention activities, such as purchasing condoms or using the needle exchange program (currently available in only one of the four communities that participated in this project).

"Probably like if somebody wants to see their doctor for a regular check-up that they could get condoms from them instead of..., instead of buying them in the store because everybody would talk about you and laugh and, the same with needle exchange. I don't know if there's a program like that here but like, if they have to go to the pharmacy and exchange their needles, like everybody would probably talk."

– Man, Age 18-29

• One participant thought that if counselling services were offered to affected individuals or their family members, people would not access them out of fear:

"No. I think, I don't know if anybody would actually really want to [see counsellors], they wouldn't wanna, mention it, it's all about the fear eh?" – Man, Age 18-22



Identity of Infected People

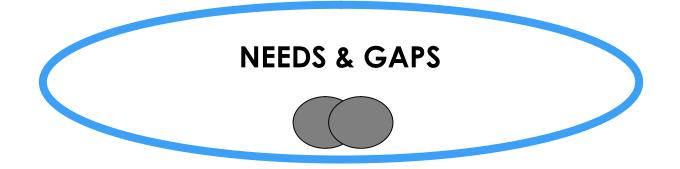
• Some participants wanted the identity of HIV – or hepatitis C-positive individuals exposed, while others felt it was not necessary because of privacy reasons. Some formed the desire to know who is affected around the desire to provide support.

"[...] it's really important that they're not identified so it is how do you support unidentified people that you don't know, if you don't know who they are... it is only the people that are identified or prepared to identify themselves that the community can rally around, can help them, I don't know..." – Elder Women Focus Group

Treatment Issues Identified by Front Line Workers (Tables 27 and 28)

Previous sections discussed issues around accessing information or testing programs for HIV/AIDS and hepatitis C. The issues identified there are also common to challenges in treating HIV- and hepatitis C-positive individuals in their home communities. These same challenges are even greater once the prospect of diagnosis has become a reality.

- Front Line Workers discussed treatment issues for HIV/AIDS (Table 28) and hepatitis C (table 29) such as:
 - Effects of geography/location on HIV/AIDS and hepatitis C treatment services – i.e. appropriate services are too far to access. Tied into this is ...
 - o ... a lack of specialists or access to specialists in the north.



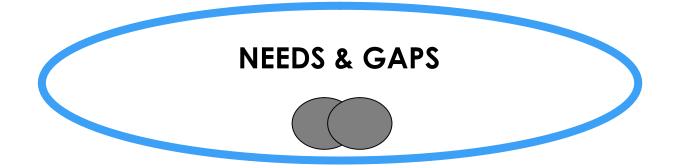
• A range of other issues identified by Front Line Workers include concerns about community level knowledge and capacity to support HIV and hepatitis C-positive individuals, and their own lack of financial and human resources to provide adequate follow-up. There is also concern about a lack of financial assistance available to affected individuals and families to facilitate their access to services, as well as the potential lack of community support, coupled with stigmatization, for affected individuals and families.

"[... We] don't do any AIDS treatment [in our community]. So, if anyone had HIV/AIDS wanted to get treatment they'd have to be treated in the city and go for all their follow-up in the city. So that would be a big factor. But I think it's still difficult in the north because the smaller [...] communities where there's no doctor, there's no hospital, these people need to have regular blood work. So unless you have someone there making sure they're coming in for their blood work, it can be very dangerous. So, I think that's one of the areas that needs to be improved as well."

- Front Line Worker

"Probably the location, the amount of resources. I mean I know there are resources out there in the cities. And I know that, I mean, there's always the potential to move out, not move your whole family, but to take yourself and go to a agency, say, in some other location, if that's possible. And I don't know if there's funding in place for that either." – Front Line Worker

"The access to resources in terms of counseling and follow-up monitoring is relatively sparse. The opportunity is there for patients to receive testing and counseling and treatment, however, because of the lack of a client base there's not of experience in dealing with patients in my experience." – Front Line Worker



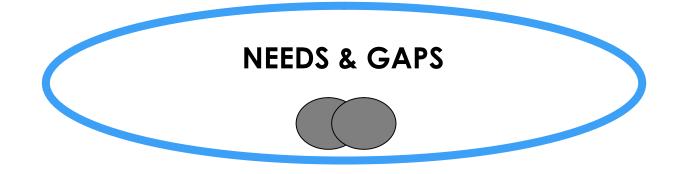
"Again, the negative stigma they have on them when they do have it and not enough supports to live with the disease. Not enough education in the community regarding these diseases so people tend to stay away from them for fear they might catch it." – Front Line Worker

Table 27: (Front Line Worker Question) What kinds of issues do you feel that your clients, or anyone in the community, are facing in relation to HIV/AIDS treatment?

Theme	Most Common Responses
Education	Health worker and community member education about treatment
Service	Lack of specialists
Availability &	Distance to services or specialists
Confidentiality	Perceptions of confidentiality

Table 28: (Front Line Worker question) What kinds of issues do you feel that your clients, or anyone in the community, are facing in relation to hepatitis C treatment?

Theme	Most Common Responses
Service	Treatment availability
Availability	Distance to services and specialists



SUMMARY OF INFORMATION UP-TAKE CHALLENGES

Information may be available, but what are the barriers to accessing this information? As previously noted, confidentiality and lower level of importance relative to other issues were just some of the barriers discussed by participants. On the next page, Figure 1 summarizes participants' discussion of barriers to information up-take and program participation. The discussion that follows elaborates on a few of these areas.

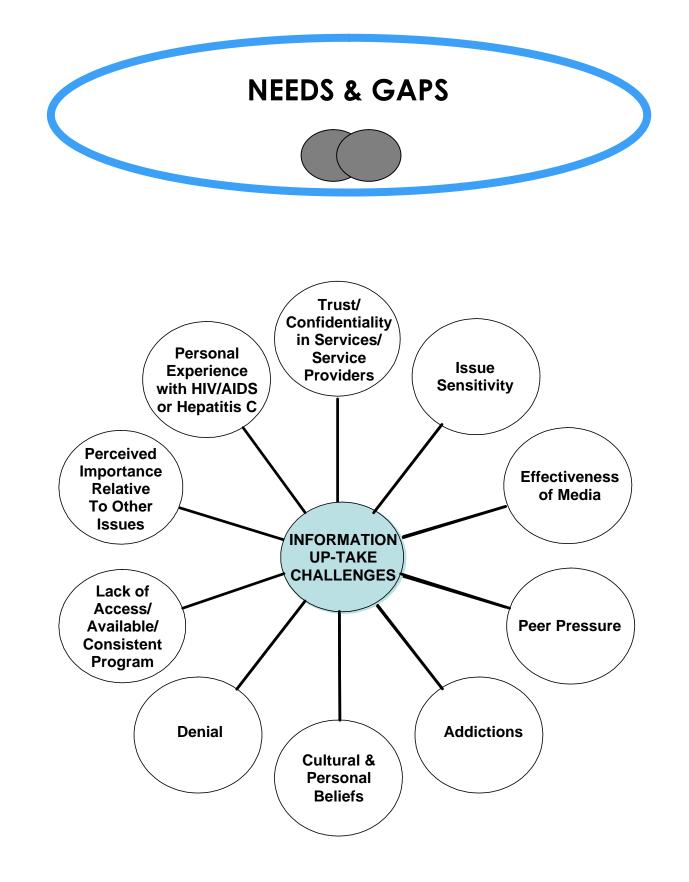
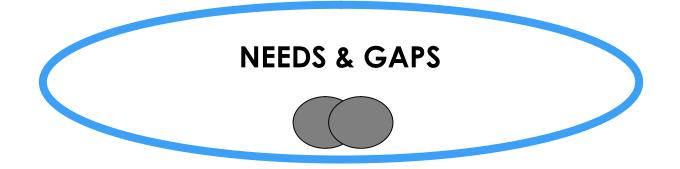


Figure 1: Information Up-take Challenges Noted by Participants



Effectiveness of Media

• More creative strategies required? Many participants suggested education and prevention strategies such as pamphlets and workshops, but, at the same time participants also felt that many of these methods are not always effective in getting the message out – either because they do not reach vulnerable populations, or because HIV/AIDS and hepatitis C are not as visible in the community as diabetes, for example.

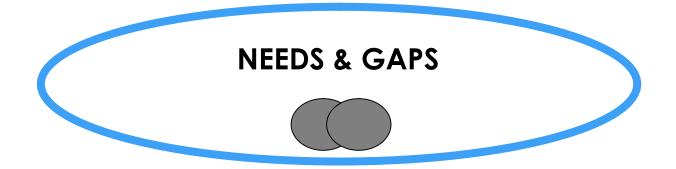
"But ah... I don't know, if all the posters, all the radio and all the TV, is it making a difference or are people still not practising safe sex... etcetera, I know we have a harm reduction program so, I don't know what, if that's a big help, the needle exchange... but education wise, I don't know what will touch young people and change people's behaviours, changing people's behaviours that's very difficult."

- Elder Woman Focus Group

"I think they would be scared [of an HIV-positive person] because there's a lot of movies or documentaries that they watch where people just die and start losing their hair and all this stuff. I think basically the majority of them would be looking for signs so when, I wonder when he's going to start losing his hair and all this stuff, because of how the, the, the videos or documentaries are presented." – Adult Men Focus Group

"... a lot of these kids have [...] not made use of the information that's given to them at hand [there's] pamphlets sitting here at the clinic and how often do they move off the shelves, not very often." – Man, Age 30-54

• One participant discussed having been exposed to various sources of information about HIV/AIDS, the most effective for him being oral, but it was having to personally deal with supporting an HIV-positive friend that triggered a direct quest for information from a doctor.



"There's a lot but when you hear it, it stays in. When you read it, it disappears, I find for me. I don't know how you are with that kind of stuff but when I hear it from somebody it stays in. Like when my friend first got AIDS I had to run into a doctor and that's where I know I had to be his friend still, you know." – Adult Men Focus Group

Personal Addictions

• While information may be available, some people may not be at a point in their life to seek information or follow advice:

"Even when I was in that [unhealthy] state, like I'm saying, that's all I thought of, you know. I got myself in a hole through negative thinking and there was no light up there. People would throw a switch on but I would just turn it off because I didn't wanna deal with it. I wasn't ready for it. And when I come to realize that there's a light at the end of the tunnel, it's up to me to make that choice."
– Adult Men Focus Group

Personal Experience with HIV/AIDS or hepatitis C

• Since the prevalence of HIV/AIDS in the project communities was not high – and not affecting many community members personally – this may be one reason why information may not be as effective:

"Um, I feel that both of them [HIV/AIDS and hepatitis C] are not a problem unless it starts to affect our community in a personal way, as in if somebody [close] to the community, that's when it would start affecting us but right now, people just brush it off, I don't think it really affects us right now." - Man, Age 18-29

YOUR THOUGHTS



This section discusses what participants had to say about:

- Holistic and cultural approaches to addressing HIV/AIDS and hepatitis C, taking into account the diversity of northern peoples and communities.
- Programs and services needed/suggested to address and prevent HIV/AIDS and hepatitis C (for example, the importance of youth education).
- Ideas to include in a plan to address and prevent HIV/AIDS and hepatitis C in northern Saskatchewan Aboriginal communities.



Community members discussed a range of issues and approaches that should be considered in the design of an HIV/AIDS or hepatitis C Strategy for their communities. Peoples' diverse beliefs about good individual and community health and the links between them, as well as their values about learning, sharing, and respect are reflected in their comments.

HOLISTIC & CULTURAL APPROACHES

- Effect of individual on community: One participant spoke about how the illness of one person in the community affects everyone in the community.
- 'Treatment' of infected person and community together: Other participants stated that not only does the actual disease have to be treated but the community has to be 'treated' as well (e.g. in terms of how they treat infected people in their community):

"Probably, yea, it does 'cause [HIV/AIDS and hepatitis C are] like an illness and any type of illness affects people in the community." – Woman, Age 18-29

"More education. People need to be aware and to have compassion. I mean, compassion is a big thing that this community is lacking, I feel, so that's a big thing. Along with that education it's not just to teach about that sickness, it's about how you treat these people with this sickness, you know. And considering they're gonna die, a little bit of compassion I feel is in order regardless of what they're dying of. It doesn't matter, you know." – Woman, Age 30-54



• Holistic healthy lifestyle: There were a few participants in one project community (all age groups) who talked about holistic ways to stay healthy that are important components of an HIV/AIDS or hepatitis C strategy:

Good nutrition, exercise, laughter, education. – Woman, Age 55+

> Wild food/meat, fish, exercise. – Man, Age 55+

We have to respect ourselves, the choices you make - good nutrition, exercise, [avoid] risky behaviors/violence fights. – Woman, Age 30-54

Exercise - walking, treating others with respect. Makes a person feel good - a sense of caring/belonging when one treats other positive. – Man, Age 18-19

• **'Sharing':** Using the word, 'share' in communicating about risk behaviours may be inappropriate in some communities where sharing in general is a positive value.

"And not, not using needles is kind of, not sharing needles is (unclear) thing eh, 'cause you'll scare the old people (laughter) you don't want to say not sharing, not using needles, kind of not sharing [...]" – Adult Male Focus Group



• Cultural approaches and translation services:

Including a role for Elders and Elder knowledge is a key point to consider in an HIV/AIDS or hepatitis C strategy in these communities:

"Elders provide traditional healing." [notes from an unrecorded interview]⁷ - Woman, Age 30-54

"Elder teaching/teach traditions/teaching values/sacredness respect spiritual/religious involvement." – Man, Age 18-29 [notes from an unrecorded interview]

Language is also an important consideration:

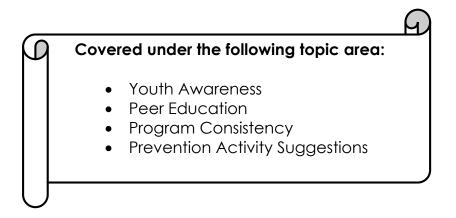
"[...Some] won't even know what you're talking about some, some of them and somebody would have to talk to them in Cree. If you went to a home that nobody knew English they'd have to talk Cree." - Woman, Age 55+

"Ahh, I don't know, I suppose if you're, if you don't speak English or something like that would be one [barrier to service access], you kind of don't trust somebody to come and interpret for you, you want to keep it to yourself and then they would have a hard time asking unless it's somebody who understands Cree I guess. " - Man, Age 55+

⁷ Quotations marked with, "notes from an interview", indicate that while the participant agreed to be interviewed but did not want their interview to be recorded with a voice recorder.



PROGRAMS & SERVICES NEEDED



Recognizing that HIV/AIDS and hepatitis C strategies should be framed in a northern context that includes diverse languages, cultures, beliefs and values, participants offered some specific direction around who and how programs and services could be delivered and to whom.

حَبُّ Youth Awareness

Youth focus groups were asked what they thought could be done to increase young peoples' awareness of HIV/AIDS and hepatitis C. They offered the following suggestions:

- Just talking about HIV/AIDS more can increase awareness
- Adults should be educated on HIV/AIDS and hepatitis C, not just kids
- Create exciting/interesting education programs/services



- Conduct home visits to inform people about HIV/AIDS and hepatitis C
- Organize school visits/presentations on these diseases
- Offer peer-to-peer education (youth educating youth)
- Show educational videos
- Hold weekly youth discussion groups

"[...] educating each other and help each other learn things. To help the community to help each other [...]." – Youth Women Focus Group

> "[...] talk about it, not just tell us, have a discussion on it." – Youth Men Focus Group

"Yah, I would think that would have to be a fairly young person [to teach about HIV/AIDS] but if it was an older person that person was like really nice and we could get along with [...]." – Youth Woman Focus Group

$\stackrel{\text{club}}{\to}$ Peer Education

• Youth focus group participants placed emphasis on the importance of peer education, but Elder and Adult focus groups also discussed this approach. Front Line Workers also noted the benefit of learning about these diseases in the school system (elementary and high school levels):



- Some participants thought information might better be conveyed to younger people by others their own age
- Young people might also absorb information better or feel more comfortable asking sensitive questions to other youth their age

"Videos, pamphlets, talks in the youth centre. Door-to-door talks. Teenagers talking to teenagers. Questionnaires." – Youth Women Focus Group

> "Workshops, have friends talk about it more often to friends." – Youth Men Focus Group

• Intergenerational involvement: One participant also noted the importance of intergenerational education, such as parents and grandparents being involved in educating and increasing HIV/AIDS and hepatitis C awareness among youth:

"But I think the key is for the parents, the grandparents to understand as well and reinforce what they're learning in school." – Elder Women Focus Group



• All project participants, in individual interviews, and in group discussions – community members and Front Line Workers - feel that a lack of consistent programming can hinder the effectiveness of education and prevention programs:



"...watched a [HIV/AIDS] video in class once that's about it."

"Yes. And, and be consistent, have it there, every Thursday, this is when they are. And no matter, if there's people at bingo or something happening, it's still on because even if one person learns, it's still a benefit." – Front Line Worker

"We're still very new at it because as a community our chief and council changes every two years which affects all your systems of organization, your committees. You get new people who come on and each time.... Because of our political system, we need to be aware of it and plan for it because you can educate one set of people and be operating very quiet for two, three, four year. They lose out in the next election and you're back to square one. So whatever you started has to be redone. That I know has to happen with any program." – Front Line Worker

"So, we've done a couple of radio programs that you know, in the hopes of reaching people with hep C, but even that, when we do it once a year, it's not hardly enough but yet how do you fit it in so you have the time to commit and make sure it's an on-going thing. So, I think consistency is, is a tough thing to keep up with."

- Front Line Worker



"Maybe that we don't teach it consistently enough. Maybe because it's not taught often enough. It's not enough to teach it once and once and once (laugh, in which every grade it's taught ah, that's not enough. It has to be repeated over and over and over. You don't teach kids to learn grade one and leave them alone. And we can't just teach about HIV or hepatitis C and just leave it alone for the next twelve years. It has to be done consistently and by everybody."

– Front Line Worker

المنافعة: Prevention Activity Suggestions (Table 29)

- Overall response Increase awareness & education: Most community member participants and Front Line Workers suggested that there was a need for:
 - o Increased community HIV/AIDS and hepatitis C awareness
 - Increased community HIV/AIDS and hepatitis C education
- Main HIV/AIDS-specific suggestions:
 - o Increase awareness and education (especially at younger ages)
 - o Hold more workshops
 - Many Front Line Workers qualified the workshop strategy by suggesting that sometimes workshops do not reach the targeted audience or workshops are not offered on a consistent basis.



- Invite an infected person to the community to speak about the disease
- Take safety precautions (e.g. not passing needles around, practicing safer sex)
- Promote networking opportunities with other northern communities or agencies (for example, to exchange information, experiences, or ideas)
- Create/show informational videos 0
- Offer programs/services on a consistent basis
- Main hepatitis C specific suggestions:
 - Increase awareness and education
 - Take safety precautions (e.g. not passing needles around, practicing safer sex)

"I don't think it's enough just... I think maybe uh, maybe videos or maybe if you got somebody who was suffering from HIV or AIDS or hepatitis C to come in and do the workshop and actually see the progress of the disease from when she was a healthy person and then like maybe through pictures or even a video of somebody dying of this disease." - Woman, Age 30-54

"Talk to the students, get into their schools and show them, you know, like things about how to protect themselves, about dirty needles and, and condoms and stuff, how to protect themselves."

- Woman, Age 30-54



"Or even in the schools, like go to different grades and do that, you know. A person could have a full-time job even just doin' that [...]." – Front Line Worker

"I think we would have to come up with something like, as a community, how do we get these people out for these [workshops]? If there was a very informative meeting or important informative workshops because it's something, it's just something that people are uncomfortable about and they don't talk about it openly."

– Front Line Worker

"Like we have, we've had AIDS workshops in the past. We've had um, hepatitis C workshops and information sessions. The people that come are not the people that you want to reach. They're not the people who are at risk or who have a potential for the disease, who you would want to go and get, have them go and get tested or whatever. So you're really not reaching the population you want to reach. And that's where we came up with having radio talk shows on hep C." – Front Line Worker

- Other prevention activity strategies suggested by participants, some of which have been in the past, or are currently being implemented, include:
 - Creating a large community informational billboard
 - Conducting smaller education groups/sessions in schools
 - o Conducting informational home visits
 - Holding some information sessions in the evening so that more people can attend



- "Piggy-backing" with other issues in order to reach a wider 0 audience or increase participation. For example, using events such as pow-wows, treaty days, or sporting events
- Radio phone-in radio show where people could phone in with their auestions and a doctor/health professional would answer them
- "Networking conferences" should be held with other communities in 0 the north, so they can learn from each other's trials and errors in disseminating information to community members and to learn about the status of HIV and hepatitis C infections in the north
- MBC could be used to air programs relating to these diseases

"I think another good way to, to prevent this in a community is to educate younger people. Like, if you're talking in a school setting in smaller groups 'cause you get a lot of people walk into the classroom and there's 20 some students, there could be teasing each other about it or laughing behind each others back to pay any attention but if you had a group of 5 people then maybe you'll have a little better response."

- Adult Men Focus Group

"Networking is always good. You could always network with other communities and see what works for them, you know, and, and trying to take it from there to see what might work you know, in your community, if certain things aren't working. Like if people aren't coming to your workshops or, you know, what has worked in other communities and ya, networking is good." - Front Line Worker



"A lot of people listen to the radio. My mom is [...] old. She sits and listens to the MBC broadcast, once done in Cree and then in English. Ah, so the radio, through MBC, is a good way to get a lot of different age groups, Cree speaking or Dene speaking or English speaking. It's one of the ways that I know a lot of people listen to the radio. Ah, sending mail out and stuff, it's always you know who sent it, but whether people read it is something else. And ah, I was thinking about [...] companies that are trying to sell their, their samples. You know what about sending an interesting information package instead of just a one-page pamphlet, you know? I don't know what you could send, but ah, [...] You never know. 'Cause I don't think you really want to send condoms (unclear, laughter), but something... it would strike their interest, you know, with a little questionnaire of what do you know about AIDS to protect yourself. And you know, something where it, it wakes them up a little bit, 'Oh, I don't know enough about this' [...]. " – Front Line Worker

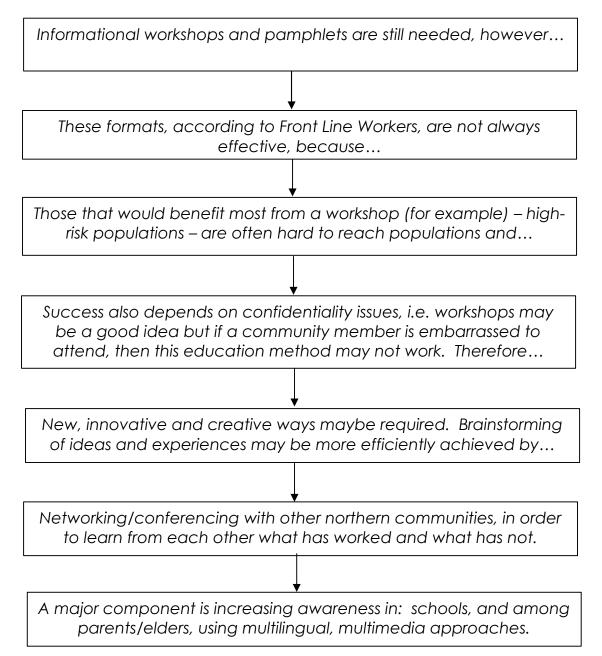
Table 29: What things could be done to prevent people in your community from getting HIV infection? hepatitis C? How should education and other prevention activities be carried out?

	Suggestions
	Increase awareness
	Increase education/information
Education & Awareness	Provide information at a young age
Education & Awdreness	Safe sex information
	Workshops
	Have a diseased person speak to the community
	Don't share needles
Safety	Protected sex
	Safety precautions (general response)
Nature of Programs	Consistent programs
Nature of Programs	Education available in school system
Correctories	Videos
Formats	Workshops
Actions	Networking with other communities/agencies



In summary, Front Line Workers and some community members discussed:

Figure 2: Summary of Prevention Activity Discussions





IDEAS FOR A PLAN

- **Main suggestions:** When asked what should be the main focus of an HIV/AIDS prevention and support plan, most community members and Front Line Workers suggested general activities, such as:
 - o Increase awareness
 - o Increase education
 - Focus on youth, but provide education across the lifespan
 - o Provide information in schools
 - o Offer programs/services on a consistent basis
 - Create an HIV/AIDS/hepatitis C coordinator position

"Ah, they should really work with the students at the school. And help them, like, try and get it to them as early as nine years old. A year, nine years old, and then they can be better prepared as they're older and, know, have all the information that they need." - Woman, Age 30-54

"Translators for Elders - for Elders to have better understanding." [notes from an unrecorded interview] - Woman, Age 30-54

"Mmm, I don't know, maybe, the kids, if the kids learn something at home maybe they can just spread it onto their parents and older people, try and educate everybody as much as they can I guess. I guess that'd be the key is to educate everyone so they understand about it." – Man, Age 30-54



"[...] but what I would like to see is to have a HIV/AIDS/hep C like ah, education program in place, and where one could just be, you know, solely interested in that program, and you know be committed into providing, bringing that information to the community, and also in the schools you know. That would be so great if we could have that in place." – Front Line Worker

Table 30: (Front Line Workers) What steps have been taken/do you think need to be taken to create a plan to address HIV or AIDS in northern Saskatchewan communities? hepatitis C?

Theme	Most Common Responses
Education &	Increase awareness
Awareness	Increase community education
Awdieness	Develop new/creative ideas to address issues
	Hire an HIV/AIDS/hepatitis C-specific program coordinator
Programming &	Network with other communities/agencies
Community Collaboration	Intercommunity or community conference
Collaboration	Consistent programs





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FUNDING/RECOGNITION OPPORTUNITIES

<u>Organization</u>	Resources	<u>Contact</u>
Federal Initiative to Address HIV/AIDS in Canada	Non-Reserve First Nations, Inuit and Métis Communities HIV/AIDS Project Fund (launched in January 2005): The Non-Reserve Fund has three main priorities	Shane Rhodes Public Health Agency of Canada Tel: (613) 946-3636
	which are: 1) to build on existing work being done in the community; 2) to enhance partnerships and sustainability; 3) and to work to make HIV/AIDS a part of the work done by existing Aboriginal services/agencies that may not presently do this type of work.	E-mail: Shane_Rhodes@phac- aspc.gc.ca Website: http://www.phac- aspc.gc.ca/aids- sida/hiv_aids/rfp/project _fund.html
Federal Initiative to Address HIV/AIDS in Canada	Regional Operational Funding: Regional Operational Funding is available to fund programming, key positions within an organization, and overhead and administrative costs. Voluntary, non-profit, non-governmental organizations whose principal mandate is community-based HIV/AIDS programming are eligible for funding. National organizations are not eligible for operational funding. Operational funds will be approved for a minimum of two years and a maximum of four years. Regional Project Funding funds time-limited, specific activities that address unmet needs and priorities around HIV/AIDS. These activities may be local, provincial/territorial or regional in scope. Voluntary, non-profit, non- governmental agencies actively dealing with HIV/AIDS issues are eligible for funding. National organizations are not eligible for regional project funding. Regional Project Funds will be approved for a maximum of three years.	HIV/AIDS Regional Operational Funding, Saskatchewan Region 18th floor, 1920 Broad St. Regina, Saskatchewan S4P 3V2 <u>Tel</u> : (306) 780-6445 <u>Fax</u> : (306) 780-6445 <u>Fax</u> : (306) 780-6207 <u>Website</u> : http://www.phac- aspc.gc.ca/aids- sida/hiv_aids/federal_init iative/community/index. html

<u>Organization</u>	<u>Resources</u>	<u>Contact</u>
Canadian Aboriginal AIDS Network	New Journal Canadian Aboriginal AIDS Network is seeking a title for a new paper and electronic journal focusing on HIV/AIDS and Aboriginal people. One of the goals of the project is to enhance dissemination of Aboriginal community-based HIV/AIDS research using a variety of methods, such as a paper journal.	Dina Epale National Community- Based Research Coordinator Canadian Aboriginal AIDS Network 602-251 Bank Street Ottawa, ON, K2P 1X3 <u>Tel</u> : (613) 567-1817 ext. 112 <u>Fax</u> : (613) 567-1817 ext. 112 <u>Fax</u> : (613) 567-4652 <u>E-mail</u> : dinae@caan.ca <u>Website</u> : http://www.caan.ca/englis h/grfx/resources/newsletter s/January_2004.pdf
Canadian Aboriginal AIDS Network	Technical Assistance Technical assistance to Aboriginal HIV/AIDS community-based researchers available from the Canadian Aboriginal AIDS Network. Technical assistance is available to Aboriginal community-based researchers. This technical assistance will assist you in securing scholarship funding to present at various conference venues as well as in the development of presentations. CAAN will offer abstract review assistance, develop resources that support the abstract and use their existing channels (newsletter, website) to advertise conference/scholarship information and tips on how to access these sources.	Dina Epale National Community- Based Research Coordinator Canadian Aboriginal AIDS Network 602-251 Bank Street Ottawa, ON, K2P 1X3 <u>Tel</u> : (613) 567-1817 ext. 112 <u>Fax</u> : (613) 567-4652 <u>E-mail</u> : dinae@caan.ca
Canadian Working Group on HIV and Rehabilitation (CWGHR)	HIV and Rehabilitation Funding CWGHR has provided funding for several projects related to rehabilitation in the context of HIV. These projects are very important in developing new knowledge and programs to address rehabilitation issues in effective and innovative ways.	Canadian Working Group on HIV and Rehabilitation 333 Sherbourne Street Toronto, ON, M5A 2S5 <u>Tel</u> : (416) 324-4182 <u>Fax</u> : (416) 324-4184 <u>Website</u> : http://www.hivandrehab.c a/

Organization	Resources	Contact
Canadian Association for HIV Research (CAHR)	Scholarships and Awards: CAHR Red Ribbon Award CAHR Research Track Scholarship CAHR Community Scholarship CAHR New Investigator Award (Basic Sciences, Clinical Sciences, Epidemiology and Public Health, Social Sciences)	Canadian Association for HIV Research c/o Jennie Prasad University of British Columbia 201 - 1200 Burrard St. Vancouver, BC, V6Z 2C7 <u>Tel</u> : (604) 642-6429 x307 <u>Fax</u> : (604) 642-6419 (Attn: Jennie Prasad) <u>E-mail</u> : info@cahr-acrv.ca <u>Website</u> : http://www.cahr-acrv.ca
Canadian	Research Grants	Canadian Foundation
Foundation for AIDS Research	CANFAR is the national charitable foundation	for AIDS Research 165 University Avenue,
(CANFAR)	created to raise awareness in order to	Suite 901
	generate funds for research into all aspects of HIV infection and AIDS.	Toronto, ON, M5H 3B8
	CANFAR allocates a portion of its resources to grants for the development of awareness programs, and for research on ethical and other implications of measures that might be proposed for the protection of public health. Grants are awarded at two levels: level one up to \$80,000, each year for a two year period, and level two up to \$25,000. Grants are awarded annually to donees whose activities qualify as charitable, and who are located primarily within Canada and its Territories. CANFAR accepts grants on an annual basis.	<u>Tel</u> : (416) 361-6281 <u>Toll Free</u> : 1 (800) 563-CURE (2873) <u>Fax</u> : (416) 361-5736 <u>E-mail</u> : grants@canfar.com or cure@CANFAR.com <u>Website</u> : http://www.canfar.ca
Canadian HIV/AIDS	HIV/AIDS and Human Rights Award	Canadian HIV/AIDS
Legal Network	The Awards for Action on HIV/AIDS and Human Rights: highlights outstanding contributions that decrease vulnerability to HIV/AIDS and protect the rights and dignity of those infected and affected. Recognizing excellence and long- term commitment to work having a direct impact on HIV/AIDS and human rights issues – in particular work that is of direct relevance to marginalized individuals and communities – an award is presented annually to one Canadian and one international recipient.	Legal Network 417 Saint-Pierre Street, Suite 408 Montréal, Québec H2Y 2M4 <u>Tel</u> : (514) 397-6828 <u>Fax</u> : (514) 397-8570 <u>E-mail</u> : info@aidslaw.ca <u>Website</u> : http://www.aidslaw.ca/

<u>Organization</u>	Resources	<u>Contact</u>
Canadian HIV Trials Network	Postdoctoral Fellowships Each year the Canadian HIV Trials Network, in partnership, provides four CTN Postdoctoral Fellowships worth \$45,000 plus \$3,000 for travel expenses to promising new HIV clinical investigators. The fellowships, which go exclusively to researchers working in Canada, provide career support and are renewable for up to two years.	Canadian HIV Trials Network 620 - 1081 Burrard Street Vancouver, BC V6Z 1Y6 <u>Tel</u> : (604) 806-8327 <u>Toll Free</u> : 1 (800) 661-4664 <u>Fax</u> : (604) 806-8210 <u>E-mail</u> : ctn@hivnet.ubc.ca <u>Website</u> : http://www.hivnet.ubc.ca/ ctn.html
Canadian Association of Nurses in AIDS Care (CANAC)	Awards of Excellence Awards of excellence are given each year in the following categories: • Award in Clinical Practice • Award for Newcomer • Award for Newcomer • Award of Excellence for an Exceptional Contribution to the Development of Nursing in HIV/AIDS Care	CANAC c/o Casey House 9 Huntley Street Toronto, ON, M4Y 2K8 <u>Fax</u> : (416) 962-5147 <u>E-mail</u> : info@canac.org <u>Website</u> : http://www.canac.org/
Canadian Institutes of Health Research (CIHR)	Institute of Aboriginal Peoples' Health We already know some of the reasons why the health of aboriginal people is worse than the health of other Canadians, but there is much that we still do not know. The Canadian Institutes of Health Research-Institute of Aboriginal Peoples' Health (CIHR-IAPH) was developed to help fill in the gaps in our knowledge. CIHR-IAPH is not only focused on illness, but on wellness too. For instance, we want to know how factors such as Aboriginal culture and spirituality can affect health and wellness. In consultation with our advisory board, CIHR- IAPH asks the health research questions, and provides funding to support researchers who will look into the important answers. We encourage aboriginal students to take up health research, so that they can bring our own perspective to making our communities	IAPH (Ottawa Office) CIHR - Institute of Aboriginal Peoples' Health University of Victoria P.O. Box 1700, STN CSC Victoria, BC, V8W 2Y2 <u>Tel</u> : (250) 472-5449 <u>Fax</u> : (250) 472-5450

<u>Organization</u>	<u>Resources</u>	<u>Contact</u>
	well. Where non-aboriginal researchers do the research, we make sure that they work well with communities, consulting with them, informing them, and partnering with them, so that community wishes are respected.	

ABORIGINAL HIV/AIDS OR HEPATITIS C RESOURCES

<u>Organization</u>	Resources	<u>Contact</u>
Assembly of First Nations	 The Assembly of First Nations (AFN) is the national organization representing First Nations citizens in Canada. The AFN Secretariat, is designed to present the views of the various First Nations through their leaders in areas such as: Aboriginal and Treaty Rights, Economic Development, Education, Languages and Literacy, Health, Housing, Social Development, Justice, Taxation, Land Claims, Environment, and a whole array of issues that are of common concern which arise from time to time. Young Eagles' Challenge: A Peer Education Training Manual for First Nations Youth on HIV/AIDS and Related Issues (2004). http://www.afn.ca/cmslib/general/Young-Eagles.pdf First Nations Health Bulletin http://www.afn.ca/cmslib/general/Action-Plan-1.pdf First Nations Health Action Plan – Part 2 (2004): http://www.afn.ca/cmslib/general/Action-Plan-2.pdf 	Assembly of First Nations 1 Nicholas Street, Suite 1002 Ottawa, ON, K1N 7B7 <u>Tel</u> : (613) 241-6789 <u>Toll Free</u> : 1 (866) 869-6789 <u>Fax</u> : (613) 241-5808 <u>Website</u> : www.afn.ca
Wabano Centre for Aboriginal Health	 The main purpose of the Centre is to create and deliver services that will prevent ill health, treat illness and provide support and aftercare. Services will be offered in a culturally-sensitive way that welcomes, accepts and represents all Aboriginal people(s). Resources include: Keep the Circle Strong. This document is an interactive training circle rooted in Aboriginal culture where Eagle, Moose, Bear and Buffalo are invited to share their stories and wisdom to help keep the circle strong. 	Wabano Centre for Aboriginal Health 299 Montreal Road, Ottawa, ON, K1L 6B8 <u>Tel</u> : (613) 748-0657 <u>Fax</u> : (613) 748-0550 <u>E-mail</u> : info@wabano.com <u>Website</u> : http://www.wabano.c om

<u>Organization</u>	<u>Resources</u>	<u>Contact</u>
Healing Our Nations (formerly	"Eagle On The Moon Project" provides performance based HIV education that is interactive and culturally based. The Eagle on the Moon's educational performances include interactive skits and games using hand made puppets, masks, and various multi media. Healing Our Nations mandate is to teach and support our people in the prevention of HIV/AIDS	Healing Our Nations 45 Alderney Drive,
known as the Atlantic First Nations AIDS Task Force)	 in the manner that is respectful of our native ways of life. They are guided on this mission by the people they help. Resources include: Interactive Medicine Wheel concept of living with HIV/AIDS. Workshops on various HIV/AIDS topics. 	Suite 607 Dartmouth, NS, B2Y 2N6 <u>Tel</u> : (902) 492-4255 <u>Toll Free</u> : 1 (800) 565-4255 <u>Fax</u> : (902) 492-0500 <u>Website</u> : http://www.healingourn ations.ca/
Red Road HIV/AIDS Network	 Red Road HIV/AIDS Network is a provincial based Aboriginal Organization. Red Road's 125 plus membership capacity is comprised of Aboriginal AIDS Service Organizations (ASO), non-Aboriginal programs, Aboriginal Persons living with HIV/AIDS (APHA), and Aboriginal community-based organizations who have HIV/AIDS programs, located in urban & rural British Columbia. Membership Provides: support programs in education, treatment and care, peer counseling, advocacy, and workshops on HIV/AIDS & hepatitis C. Available resources: Red Road E-Newsletter Bloodlines: a full colored, quarterly magazine featuring Aboriginal persons living with HIV/AIDS (APHA). This magazine offers a forum in which APHA's can share their personal experiences, discuss issues affecting them, offer advice and suggestions to their peers. Copies are available to download off their website or by using the contact information below. <i>Red Road Map</i>: Red Road has developed an Internet-based mapping system that highlights services for people affected or infected with HIV or AIDS. The map serves as a useful tool for 	Red Road HIV/AIDS Network 804-100 Park Royal South West Vancouver, BC V7T 1A2 <u>Tel</u> : (604) 913-3332 <u>Toll Free</u> : 1 (866) 913-3332 <u>Fax</u> : (604) 913-3352 <u>E-mail</u> : info@red-road.org <u>Website</u> : http://www.red- road.org/

<u>Organization</u>	<u>Resources</u>	<u>Contact</u>
	finding services that are located close to the map user. This innovative project was developed with enhancement funds provided by the Greater Vancouver Urban Aboriginal Strategy. More information at: http://www.redroad.org/download/vanmap.pdf	
	• Pathways to Wholeness (1999): One of the primary achievements of the BC Aboriginal HIV/AIDS Task Force has been the development and implementation of the Red Road: Pathways to Wholeness, An Aboriginal Strategy for HIV and AIDS in BC. Available for download at: http://www.red- road.org/download/PathwaysWholeness.pdf or by contacting RRHN.	
	• The Red Road: Pathways to Wholeness, An Aboriginal Strategy for HIV and AIDS in BC Implementation Guide (2001). The purpose of the guide is to provide relevant information and concrete examples of what individuals and communities can do to make progress towards the strategic goals that have been outlined in the Strategy. This Guide has been developed for use by any one that has an interest in the prevention and treatment of HIV/AIDS. This may include health care professionals, educators, community service providers, band administrators, Aboriginal leadership, community members and families. Available for download at: http://www.red- road.org/download/implementationGuide.pdf or by contacting RRHN.	
	• Pathways To Community Healing HIV/AIDS Education Model (2002): The HIV/AIDS Education Manual is designed to offer standardized information on HIV/AIDS that can be used by facilitators and educators in Aboriginal and non-Aboriginal communities. This manual has been developed for use by Aboriginal educators, speakers, Aboriginal people living with HIV/AIDS, community health representatives and individuals presenting HIV/AIDS information. Available for download at: http://www.red- road.org/download/educationManual.pdf or by contacting RRHN.	

<u>Organization</u>	Resources	<u>Contact</u>
All Nations Hope AIDS Network	 Communicating about HIV/AIDS within BC's Aboriginal Community: This booklet aims to provide community-based educators, care givers and leaders in Aboriginal communities across the province with practical information on how to increase awareness on HIV/AIDS. It provides some tools and advice that will assist in your prevention efforts. This guide complements other resources available on the subject of Aboriginal HIV/AIDS in BC including the BC Aboriginal HIV/AIDS Task Force. Part of this document is not included with the download, the information that is missing is the Media contact lists, to get a copy of these lists please. Available for download at: http://www.red-road.org/download/communicatin gAboutHIVAIDS.pdf All Nations Hope is a coalition of Aboriginal People, organizations and agencies who care about HIV/AIDS among First Nations, Métis and Inuit people in Saskatchewan. Their website contains fact sheets, resources, links, and information on their services. In 2005, All Nations Hope will be hosting/hosted 3rd annual National Aboriginal hepatitis C Conference. Publishes the Positive Voice Newsletter. Issues available for download on their website. Basic HIV/AIDS & HCV (hepatitis C) Informational Workshops: A workshop hosted on HIV and AIDS for AIDS Educators, community health representatives and alcohol and drug counselors. Presentations delivered on HIV/AIDS & hepatitis C for the community members, youth members, special groups, community-based organizations and schools. Topics discussed could include basic HIV/AIDS information, transmission, healthy relationships, condom demonstration, prevention, ham reduction, and statistics. Requests for guest speakers that are HIV-positive or hepatitis C- positive to share personal stories. 	All Nations Hope AIDS Network 2815 5th Ave. Regina, SK <u>Tel</u> : (306) 924-8424 <u>Toll Free</u> : 1 (877) 210-7622 <u>Website</u> : http://www.allnationsh ope.ca/

<u>Organization</u>	Resources	<u>Contact</u>
Healing Our Spirit B.C. Aboriginal HIV/AIDS Society	 The mandate of Healing Our Spirit is to prevent and reduce the spread of HIV and AIDS and provide care and support services to Aboriginal peoples infected and affected by HIV/AIDS. Their website contains a wide range of information to download including: Community tools Fact sheets Information on legal issues Holistic information sheets on the needs of Aboriginals infected or affected by HIV/AIDS. Youth educational resources including: games/energizers, workshop activities, and information sheets. Aboriginal HIV/AIDS Community Education Program: The education program provides holistic and culturally appropriate HIV/AIDS prevention workshops to health professionals, students, communities, youth, incarcerated people, Elders, families and Chiefs and Council. The education program trains speakers living with HIV/AIDS to educate and share their life experiences with Aboriginal communities and organizations. (Available only to BC communities). Resource Centre: The Resource Centre collection consists of over 2000 titles, including books, videos, magazines, articles, abstracts, newsletters, and professional journals. The collection consists of over 2000 titles, including books, videos, magazines, articles, abstracts, newsletters, and professional journals. The collection consists of over 2000 titles, including books, videos, magazines, articles, abstracts, newsletters, and professional journals. The collection consists of over 2000 titles, including books, videos, magazines, articles, abstracts, newsletters, and professional journals. The collection consists of over 2000 titles, including books, videos, magazines, articles, abstracts, newsletters, and professional journals. The collection consists of over 2000 titles, including books, videos, magazines, enticles, abstracts, newsletters, and professional journals. The collection consists of over 2000 titles, including books, videos, magazines, enticles, abstracts, newsletters, and professional journ	Healing Our Spirit BC Aboriginal HIV/AIDS Society Suite 100 - 2425 Quebec St. Vancouver, BC,V5T4L6 <u>Tel:</u> (604) 879-8884 <u>Toll Free:</u> 1 (866) 745-8884 <u>Fax:</u> (604) 879-9926 <u>E-mail:</u> info@healingourspirit.org <u>Website:</u> http://www.healingou rspirit.org/

Community-based research project information. Sample of completed projects or in process (see website for more details or
 contact Healing Our Spirit): "Giving Voice to Wellness" is a project designed to provide resources and support for caregivers and Front Line Workers within the Aboriginal HIV/AIDS field. Anticipated end date is April 23, 2004. The Economic Costs, Resource Impacts and Access to Care for Aboriginal Persons Living with HIV/AIDS in Rural and/or on Reserve Locations in British Columbia. Community-based Aboriginal HIV/AIDS Research Planning Resource 2002. This kit contains resource sheets that will assist you in initiating community based HIV/AIDS research in Aboriginal communities. The resource sheets are primarily for Aboriginal communities interested in initiating HIV/AIDS research. However, the issues and concepts are generally applicable for other types of health and social research in Aboriginal communities. An Overview of Models for Community- based Aboriginal HIV/AIDS Research 2002. This paper was written to provide a general overview of models for Aboriginal HIV/AIDS community- based research. This is new and expanding area that is gaining more visibility in Aboriginal HIV/AIDS community based research. This is a new and expanding area that is gaining more visibility in Aboriginal people working the area of health and research. This introduction to models currently being utilized is intended for anyone with an interest in this emerging area – students, health researches, Aboriginal communities and organizations.

<u>Organization</u>	Resources	<u>Contact</u>
Information Centre on Aboriginal Health	Information Centre on Aboriginal Health is a service provided by the National Aboriginal Health Organization. ICAH is a database of information on bibliographic and Web-based resources, programs and services, health careers, and scholarships and bursaries.	Information Centre on Aboriginal Health (ICAH) 56 Sparks Street, Suite 400 Ottawa, ON, K1P 5A9 <u>Fax</u> : (613) 237-8707 <u>E-mail</u> : icah@naho.ca <u>Website</u> : http://www.icah.ca
Publication Resource Centre, First Nations and Inuit Health Branch	 Resources available to order include: HIV/AIDS [video]: Presentation from the Aboriginal Nurses Association's First National Teaching Conference "Keeping Our Children Safe". 1997. Healing Our Nations: Proceedings of the 4th Canadian Aboriginal Conference on HIV/AIDS and related issues. November, 1996. Indigenous Traditional Medicine and HIV/AIDS: A Literature Review: An examination of the historical beliefs of the First Nations, their approach to healing and how this might be used to develop culturally relevant HIV/AIDS training and education. August, 1996. First Nations HIV/TB Training Kit: Designed to address ways in which community health educators can assist in the prevention, care and treatment of HIV/TB and Dual Infection within First Nations communities. April, 1997. English/French. Coping With HIV/AIDS in Aboriginal Communities: This resource manual was developed by NIICHRO to provide an outline for conducting AIDS 101 workshops. March 1998. Research on HIV/AIDS in Aboriginal People - A Background Paper: HIV/AIDS burden of illness among Aboriginal peoples in Canada; determinants and risk factors; interventions; and research methods and ethics. Aboriginal people throughout Canada provided 	Publication Resource Centre First Nations and Inuit Health Branch 20th Floor, Jeanne Mance Bldg. Tunney's Pasture, Postal Locator 1920A Ottawa, ON, K1A 0L3 <u>Fax</u> : (613) 954-8107

<u>Organization</u>	Resources	<u>Contact</u>
	 feedback on the content of this paper. English/French. 11th Annual International Two Spirit Gathering: This report is about a gathering of Aboriginal People held at the Dr. Jessie Saulteaux Resource Centre. This is a project sponsored by the Manitoba Aboriginal AIDS Task Force. December, 1998. Aboriginal Peoples: Community Action Resources for Inuit, Métis and First Nations (1998): Tool kit includes information on: needs assessment, planning, finding resources, making it happen, evaluation. 	
Vancouver Native Health Society	 The mission of the Vancouver Native Health Society is to improve and promote the physical, mental, emotional and spiritual health of individuals, focusing on the Aboriginal community residing in Greater Vancouver. Resources include: <i>"Positive Outlook"</i> HIV/AIDS Program: The Positive Outlook Program model encompasses an approach that addresses the physical, spiritual/traditional, mental and emotional needs of HIV/AIDS persons. More information available at: http://www.vnhs.net/programs/positive.htm 	Vancouver Native Health Society 449 East Hasting St. Vancouver, BC V6A 1P5 <u>Tel</u> : (604) 254-9949 <u>Fax</u> : (604) 254-9948 <u>E-mail</u> : vnhs@shawbiz.ca <u>Positive Outlook Tel</u> : (604) 254-9937
Aboriginal Youth Network	Aboriginal Youth Network is a virtual network that runs across Canada (and beyond) connecting all Aboriginal youth. They are operated totally for and by Aboriginal youth. The job of the AYN staff is to get the word out about health, education and employment opportunities for Aboriginal youth, as well as provide the latest news and events happening across our country. AYN Health Centre presents information on various subjects such as addictions, abuse, body talk, pregnancy, wellness and solvent abuse.	Mailing address: Aboriginal Youth Network Box 34007 Kingsway Mall PO Edmonton, AB T5G 3G4 Office Location & Courier Address: Nechi Institute Aboriginal Youth Network #1 Poundmaker Rd. St. Albert, AB, T8N 1M9 <u>Tel</u> : (780) 459-1884

<u>Organization</u>	Resources	<u>Contact</u>
Canadian Aboriginal AIDS Network	The Canadian Aboriginal AIDS Network Inc. (CAAN) is a non-profit coalition of individuals and organizations which provides leadership, support,	Toll Free:1 (800) 459-1884Fax: (780) 458-1883E-mail: see websiteWebsite:http://www.ayn.ca/health/Canadian AboriginalAIDS Network602-251 Bank St.
	 and advocacy for Aboriginal people living with and affected by HIV/AIDS, regardless of where they reside. Resources available include: fact sheets, newsletters, web links, and a searchable on-line library (http://www.linkup-connexion.ca/), including: "Joining the Circle: Aboriginal Harm Reduction, Phase II" project deals specifically with the issue of Harm Reduction programs for injection drug users (IDU) in the Aboriginal community. Phase II of "Joining the Circle" gathered information on current harm reduction programs accessed by Aboriginal IDU across the country. The information gathered in the "Joining the Circle: Phase II" manual provides a step-by-step approach to setting up these services in both urban and rural Aboriginal communities. The manual also provides a list of Aboriginal HIV/AIDS Service Organizations, a list of Needle Exchange programs, samples of Harm Reduction policies, and a list of possible funding sources to set up programs and services. http://www.caan.ca/english/circle.htm Aboriginal HIV/AIDS Yearbook 2003-2004: Each entry in the HIV/AIDS Yearbook summarizes basic information about the highlighted project, including target populations, project 	Ottawa, ON, K2P 1X3 <u>Tel</u> : (613) 567-1817 <u>Fax</u> : (613) 567-4652 <u>Toll Free</u> : 1 (888) 285-2226 <u>E-mail</u> : info@caan.ca <u>Website</u> : http://www.caan.ca/
	 activities, coordination contact information and, where applicable, project logos and art work. http://www.caan.ca/english/grfx/resources/pu blications/Yearbook.pdf Experience and HIV-related Stigma (One Aboriginal Person's Perspective): Implications for Nursing Practice. Jackson, Randy. May 12, 	

<u>Organization</u>	Resources	<u>Contact</u>
	2002 Aboriging Persons Living with LIV/(AIDS	
	2003. Aboriginal Persons Living with HIV/AIDS Coordination Program. Ottawa: CAAN.	
	 Foundations of a Good Practices Approach for Aboriginal Organizations in Canada: Integration of STI Prevention Education with HIV/AIDS and Addictions Programs (2004). http://www.caan.ca/english/grfx/resources/pu blications/CAAN_BPM_eng.pdf 	
	 Community Based HIV/AIDS Research Environmental Scan: The purpose of the Community Based HIV/AIDS Research Environmental Scan is to assess the research skill levels of CAAN member organizations and their willingness to conduct their own HIV/AIDS research. http://www.caan.ca/english/grfx/resources/pu blications/CAAN%27s_Environment.pdf 	
	 Strengthening Ties – Strengthening Communities: An Aboriginal Strategy on HIV/AIDS in Canada (2003): This strategy will offer a vision for Inuit, Métis and First Nations (status or non-status, on or off-reserve) people to respond to HIV/AIDS. It will outline and describe key issues and nine strategic areas which can be taken to ensure that a range of programs and services are in place to meet the needs of Aboriginal People Living with and affected by HIV/AIDS. http://www.caan.ca/english/grfx/resources/pu blications/strengthening_ties.pdf 	
	 HIV/AIDS Prevention: Messages for Canadian Aboriginal Youth (2004): This is the final report of a selected literature review and survey on HIV prevention messages for Canadian Aboriginal youth. The information in this report will help Aboriginal communities, Aboriginal youth and youth workers strengthen an existing prevention message, design a new one, or adapt an existing message for use in their own communities. Surveys were collected from 35 Aboriginal and non-Aboriginal organizations and AIDS service organizations from across Canada. Participants provided information on the range of prevention messages that are currently being offered to First Nations, Métis 	

<u>Organization</u>	Resources	<u>Contact</u>
	 and Inuit youth; on the groups most in need of prevention messages; and their recommendations on how best to design and deliver HIV prevention messages for Canadian Aboriginal youth. http://www.caan.ca/english/grfx/resources/publications/youth_prevent.pdf Summer Training Awards (2004): The Summer Training Awards, now finishing its third year of operation, continues to involve undergraduate Aboriginal students, Aboriginal host organizations and academic advisors in an innovative capacity-building approach to Aboriginal HIV/AIDS Community-Based Research. The purpose of this report is to provide a short description of the Summer Training Awards, provide a written summary and justification for each of the Summer Training Award projects that were selected to participate, and present the findings of an evaluation of Summer Training Awards_eng.pdf Sample of Current Projects: http://www.caan.ca/english/projects.htm: 	
	 Strengthening Aboriginal Community Based HIV Research Capacity Diagnosis and Care of HIV Infection in Canada Aboriginal Youth Aboriginal HIV/AIDS Anti-Discrimination (AHAAD) Aboriginal Strategy on HIV/AIDS 	
British Columbia Centre for Excellence in HIV/AIDS	BC Centre for Excellence in HIV/AIDS provides education to health care providers, conducts natural history and observational studies, develops innovative laboratory tests and carries out clinical trials. Resources include: live web broadcasts, clinical and laboratory resources, clinical and population health research. Some projects include:	Providence Health Care BC Centre for Excellence in HIV/AIDS Saint Paul's Hospital 608 – 1081 Burrard St. Vancouver, BC V6Z 1Y6
	CEDAR – Understanding HIV vulnerability in young Aboriginal drug users (A multi-disciplinary northern-southern collaboration). The Centre is	<u>Website</u> : http://www.cfenet.ubc.ca

<u>Organization</u>	<u>Resources</u>	<u>Contact</u>
	currently undertaking studies focusing on young Aboriginal drug users to determine why these people are at particularly high risk of HIV infection and to develop strategies that reduce this risk.	
Pauktuutit Inuit Women's Association	Pauktuutit is the national non-profit association representing all Inuit women in Canada. Its mandate is to foster a greater awareness of the needs of Inuit women, and to encourage their participation in community, regional and national concerns in relation to social, cultural and economic development. Their website has many culturally-relevant HIV/AIDS information documents of concern to Inuit (documents also available in Labrador orthography and Inuktitut syllabics).	Pauktuutit Inuit Women's Association 131 Bank Street, 3rd Floor Ottawa, ON, K1P 5N7 <u>Tel</u> : (613) 238-3977 <u>Toll Free</u> : 1 (800) 667-0749 <u>Fax</u> : (613) 238-1787 <u>E-mail</u> : info@pauktuutit.ca <u>Website</u> : http://www.pauktuutit .ca/publications_e.as p (scroll down to HIV/AIDS documents)
National Indian and Inuit Community Health Representatives Organization (NIICHRO)	 NIICHRO is a national not-for-profit non- governmental organization representing Aboriginal Community Health Representatives. Resources include: HIV/AIDS Antiretroviral Therapy Information Booklet (for people living with HIV) http://www.niichro.com/AIDSbook.html. This plain-language booklet provides basic information about HIV/AIDS and explains how First Nations and Inuit people can get special access to treatment. Free. 	NIICHRO P.O. Box 1019 1 Roy Montour Lane Kahnawake, QC JOL 1BO <u>Tel</u> : (450) 632-0892 <u>Fax</u> : (450) 632-2111 <u>E-mail</u> : niichro@niichro.com <u>Website</u> : http://www.niichro.co m/2004/
Aboriginal Nurses Association of Canada	A.N.A.C. is a non-governmental, non-profit organization that was established out of the recognition that Aboriginal people's health needs can best be met and understood by health professionals of a similar cultural background. An affiliate group of the Canadian Nurses Association, it is the only Aboriginal professional nursing organization in Canada. Resources include:	ANAC 56 Sparks St., Suite 502 Ottawa, ON, K1P 5A9 <u>Tel</u> : (613) 724-4677 <u>Fax</u> : (613) 724-4718

<u>Organization</u>	Resources	<u>Contact</u>
	Finding Our Way: A Sexual and Reproductive Health Source Book for Aboriginal Communities. (2002). http://www.anac.on.ca/FindingOurWay.html	
Department of Health and Social Services, Government of the NWT, Yellowknife	Resource: Free education booklet for Elders: Marmalade or Jam A Recipe for Understanding AIDS. (1995).	NWT Health and Social Services Lona Hegeman, Health Promotion Specialist Box 1320 Yellowknife, NT X1A 2L9 <u>Tel</u> : (867) 873-7051 <u>E-mail</u> : Iona_hegeman@gov. nt.ca
B.C. Centre for Disease Control	 Resources include: Chee Mamuk (STD's/AIDS Education: Aboriginal Program). Brochures, pamphlets, and other educational materials available on- line at (to order, refer to contact info): http://www.bccdc.org/content.php?item=96# 2 and http://www.bccdc.org/content.php?item=96. Also available at the B.C. Centre for Disease Control: Healing House: hepatitis C Information Kits - a teaching toolkit for Aboriginal communities: http://www.bccdc.org/content.php?item=39 Chako, Coming of Age Model Project 2002 http://www.bccdc.org/content.php?item=96#3 Youth Strengthening the Circle Game 2003 http://www.bccdc.org/content.php?item=96#3 Aboriginal Youth Videos: http://www.bccdc.org/content.php?item=96#6 * Youth Strengthening the Circle * Chako, Coming of Age Aboriginal Youth Videos: http://www.bccdc.org/content.php?item=96#6 * Youth Strengthening the Circle * Chako, Coming of Age Aboriginal Youth Videos: http://www.bccdc.org/content.php?item=96#6 * Youth Strengthening the Circle * Chako, Coming of Age * Chako, Coming of Age * Chako, Coming of Age 	Chee Mamuk, Aboriginal Program STD/AIDS Control BC Centre for Disease Control 655 12th Ave. W Vancouver BC V5Z 4R4 <u>Tel</u> : 604-660-1673 <u>Fax</u> : 604-775-0808 <u>E-mail</u> : cheemamuk@bccdc.ca

<u>Organization</u>	Resources	<u>Contact</u>
Canadian AIDS Clearing House	Ratnam, Sam et al. (2000). Community Perspectives on HIV Research and Programs in Aboriginal Communities of Coastal Labrador: A Research Needs Assessment and Feasibility Study. Ottawa: Canadian AIDS Clearing House.	Canadian AIDS Clearing House 400-1565 Carling Avenue Ottawa, ON, K1Z 8R1 <u>Tel</u> : (613) 725-3434 <u>Toll Free</u> : 1 (877) 999-7740 <u>Fax</u> : (613) 725-1205 <u>E-mail</u> : aidssida@cpha.ca <u>Website</u> : http://www.aidssida.c pha.ca
ACADRE Centres (CIHR)	pha.caThe CIHR-Institute of Aboriginal Peoples' Health (IAPH) established Aboriginal Capacity and Developmental Research Environments (ACADRE) centres to develop a network of supportive research environments across Canada that facilitates the development of aboriginal capacity in health research. Supportive research environments in this field require a unique blend of scientific leadership and community partnerships. The ACADRE's are as follows:• Alberta ACADRE Network, Edmonton Their research has evolved in a responsive manner through collaborative community partnerships and research requests. Three research themes have evolved from community requests that will guide and enhance the work of the Alberta Network over the next three years: traditional knowledge and ethics; northern community environmental health; and community access to health services.Tel: (780) 492-1827 Fax: (780) 492-1827 Fax: (780) 492-1153 E-mail: acadre@ualberta.ca Website: http://www.acadre.u alberta.ca/	
	• Anisnawbe Kekendazone, Ottawa Initial health research priorities at the Ottawa ACADRE facility are: perinatal health; youth at risk and resilience; and knowledge translation i.e. communicating health research knowledge to aboriginal communities in a way that is readily understood.	<u>Tel</u> : (613) 241-2081 <u>Fax</u> : (613) 241 5399 <u>E-mail</u> : cietinfo@ciet.org <u>Website</u> : http://www.ciet.org/w ww/image/Canada/L oPHID/LoPHID- indig.html

<u>Organization</u>	<u>Resources</u>	<u>Contact</u>
	 Atlantic Aboriginal Health Research Program, Halifax The program fosters community-generated indigenous research in three broad areas: prevention research, such as reducing smoking and alcohol consumption; mental health and addictions research; and enhancing the understanding of health determinants, such as, housing conditions, income, and cultural and spiritual factors. 	<u>Tel</u> : 1 (866) 867-9616 <u>Fax:</u> (902) 494-1653 <u>E-mail</u> : aahrp@dal.ca <u>Website</u> : http://aahrp.socialwor k.dal.ca/
	British Columbia ACADRE, Vancouver The Centre is concentrating on four research theme areas: developing health assessments that are ethical and respect community values; ensuring aboriginal health researchers act responsibly; holistic wellness in mental health and addictions; and community motivated research themes.	Tel: 1 (866) 880-5464 Fax: (604) 822-2495 E-mail: dmhughes@interchan ge.ubc.ca Website: http://www.health- disciplines.ubc.ca/iah/ acadre/index.php
	 Centre for Aboriginal Health Research, Winnipeg Primary research themes addressed by this ACADRE include: population health; health services; child health and development; and ethical issues in aboriginal health research. 	<u>Tel</u> : (204) 789-3250 <u>Fax</u> : (204) 975-7783 <u>E-mail</u> : rogersde@ms.umanito ba.ca <u>Website</u> : http://www.umanitob a.ca/centres/cahr/
	 Indigenous Health Research Development Program, U of Toronto, McMaster 	<u>Tel</u> : (519) 445-0023 ext. 236 <u>Fax</u> : (519) 445-4416 <u>E-mail</u> : vobrien@mcmaster.ca <u>Website</u> : http://www.ihrdp.ca/

<u>Organization</u>	Resources	<u>Contact</u>
	 Indigenous Peoples' Health Research Centre, Regina Research at the Regina location takes a holistic approach. It focuses on the following four areas: chronic diseases, nutrition and lifestyle; indigenous/traditional healing methods; health delivery and control, (such as ethics, community development and governance); and environmental health. 	Tel: (306) 337-2461 Fax: 585-5694 E-mail: ekinequon@firstnations university.ca Website: http://www.iphrc.ca
	 Nasivvik Centre for Inuit Health and Changing Environments, Quebec City The Centre provides training and education opportunities and is conducting multi-disciplinary research on environmental change and influences on Inuit health, environmental public health surveillance and monitoring and Inuit scientific knowledge in environmental health research. 	<u>Tel</u> : (418) 650-5115 ext. 5248 <u>Fax</u> : (418) 654-3132 <u>E-mail</u> : susie.bernier@crchul.ul aval.ca <u>Website</u> : http://www.nasivvik.ul aval.ca

Request for Proposals from the Non-Reserve First Nations, Inuit and Métis Communities HIV/AIDS Project Fund under the Canadian Strategy on HIV/AIDS (2003)

The Non-Reserve First Nations, Inuit and Métis Communities HIV/AIDS Project Fund (the Non-Reserve Fund) is an important component of the Canadian Strategy on HIV/AIDS (CSHA). The Non-Reserve Fund supports Aboriginal community action in response to the Canadian HIV/AIDS epidemic by funding projects undertaken by Aboriginal voluntary, non-profit, non-governmental organizations and community-based organizations that have identified the need to address HIV/AIDS issues in their communities. Under the CSHA, \$1.2 million has been allocated to the Non-Reserve Fund per fiscal year. This project funding is administered and monitored through the HIV/AIDS Policy, Coordination and Programs Division of Health Canada. All projects are to end on or before March 31, 2006.

Organization/	Project Description	Contact
Project Title		
	British Columbia Region	
Lillooet Friendship Centre Society Open Arms: Communities Accepting HIV/AIDS	Through community partnerships, attendance at regional and local health planning meetings, the provision of annual health fairs, World AIDS Day and HIV Awareness Week events, and the provision of HIV/AIDS training sessions, the Lillooet Friendship Centre Society will increase community HIV/AIDS partnership activities and increase the knowledge of HIV/AIDS among health and social service providers, Aboriginal youth and community members in the Lillooet area.	Lillooet Friendship Centre 357 Main Street, Box 2170 Lillooet, BC, VOK 1V0 <u>Tel</u> : (250) 256-4146 <u>Fax</u> : (250) 256-7928 <u>E-mail</u> : Ifcs@lillonet.ca <u>Website</u> : http://www.bcaafc.com/ centres/lillooet/
Okanagan Aboriginal AIDS Society HIV & Harm Reduction: Traditional Learning For The Urban Aboriginal Community	Through the use of training and facilitated inter-generational training workshops, the Okanagan Aboriginal AIDS Society (OAAS) will increase the knowledge of participating Elders of the Okanagan region in relation to HIV/AIDS and increase their capacity to facilitate harm reduction focused inter-generational training workshops to increase the knowledge of Aboriginal youth in the Okanagan region on issues of HIV/AIDS and harm reduction.	Okanagan Aboriginal AIDS Society 101 - 266 Lawrence Avenue Kelowna BC. V1Y 6L3 <u>Tel</u> : (250) 862-2481 <u>Fax</u> : (250) 862-8662 <u>Toll Free</u> : 1-800-616-2437 <u>E-mail</u> : info@oaas.ca <u>Website</u> : http://www.oaas.ca/

Organization/	Project Description	<u>Contact</u>
Project Title Positive Living North: No kheyoh t'sih'en t'sehena Society The Fire Pit: Sharing Responsibility for HIV	The goal of the project is to increase awareness and knowledge around HIV/AIDS within the community and develop the capacity of health and social service organizations to respond to the HIV epidemic. Through the creation and provision of an initial needs assessment, a training curriculum will be developed that will be utilized to facilitate one or more training sessions to front-line staff in at least five Prince George and area health and social service organizations per year. In addition, the project will provide coordination of Prince George organizations around HIV/AIDS events such as World AIDS Day, AIDS Awareness Week and AIDS Walk Canada.	Positive Living North: No kheyoh t'sih'en t'sehena Society 1 - 1563 2nd Avenue Prince George, BC V2L 3B8 <u>Tel</u> : (250) 562-1172 <u>Fax</u> : (250) 562-3317 <u>E-mail</u> : info@positivelivingnorth.ca <u>Website</u> : http://positivelivingnorth. ca/
Wachiay Friendship Centre Aboriginal HIV/AIDS Education and Prevention Program	Through the provision of HIV/AIDS and HCV awareness workshops for the general population and for Aboriginal People Living With HIV/AIDS and/or HCV (APHAs) and conducting an Aboriginal Youth Health Fair, Wachiay Friendship Centre will increase the knowledge of the general Aboriginal population and of APHAs in the Comox Valley on the transmission of HIV/AIDS and HCV and on how to care for yourself if living with the diseases.	Unsure: Wachiay Friendship Centre P.O. Box 3204 Courtenay, BC, V9N 5N4 <u>Tel</u> : (250) 338-7793 <u>Fax</u> (250) 338-7287 <u>E-mail</u> : Wachiay1@telus.net <u>Website</u> : http://valleylinks.net/com munityservices/aboriginal /wachiay/
Western Aboriginal Harm Reduction Society Building The Capacity of Aboriginal People in Vancouver's Downtown East Side Most at Risk of Catching and/or Spreading HIV	Through the provision of HIV/AIDS prevention, peer support and capacity building workshops, the Western Aboriginal Harm Reduction Society (WAHRS) will increase the HIV/HCV transmission knowledge amongst Aboriginal people who use illicit drugs in the Vancouver Downtown Eastside (DTES). WAHRS will also increase condom usage, increase the peer-support capacity, and increase knowledge about access to treatment, housing, income supplements and food for Aboriginal people living with HIV/AIDS in the Vancouver DTES. As well, WAHRS will provide policy input to policy makers and service providers locally, provincially and nationally on issues of HIV, HCV, harm reduction and Aboriginal people.	Western Aboriginal Harm Reduction Society c/o Vancouver Area Network of Drug Users (VANDU) 2d Floor - 50 East Hastings Street Vancouver, BC, V6A 1N1 <u>Tel</u> : (604) 683-8595 <u>E-mail</u> : livingstonechris@yahoo.c om or vandu@vandu.org <u>Website</u> : http://www.vandu.org/v wahrsgroup.html

Organization/ Project Title	Project Description	<u>Contact</u>
Alberta Region		
Sik Ooh Kotoki Friendship Society Niitakkaamotsiiyio' pi	After an initial needs assessment, HIV/AIDS training will be provided and HIV/AIDS resources created for health and social service agencies with Aboriginal clientele in the Lethbridge area. The objectives of this project are to increase the knowledge of the factors involved in HIV/AIDS (and HepC and other STIs, where appropriate) transmission among the off-reserve Aboriginal population in the Lethbridge area and to increase the HIV/AIDS partnership, collaboration, and resource sharing activities among health and social service providers to the Aboriginal population in the Lethbridge Area.	Sik Ooh Kotoki Friendship Society 1709 2 Avenue South Lethbridge, AB, T1J OE8 <u>Tel</u> : (403) 328-2414 <u>Fax</u> : (403) 327-0087 <u>E-mail</u> : sikooh@telusplanet.net <u>Website</u> : http://209.115.241.19/lcn/ Webpages/Sik- 33/index.aspx
NECHI Training, Research and Health Promotions Institute Two Spirits on Training Development Project	Through the use of a needs assessment and the creation and provision of a Two Spirit and HIV/AIDS training curriculum, NECHI will increase the knowledge of Edmonton addictions, HIV/AIDS and wellness workers in relation to working with Two Spirit people at risk of HIV/AIDS in Edmonton, and improve the delivery of community service/support programs to the Two Spirit population in Edmonton.	NECHI Training, Research and Health Promotions Institute PO Box 34007 Kingsway Mall Edmonton, AB, T5G 3G4 <u>Tel</u> : (780) 459-1884 <u>Fax</u> : (780) 459-1883 <u>E-mail</u> : click "Contact" link on website <u>Website</u> : http://www.nechi.com/
Kimamow Atoskanow Foundation (KAF) Adapting with HIV	Through the "Adapting with HIV" project, Aboriginal people living with and affected by HIV/AIDS (APHA) in Alberta will increase their knowledge of care and support options through HIV/AIDS health and wellness workshops. Also, the project will increase the knowledge and capacity of health and social service providers in at least six Alberta communities to appropriately respond to APHA needs.	Kimamow Atoskanow Foundation (KAF) RR1 Site 1 Box 133 Onoway, AB, TOE 1V0 <u>Tel</u> : (780) 913-9036 <u>Fax</u> : (780) 967-4868 <u>E-mail</u> : info@treeofcreation.ca <u>Website</u> : http://www.treeofcreatio n.ca/
Métis Nation of Alberta Association (MNAA)	Through the "Increase Your Knowledge, Reduce Your risk: An HIV/AIDS Education & Awareness workshop for the Métis Nation of Alberta (MNA)" project, the MNA will provide culturally sensitive HIV/AIDS training sessions to	Métis Nation of Alberta Association 100-17738 Kingsway Ave Edmonton, AB, T5G 0X5

Organization/	Project Description	Contact
Project Title	<u>Indect beschpholi</u>	
Increase Your Knowledge, Reduce Your Risk: An HIV/AIDS Education & Awareness Workshop for the Métis Nation of Alberta Provincial Council	MNA Provincial Council members to increase their knowledge of HIV/AIDS and its impact on Métis communities and to identify how they can address HIV/AIDS in their own communities.	<u>Tel</u> : (780) 455-2200 <u>Toll Free Alberta</u> : 1 (800) 252-7553 <u>Fax</u> (780) 452-8946 <u>Website</u> : http://www.metis.org
	Prairies Region	<u> </u>
Building A Nation Family Healing Centre Recovering the Two Spirit Traditions	Through the development and implementation of training presentations on HIV/AIDS and Two Spirit Culture to health and social service providers in Saskatoon and through the creation of community resources, Building A Nation Family Healing Centre will increase the knowledge of the risk factors involved in HIV infection and of the resources available among the Two Spirit population in Saskatoon and increase the knowledge of HIV/AIDS and Two Spirit culture among health and social service providers and family members in Saskatoon.	Building A Nation Family Healing Centre 123 20 th St. W Saskatoon, SK, S7M 0W7 <u>Tel</u> : (306) 651-2000 <u>Fax</u> : (306) 651-2001
Brandon Friendship Centre Prison Outreach Project	Through training, conference presentations and the creation of resource materials, the Brandon Friendship Centre will increase the knowledge of the factors involved in HIV/AIDS transmission among 50% of the institution population in each of the nine provincial correctional institutions and increase the knowledge of other community-based Aboriginal and non-Aboriginal organizations of programmatic approaches in working with incarcerated Aboriginal populations on issues of HIV/AIDS transmission and prevention.	Brandon Friendship Centre 836 Lorne Ave. Brandon, Manitoba R7A 0T8 <u>Tel</u> : (204) 727-1407 <u>Fax</u> : (204) 726-0902 <u>Website</u> : http://www.mac.mb.ca/ brandon/
Battlefords Family Health Centre Inc. Mobilizing Community Supports for the Prevention of HIV/AIDS	Through an initial needs assessment, the creation of training resources based on the identified needs and the provision of training sessions in various youth venues and to service providers in North Battleford, the Battlefords Family Health Centre (BFHC) will increase the HIV/AIDS knowledge of at-risk Aboriginal youth in North Battleford and their health, social service and education providers. In addition,	Battlefords Family Health Centre 1192 101st Street North Battleford, SK S9A 0Z6 <u>Tel</u> : (306) 937-6840 <u>Fax</u> : (306) 446-6546

Organization/ Project Title	Project Description	<u>Contact</u>
	the project will increase the community awareness and use of the BFHC Sexual Health Team as a resource for sexual health services in North Battleford.	
Northern AIDS Initiative Inc. APATH - Aboriginal People, HIV/AIDS and Traditional Healing	Through the creation and training of a Project Advisory Committee of traditional healers, Elders, APHAs and other community stakeholders, and through regional discussions on HIV/AIDS and traditional healing, the Northern AIDS Initiative will establish, publish and disseminate culturally appropriate protocols and guidelines for traditional healing in relation to HIV/AIDS. These will be used to increase the knowledge and use of traditional healing practices in relation to HIV/AIDS among APHAs and traditional healers in Manitoba.	No contact information available.
Regina Friendship Centre Corporation Aboriginal HIV/AIDS Program Saskatchewan	Through the creation and provision of train- the-trainer workshops and through on-going support and cooperation with the Aboriginal two-spirit group, The Vision Keepers, the Regina Friendship Centre will increase the knowledge of HIV/AIDS (and HCV and other STIs, where appropriate) among the 17 member Saskatchewan friendship centres' staff, at-risk youth and two-spirit people in 17 urban centres in Saskatchewan and will increase the capacity of the Saskatchewan two-spirit community to deal with HIV/AIDS.	Regina Friendship Centre 3100 Dewdney Ave Regina, SK S4T OY7 <u>Tel</u> : (306) 525-5459 <u>Fax</u> : (306) 525-3005 <u>Website</u> : http://www.afcs.com/reg ina/
Ile à la Crosse Friendship Centre Inc. Ile à la Crosse HIV/AIDS Project	Through an HIV/AIDS needs assessment of IIe à la Crosse Friendship Centre (ICFC) programs and clientele, the acquisition of HIV/AIDS resources, training sessions for Aboriginal youth, ICFC staff, clientele the general Aboriginal community, the ICFC will increase the integration and use of HIV/AIDS information and resources in other ICFC program areas, increase the knowledge of the factors involved in HIV/AIDS transmission among ICFC clientele across all program areas and increase the knowledge of the factors involved in HIV/AIDS transmission among 400 youth and members of the general Aboriginal public in the IIe à la Crosse area.	ILXFC Box 160 Lajeunesse Ave. Ile à la Crosse, SK SOM 1C0 <u>Tel</u> : (306) 833-2313 <u>Fax</u> : (306) 833-2216 <u>E-mail</u> : ilx.friendctr.inc@sk.sympa tico.ca

Organization/	Project Description	<u>Contact</u>	
<u>Project Title</u>	Ontario Region		
2 Spirited Deeple of			
2 Spirited People of the 1st Nations HIV/AIDS Prevention Initiative for Two Spirit Men	Through the collection of information on social marketing campaigns directed at Two Spirit men in Ontario, the use of focus groups to test the efficacy of existing social marketing campaigns and through the final creation and distribution of a report outlining successful social marketing strategies for Two Spirit men, the 2 Spirited People of the First Nations will increase the knowledge of effective HIV/AIDS prevention social marketing campaigns directed at Two Spirit Men in Ontario among health and social service providers for Two Spirit Men in Canada.	2 Spirited People of the 1st Nations 43 Elm Street, 2nd Floor Toronto, ON, M5G 1H1 <u>Tel</u> : (416) 944-9300 <u>Fax</u> : (416) 944-8381 <u>Website</u> : http://www.2spirits.com/	
Wabano Centre for Aboriginal Health Inc. Eagle on the Moon: Re-Shaping the Future of Aboriginal HIV Health Promotion	Through research, development and provision of HIV/AIDS theatre performances, the Wabano Centre will create a cultural and performance-art-based HIV/AIDS health promotion model which is appropriate for urban Inuit, Métis and First Nations audiences. This project will raise the HIV/AIDS awareness of 20-30 performers/educators and 2,500 performance attendees, annually.	Wabano Centre for Aboriginal Health 299 Montreal Road Ottawa, ON, K1L 6B8 <u>Tel</u> : (613) 748-0657 <u>Fax</u> : (613) 748-9364 <u>E-mail</u> : info@wabano.com <u>Website</u> : http://www.wabano.co m/	
Barrie Area Native Advisory Circle HIV/AIDS Awareness Through Sharing & Vision	Through the development and dissemination of an HIV/AIDS training DVD, theatre troupe performances and training activities on policy development, the Barrie Area Native Advisory Circle will increase the knowledge of 900 members (500 of unspecified age and 400 youth) of the Aboriginal communities of Simcoe County and Northern York Region of the factors related to HIV/AIDS transmission and increase the capacity of 7 urban Aboriginal organizations to address HIV/AIDS stigma and discrimination in the Simcoe County and Northern York Region.	Barrie Area Native Advisory Circle 431 Huronia Road, Unit 10 Barrier, ON, L4N 9B3 Tel: (705) 734-1818 <u>Fax</u> : (705) 734-1812 <u>E-mail</u> : banac@banac.on.ca <u>Website</u> : http://www.banac.on.ca	
Québec Region			
Centre d'Amitié Autochtone de Val-d'Or	Through "Projet de lutte au VIH/sida chez les Autochtones de la communauté Autochtone de Val-d'Or," the Native Friendship Centre of Val-d'Or will use support groups, sharing circles	Centre d'Amitié Autochtone de Val-d'Or 1272 Rue 7E Val-D'Or, QC, J9P 6W6	

Organization/ Project Title	Project Description	<u>Contact</u>
Projet de lutte au VIH/Sida chez les Autochtones de la communauté autochtone de Val-d'Or	and HIV/AIDS resources and material to increase Aboriginal people's awareness of HIV/AIDS transmission, local resources and services available in the Val-d'Or area.	<u>Tel</u> : (819) 825-6857 <u>Fax</u> : (819) 825-7515
Native Friendship Centre of Montreal Inc. Fostering Peer Support and Peer Leadership Amongst HIV Positive Aboriginal Peoples in Montréal	Through the "Fostering Peer Support and Peer Leadership Amongst HIV Positive Aboriginal Peoples in Montreal" project, the Native Friendship Centre of Montreal will increase the HIV/AIDS transmission knowledge, self-care and peer-support skills amongst Aboriginal People Living With HIV/AIDS (APHAs) in Montréal. In addition, the project will increase the HIV/AIDS knowledge of Montreal community-based health centres to respond to APHA needs.	Native Friendship Centre of Montreal 2001 St. Laurent Boulevard Montreal, QC, H2X 2T3 <u>Tel</u> : (514) 499-1854 <u>Fax</u> : (514) 499-9436 <u>E-mail</u> : info@nfcm.org <u>Website</u> : http://www.nfcm.org/
	Atlantic Region	
Healing Our Nations Completing the Circle: Connecting with Our Members and Communities	Healing Our Nations (HON) will continue their ongoing commitment to connect with community and specifically APHA members in a meaningful way. Through new HIV/AIDS resources and the provision of APHA capacity building training, HON will increase the capacity for a unified response to HIV/AIDS and increase the involvement of Aboriginal people living with HIV/AIDS in HIV prevention initiatives. In addition, Healing Our Nations will host the Atlantic Aboriginal HIV/AIDS Circle initiative composed of Aboriginal community- based AIDS organizations, Health Canada funders, APHAs and Elders from the Atlantic region. The Circle enhances the capacity of the two lead partner organizations which are HON and the Labrador HIV/AIDS Project at the Labrador Friendship Centre.	Healing Our Nations 45 Alderney Drive, Suite 607 Dartmouth, NS, B2Y 2N6 <u>Tel</u> : (902) 492-4255 <u>Fax</u> : (902) 492-0500 <u>Toll Free</u> : 1 (800) 565-4255 <u>Website</u> : http://www.healingourna tions.ca/
Labrador Friendship Centre HIV/AIDS Labrador Project	The Labrador Friendship Centre (LFC) will provide training sessions for medical staff and workers at the Voisey's Bay Nickel Site, participate in the Atlantic Aboriginal HIV/AIDS Circle and hold HIV/AIDS Fairs for Métis youth on the South Coast and HIV/AIDS awareness training for Inuit populations on the North Coast. Through these activities, the LFC will increase the HIV/AIDS knowledge of health care professionals who service the Inuit	Labrador Friendship Centre HIV/AIDS Labrador Project 49 Grenfell Street P. O. Box 767, Stn. B Happy Valley - Goose Bay, NL, A0P 1E0 <u>Tel</u> : (709) 896-5144

Organization/ Project Title	Project Description	<u>Contact</u>
	communities of Sheshatshiu and Natuashish, increase the HIV/AIDS knowledge of Inuit and Métis Youth, and increase the HIV/AIDS knowledge of staff and workers at the Voisey's Bay Nickel Site.	Fax: (709) 896-8731 <u>E-mail</u> : Hiv-aidslabradorproject@ superweb.ca <u>Website</u> : http://www.labradorfrien dshipcentre.ca/hlp.htm
Mi'kmaq Native Friendship Centre HIV/AIDS Kitpu Youth Project	Through the "HIV/AIDS Kitpu Youth Project," the Mi'kMaq Native Friendship Centre (MNFC) will conduct HIV/AIDS and peer-educator training workshops to increase the knowledge of HIV/AIDS among Aboriginal youth and youth- at-risk who use MNFC programs. In addition, the project will increase the skills and capacity of at least five Aboriginal community-based organizations based in the Halifax area to deliver HIV/AIDS programming to Aboriginal youth.	Mi'kmaq Native Friendship Centre 2158 Gottingen St. Halifax, NS, B3K 3B4 <u>Tel:</u> (902) 420-1576 <u>Fax</u> : (902) 423-6130 <u>E-mail</u> : micmacfriendshipcentre @msn.com <u>Website</u> : http://www.micmaccentr e.ca
	Territories Region	
Pauktuutit Inuit Women's Association Canadian Inuit HIV/AIDS Network	Through the organization of AIDS Walks, Arctic Youth AIDS Fairs and the creation of Inuit- specific treatment information fact sheets and materials, Pauktuutit will continue the efforts of Canadian Inuit HIV/AIDS Network (CIHAN) to address HIV/AIDS issues in order to decrease the infection rates of HIV among Inuit, ensure the continued meaningful participation of Inuit in discussions around the development of HIV/AIDS related programs and policies, and create an environment of understanding for HIV/AIDS prevention that encourages community members to make informed choices.	Pauktuutit Inuit Women's Association 131 Bank Street, 3rd Floor Ottawa, ON, K1P 5N7 <u>Tel:</u> (613) 238-3977 <u>Toll Free</u> : 1 (800) 667-0749 <u>Fax</u> : (613) 238-1787 <u>E-mail</u> : info@pauktuutit.ca <u>Website</u> : http://www.pauktuutit.ca/
Yukon Aboriginal Women's Council Honouring Aboriginal Women of the Yukon: Reducing Vulnerability to HIV	Through the creation of a curriculum to increase HIV/AIDS knowledge and facilitation skills for 14 Aboriginal contact/resource women from 14 different Aboriginal communities in the Yukon, the Yukon Aboriginal Women's Council will plan and conduct a three day training seminar and, following this, the trained women will hold HIV/AIDS awareness raising workshops in their own communities. The expected result of the	Yukon Aboriginal Women's Council 103-307 Jarvis Street Whitehorse, Yukon Y1A 2H3 <u>Tel:</u> (867) 667-6162 <u>Toll Free</u> : 1 (866) 667-6162 <u>Fax</u> : (867) 668-7539 <u>E-mail</u> : yawc@yknet.ca

Organization/ Project Title	Project Description	<u>Contact</u>
	project is an increase of HIV/AIDS knowledge among at-risk women in 14 Yukon communities.	
	National Level	
The Canadian Aboriginal AIDS Society Making It Our Way: Engaging Diverse Aboriginal Participation and Leadership on HIV/AIDS in Canada	Through training and the creation of community mobilization tools, the Canadian Aboriginal AIDS Network will develop and strengthen the current HIV/AIDS advocacy skills of Aboriginal leaders in all regions of Canada while at the same time increasing their knowledge of HIV/AIDS transmission issues. This project will also increase the awareness of Aboriginal HIV/AIDS issues among Aboriginal and non-Aboriginal stakeholders.	Canadian Aboriginal AIDS Network 602-251 Bank St. Ottawa, ON ,K2P 1X3 <u>Tel:</u> (613) 567.1817 <u>Fax</u> : (613) 567.4652 <u>Toll Free</u> : 1 (888) 285-2226 <u>E-mail</u> : info@caan.ca <u>Website</u> : http://www.caan.ca/

GENERAL HIV/AIDS & HEPATITIS C RESOURCES

<u>Organization</u>	Resources	<u>Contact</u>
AIDS Programs South Saskatchewan	 AIDS Programs South Saskatchewan: APSS is a knowledge and care-based community organization that promotes understanding of HIV/AIDS, influencing legislators and policy maker on issues related to HIV/AIDS. APSS provides: Accessible holistic and culturally sensitive services. Programs specific to women. Consultation services to rural, urban, community, and professional groups. Resource development and distribution. The only HIV/AIDS library in the Prairies recognized by the Canadian HIV Resource Centre Network. 	AIDS Programs South Saskatchewan 1504B Albert St. Regina, SK, S4P 2S4 <u>Tel:</u> (306) 924-8420 <u>Toll Free</u> : 1 (888) 210-7622 <u>Website</u> : http://www.aidsresour cesask.ca
Canadian Working Group on HIV and Rehabilitation	CWGHR is a national charitable nonprofit organization that promotes innovation and excellence in rehabilitation in the context of HIV disease. CWGHR develops rehabilitation resources, new knowledge, and awareness in a multi-sector collaboration with partners in the HIV/AIDS sector and with disability groups on issues of common concern. CWGHR also provides funding for projects related to rehabilitation in the context of HIV.	Canadian Working Group on HIV and Rehabilitation 333 Sherbourne Street Toronto, ON, M5A 2S5 <u>Tel:</u> 416-324-4182 <u>Fax</u> : 416-324-4184 <u>Website</u> : http://www.hivandreh ab.ca/
Living Positive Resource Centre Okanagan	Living Positive Resource Centre has delivered support services to persons living with HIV/AIDS in the Okanagan and region since 1992. They offer support, awareness, education and prevention programs for HIV/AIDS throughout the community, and more recently have begun education and support programs to meet the needs of those living with hepatitis C. Resources include:	Living Positive Resource Centre Okanagan #101-266 Lawrence Avenue Kelowna, BC, V1Y 6L3 <u>Tel</u> : (250) 862-2437

<u>Organization</u>	Resources	<u>Contact</u>
	 Survey of Physicians in the Okanagan in regards to the hepatitis C issue (2000-2001): http://www.livingpositive.ca/docs/HCV%20medi cal%20survey.pdf A Time to Remember: a youth peer education video. This drama was written and acted by local youth. To request a copy, contact the Living Positive Resource Centre. 	<u>Fax</u> : (250) 868-8662 <u>BC Toll Free</u> : 1 (800) 616-2437 <u>Website</u> : http://www.livingpositi ve.ca
Canadian HIV/AIDS Information Centre (Canadian Public Health Association)	 The Canadian HIV/AIDS Clearinghouse is the largest information centre on HIV/AIDS in Canada. Their mandate is to provide information on HIV/AIDS prevention, care and support to health professionals, schools, community-based organizations and to a broad audience of individuals and other groups. At the Clearinghouse, we have a specific focus to support Canadian activities in the area of HIV prevention. Resources include: Media and community advertisement/social marketing resources to download: http://www.doyou.cpha.ca/resdown.htm and http://www.doyou.cpha.ca/archive/smc03_e/m ain.htm. <u>E-mail</u>: doyouetvous@cpha.ca Searchable library (topics such as: drug use, families, funding, treatment, prevention, bereavement, health professionals, sexual health, health promotion, etc). Video loan library Posters (Aboriginal and non-Aboriginal) Other documents in their library include: Nashine ginwenimawaziwin : constant care [manual]. / Vanderhoef, Shelly.; Gray, Wendy (editor). — Toronto : 2-Spirited People of the 1st Nations, c1999. <u>Abstract:</u> This manual is aimed at Aboriginal people who have AIDS and provides suggestions on palliative care. HIV testing and confidentiality : issues for the 	Canadian HIV/AIDS Information Centre 400-1565 Carling Avenue, Ottawa, ON, K1Z 8R1 <u>Tel</u> : 1 (877) 999-7740 <u>Tel</u> : (613) 725-3434 <u>Fax</u> : (613) 725-1205 <u>E-mail</u> : aidssida@cpha.ca <u>Website</u> : http://www.aidssida.c pha.ca/

<u>Organization</u>	Resources	<u>Contact</u>
	Matiation, Stefan. — Montréal : Canadian HIV/AIDS Legal Network c1999. <u>Abstract:</u> This discussion paper examines issues raised for the Aboriginal community by HIV antibody testing and confidentiality.	
	 Community action toolkit : a guide to planning, promoting and evaluating HIV activities for community-based organizations / Canadian Public Health Association. Canadian HIV/AIDS Information Centre — Ottawa : Canadian Public Health Association. Canadian HIV/AIDS Information Centre, 2003. <u>Abstract</u>: This toolkit is part of the Canadian HIV/AIDS Social Marketing Campaign 2003. It is intended to help community-based organizations plan, promote and evaluate activities related to this year's campaign. The campaign's theme is Stigma and Discrimination, and the slogan is "Anytime. Anywhere. Anyone. HIV/AIDS does not discriminate." 	
	 HIV/AIDS. Fear. Discrimination. It can end with us (Métis man) [fact sheet] / Canadian Aboriginal AIDS Network — [Ottawa] Canadian Aboriginal AIDS Network, [2002]. [2] p. : ill. ; 22 x 28 cm. <u>Abstract:</u> This document is part of the Aboriginal AIDS Awareness Day Campaign 2002. This particular fact sheet consists of personal views about HIV/AIDS, discrimination and other related issues, from Duane Morrisseau-Beck, a Métis man. 	
	 Basic manual on How to Operate an HIV Resource Centre [manual] / Canadian HIV Resource Centre Network (CANNET) National Secretariat; Canadian Public Health Association; Tang, Hui (research & writing); Chagnon, Danielle (project management); Kenny, Janice (design & production); Young, Andrew (illustrator); Lee, Sylvie (translation); Beck, Jocelyne Chaperon (revisions) — Ottawa : Canadian Public Health Association, 1999, c1997. xii, [83] p. ; 29 cm. <u>Abstract:</u> This manual is intended to enable resource centre staff members who have little or no formal library training to successfully operate an HIV resource centre. 	

<u>Organization</u>	Resources	<u>Contact</u>
Canadian AIDS Society	Registered as a charity since 1988, the Canadian AIDS Society (CAS) is a national coalition of 123 community-based AIDS organizations across Canada. They are dedicated to strengthening the response to HIV/AIDS across all sectors of society, and to enriching the lives of people and communities living with HIV/AIDS. CAS advocates on behalf of people and communities affected by HIV/AIDS, facilitate the development of programs, services and resources for our member groups, and provide a national framework for community-based participation in Canada's response to AIDS. Some resources they offer are:	Canadian AIDS Society 309 Cooper St. 4th Floor Ottawa, ON, K2P 0G5 <u>Tel</u> .: (613) 230-3580 <u>Fax</u> .: (613) 563-4998 <u>E-mail</u> : casinfo@cdnaids.ca <u>Website</u> : http://www.cdnaids.ca/
	 Sliced Bread: Models of HIV/AIDS Youth Programs in Canada (1998) - Note: some of the programs in this document are no longer running, but still provide helpful information for organizing youth groups to address HIV/AIDS). Position papers Information sheets/FAQ's "InfoCAS"/"InFocus": a quarterly newsletter; includes updates on some of the work that CAS does and regional updates from membership 	
	 Youth resources (e.g. Connecting Youth with Youth: A Guide to Youth and HIV/AIDS-Related Programs and Projects across Canada [2004]) Impact Prison Survey: an on-line tool to capture the HIV/AIDS and hepatitis C-related care, treatment and support issues of prisoners across Canada 	
	The 5th Canadian HIV/AIDS Skills Building Symposium, October 27-30, 2005 Delta Centre-Ville, Montreal, Quebec: a project of the Canadian AIDS Society, presents a unique opportunity for interactive learning, skills training and networking to strengthen our nation's community- based response to HIV/AIDS. Skills 2005 features cutting-edge workshops and presentations under eight learning tracks: prevention, care/counselling/support, treatment, human rights, law, policy and advocacy.	

<u>Organization</u>	Resources	<u>Contact</u>
	organizational and community development, community-based research, international action, rehabilitation. To be attended by over 800 participants.	
Canadian Association for HIV Research	Since its founding in 1990, CAHR has been dedicated to fostering collaboration among all researchers working in HIV research, improving the quality of HIV research and advancing its cause. The Association holds an annual multi-disciplinary scientific conference to exchange information acquired in the ongoing search to understand, control and prevent the spread of HIV infection and to improve the care of people living with HIV/AIDS. Membership is open to anyone with an interest in HIV/AIDS research. Resources include: CAHR newsletter, web links, archive of CAHR conference abstracts, and New Investigator, scholarship, and community awards.	Canadian Association for HIV Research c/o Jennie Prasad University of British Columbia 201 - 1200 Burrard St. Vancouver, BC V6Z 2C7 <u>Tel</u> : (604) 642-6429 x307 <u>Fax</u> : (604) 642-6419 (Attn: Jennie Prasad) <u>E-mail</u> : info@cahr- acrv.ca <u>Website</u> : http://www.cahr- acrv.ca
British Columbia Centre for Excellence in HIV/AIDS	 BC Centre for Excellence in HIV/AIDS provides education to health care providers, conducts natural history and observational studies, develops innovative laboratory tests and carries out clinical trials. Resources include: live web broadcasts, clinical and laboratory resources, clinical and population health research. Some projects include: CEDAR – Understanding HIV vulnerability in young Aboriginal drug users (A multi-disciplinary northern-southern collaboration). The Centre is currently undertaking studies focusing on young Aboriginal drug users to determine why these people are at particularly high risk of HIV infection and to develop strategies that reduce this risk. Health professional education, including: O HIV/AIDS Nursing Elective – An undergraduate course in HIV/AIDS, now offered online, is offered in collaboration with University of British Columbia's School of Nursing. The elective (N410M) is 	Providence Health Care BC Centre for Excellence in HIV/AIDS Saint Paul's Hospital 608 – 1081 Burrard St. Vancouver, BC V6Z 1Y6 <u>Website</u> : http://www.cfenet.ub c.ca

<u>Organization</u>	Resources	<u>Contact</u>
	available to senior nursing students across the province as a visiting student at UBC.	
	 Inter-professional Elective in HIV/AIDS Prevention and Care – An undergraduate course in HIV/AIDS is open to students in medicine, nursing, pharmacy, social work and nutrition through UBC's College of Health Disciplines. 	
	 Interdisciplinary AIDS Care Rounds – A free lecture series held at St. Paul's. All interested in HIV/AIDS are invited to attend. No registration or RSVP is necessary. The Rounds can also be seen on the Centre's website at www.cfenet.ubc.ca/presentations. Rounds are also videotaped. 	
	 ABC Educational Program – A basic HIV/AIDS educational program for health care professionals and the community that travels across the province. The program is coordinated in collaboration with the BC Persons With AIDS Society. 	
YouthCO	 YouthCO is a Canadian AIDS service organization working to meet the needs of both HIV-positive and HIV-negative youth. Resources include: Information on HIV/AIDS and hepatitis C and sexual health hepatitis C videos Quizzes Stickers Pamphlets Temporary tattoos On-line chat group Newsletter Product catalogue Your Awareness of hepatitis C – Youth Peer Education Training Manual: designed to assist youth support workers and educators in facilitating hepatitis C prevention and education workshops. It provides its audience with opportunities to develop skills and increase knowledge of hepatitis C and related issues using a series of activities, discussions, and a demonstration of YouthCO's hepatitis C 101 	YouthCO AIDS Society #205-1104 Hornby Street Vancouver, BC V6Z 1V8 <u>Tel</u> : (604) 688-1441 <u>Toll Free</u> : 1 (877) youthco <u>Fax</u> : (604) 688-4932 Confidential support phone number: (604) 808-7209 <u>E-mail</u> : information@youthco. org <u>Website</u> : www.youthco.org

<u>Organization</u>	Resources	<u>Contact</u>
	prevention education presentation. Available free for download off their website or you can order a paper copy (\$10).	
Women and AIDS Virtual Education (WAVE)	WAVE is a website designed for women and service providers. WAVE is a place where women living with HIV can come together, gather support and information from each other, and talk about important issues. WAVE also provides online information and resources to healthcare educators and professionals in order to help them support women living with HIV. Resources for <u>service providers</u> include (see contact information for ordering or more details):	Women & AIDS Virtual Education (WAVE) c/o Positive Women's Network 1033 Davie Street, Suite #614 Vancouver, BC V6E 1M7 <u>E-mail</u> : pwn@pwn.bc.ca
	 Treatment Roundtable: The Treatment Roundtable is a discussion about HIV treatments for women and their care providers. It provides information and strategies on treatment decision- making and on life with HIV medications. The Women & HIV Education Toolkit: is aimed at healthcare providers, social and community workers, and HIV/AIDS educators. It provides simple, interactive exercises, handouts and other "tools" to help you to improve HIV services for women in your community. 	pwn@pwn.bc.ca <u>Website</u> : http://www.pwn- wave.ca/ <u>Tel</u> : (604) 692.3000 <u>Toll Free</u> : 1 (866) 692-3001 (British Columbia only) <u>Fax</u> : (604) 684-3126
	 HIV Trends and Women's Sexual Health Report (quarterly). Available via e-mail subscription or website download. Submissions are welcomed. HIV library and resources access: includes topics such an HIV and violence. HIV trends. HIV 8 	
	such as: HIV and violence, HIV trends, HIV & gynecological conditions, HIV and pregnancy. Resources for <u>HIV/AIDS-positive women</u> include (see contact information below for ordering or more details):	
	 Treatment talks with HIV-positive women. Bulletin board discussions with HIV-positive women 	
	 Information on HIV and abusive relationships and disclosing one's positive status. 	

<u>Organization</u>	<u>Resources</u>	<u>Contact</u>
	 Resource library, including topics such as: HIV and pregnancy, HIV and hepatitis C issues, and HIV prevention. Support and advocacy services (only for women living in BC). 	
Positive Women's Network	 PWN supports women living with HIV/AIDS to make informed choices about their health. We provide safe access to HIV/AIDS-related support, advocacy and education/prevention to women and their communities throughout British Columbia, Canada. Some services include (available only to women living in BC): Aboriginal-specific activities Advocacy Annual wellness retreats Food bank and lunch program Hospital visits Support for family and care providers HIV/AIDS information for healthcare providers HIV/AIDS information for newly diagnosed women and women living with HIV/AIDS Toolkit on women and HIV/AIDS education. Other resources include: basescovered.ca: an online HIV/AIDS prevention resource for young women http://www.basescovered.ca "Listen Up!" is a community-based research project by PWN that examines how social factors increase women's risk for HIV infection and illness progression. Women living with and affected by HIV have been involved in the design, development and implementation of this research as advisors, peer researchers and participants since the project's inception in 1999. The research format of the project includes both focus groups and one-on-one interviews. Documents available for download on their website at: http://www.pwn.bc.ca/cms/page_1412.cfm (or contact the PWN). 	Positive Women's Network 1033 Davie Street, Suite #614 Vancouver, BC V6E 1M7 <u>Tel</u> : (604) 692-3000 <u>Toll Free</u> : 1 (866) 692-3001 (British Columbia only) <u>Fax</u> : (604) 684-3126 <u>E-mail</u> : pwn@pwn.bc.ca <u>Website</u> : http://www.pwn.bc.c a/cms/

<u>Organization</u>	Resources	<u>Contact</u>
Canadian Foundation for AIDS Research	 CANFAR is the national charitable foundation created to raise awareness in order to generate funds for research into all aspects of HIV infection and AIDS. Initiatives include: CANFAR allocates a portion of its resources to grants for the development of awareness programs, and for research on ethical and other implications of measures that might be proposed for the protection of public health. Grants are awarded at two levels: level one up to \$80,000, each year for a two year period, and level two up to \$25,000. Have a Heart campaign: For a minimum donation of \$1, students at schools nationwide send Heart o' Grams to each other on Valentine's Day. (A Heart o' Gram consists of a clear Have a Heart bag filled with a Valentine's treat, a customized campaign iron-on, a colourful HIV/AIDS information pamphlet and a sticker with space to write a message to your friend.) CANFAR supplies campaign materials at no cost to participating schools. Students generate enthusiasm and awareness, with accompanying events, while raising funds specifically for HIV/AIDS research projects. Have a Heart is a major Valentine's construction projects. Have a Heart is a major Valentine's company. The schools, universities and colleges across Canada. An enthusiastic 770 schools participated during the last Have a Heart campaign. Spring for Life: Spring for Life is CANFAR's nationwide HIV/AIDS awareness and fundraising campaign, held annually around the first day of Spring. Hundreds of businesses in Calgary, Edmonton, Halifax, Montreal, Ottawa, Toronto, Vancouver and Winnipeg participated in one campaign by donating a portion of funds (suggested at 10%). Canadian HIV/AIDS research and enhanced services and care for people living with HIV or AIDS in communities across Canada. 	Canadian Foundation for AIDS Research 165 University Avenue, Suite 901 Toronto, ON, M5H 3B8 <u>Tel: (416) 361-6281</u> <u>Toll Free: 1 (800) 563-</u> CURE (2873) <u>Fax: (416) 361-5736</u> <u>E-mail:</u> cure@CANFAR.com <u>Website:</u> http://www.canfar.ca

<u>Organization</u>	Resources	<u>Contact</u>
Health Canada	 Get the Facts: Collection of Project Case Studies: hepatitis C Prevention, Support and Research Program. 2003. Health Canada. Available for download at http://www.phac- aspc.gc.ca/hepc/hepatitis_c/pdf/projectCaseSt udies.pdf 	hepatitis C Prevention, Support & Research Program Community Acquired Infections Division Centre for Infectious Disease Prevention and Control Public Health Agency of Canada A.L. 6201C 100 Colonnade Road Ottawa, ON K1A 0K9 <u>Fax</u> : (613) 941-7563
Canadian AIDS Treatment Information Exchange (CATIE)	 CATIE is Canada's national bilingual source for HIV/AIDS treatment information. It provides information on HIV/AIDS treatments and related health care issues to people living with HIV/AIDS, their care providers and community-based organizations. Other resources offered include: internships, fact sheets, electronic resource library (books, journal articles, videos), and a newsletter. Other publications available to download from the CATIE website or order/loan from CATIE include: Inuit fact sheets on HIV/AIDS treatment and related illnesses. Home care for Aboriginal peoples living with HIV/AIDS : framework document / principal investigators Ruth Ann Cyr, James L. Dunn Ottawa: Aboriginal Nurses Association of Canada, 2000. Coping with HIV/AIDS in Aboriginal communities : a 1998 resource manual National Indian & Inuit Community Health Representative Organization, 1998. Keepers of the earth, women, health and HIV/AIDS : a resource manual / created by: Susan Judith Ship and Laura Norton Kahnawake, PQ: National Indian and Inuit Community Health Representative Organization, 1999. Managing Your Health, 1999 Edition. The must- read handbook on living with HIV. 	Canadian AIDS Treatment Information Exchange 555 Richmond Street West, Suite 505 Box 1104 Toronto, ON, M5V 3B1 <u>Tel</u> : (416)-203-7122 <u>Toll Free:</u> 1 (800) 263-1638 (private and confidential) <u>Fax</u> : (416) 203-8284 <u>E-mail</u> : info@catie.ca <u>Website</u> : http://www.catie.ca/

<u>Organization</u>	Resources	<u>Contact</u>
	• A Practical Guide to HAART (Highly Active Anti- retroviral Therapy).	
	• A Practical Guide to HIV Drug Side Effects.	
	• A Practical Guide to Complementary Therapies for People Living with HIV and AIDS.	
	• A Practical Guide to Herbal Therapies for People Living with HIV and AIDS.	
	• A Practical Guide to Nutrition for People Living with HIV and AIDS.	
Canadian Association of Nurses in AIDS Care (CANAC)	The Canadian Association of Nurses in AIDS Care (CANAC) is a national professional nursing organization committed to fostering excellence in HIV/AIDS nursing, promoting the health, rights and dignity of persons affected by HIV/AIDS and to preventing the spread of HIV infection. CATIE has also teamed up with CANAC to provide an extensive resource centre for HIV/AIDS related nursing information. Within the following website, there is a host of information, including new drug information, symptom management, practical guides for nursing practice, clinical practice guidelines and much more -	CANAC c/o Casey House 9 Huntley Street Toronto, ON, M4Y 2K8 <u>Fax</u> : (416) 962-5147 <u>E-mail</u> : info@canac.org <u>Website</u> : http://www.canac.org/
Live Positive	http://www.catie.ca/e/nurses/index.htm Need help with a school project or homework assignment about HIV and AIDS? This Website was produced by the Canadian AIDS Treatment Information Exchange (CATIE). The Living Positive website has what you need to know about the disease, from the basics to what it's like to live positive. Resources include basic information on HIV/AIDS and a library of school topics on HIV/AIDS.	<u>Website</u> : http://www.livepositiv e.ca/
Canadian HIV/AIDS Legal Network (CHLN)	The Canadian HIV/AIDS Legal Network promotes the human rights of people living with and vulnerable to HIV/AIDS, in Canada and internationally. We accomplish this through research, legal and policy analysis, education, advocacy, and community mobilization. Resources include: e-mail list-serve, info sheets, and resource centre. Documents	Canadian HIV/AIDS Legal Network 417 Saint-Pierre Street, Suite 408 Montréal, QC H2Y 2M4

<u>Organization</u>	Resources	<u>Contact</u>
	 available for download/request inlcude: Discrimination, HIV/AIDS and Aboriginal People (1999) HIV/AIDS and Aboriginal People: Problems of Jurisdiction and Funding – a Discussion Paper (1999) HIV Testing and Confidentiality: Issues for the Aboriginal Community – a Discussion Paper 	<u>Tel</u> .: (514) 397-6828 <u>Fax</u> : (514) 397-8570 <u>E-mail</u> : info@aidslaw.ca <u>Website</u> : http://www.aidslaw.ca/
Canadian Treatment Action Council (CTAC)	(1999) CTAC is a national organization directed by people living with HIV/AIDS, the Canadian Treatment Action Council promotes informed public policy and public education, and promotes awareness on issues that impact on access to treatment and health care for people living with HIV/AIDS and for other vulnerable populations. Treatment is a broad concept which includes traditional as well as complementary and alternative medicine. Web resources include a newsletter, position papers, and links of interest.	Canadian Treatment Action Council P.O. Box 116, Stn "F" Toronto, ON, M4Y 2L4 <u>Tel/Fax</u> : (416) 410-6538 <u>E-mail</u> : ctac@ctac.ca <u>Website</u> : http://www.ctac.ca/
Canadian HIV Trials Network (CTN)	CTN is an innovative partnership of clinical investigators, physicians, nurses, people living with HIV/AIDS, pharmaceutical manufacturers and others that facilitates HIV/AIDS clinical trials of the highest scientific and ethical standards. CTN is funded by the Canadian Institutes of Health Research (CIHR) and provides a national and regional infrastructure to facilitate clinical trials in HIV/AIDS (developing and managing clinical trials). Web resources include links to research opportunities, training opportunities, research references, and research publications.	Canadian HIV Trials Network 620 - 1081 Burrard Street Vancouver, BC V6Z 1Y6 <u>Tel</u> : (604) 806-8327 <u>Fax</u> : (604) 806-8210 <u>Toll Free</u> : 1 (800) 661-4664 <u>E-mail</u> : ctn@hivnet.ubc.ca <u>Website</u> : http://www.hivnet.ubc .ca/ctn.html
Ministerial Council on HIV/AIDS	 HIV/AIDS and Health Determinants: Lessons for Coordinating Policy and Action (2002) <u>Abstract:</u> Canada needs to pursue other approaches if it is to prevent HIV/ AIDS and manage the HIV/ AIDS epidemic. The population health model offers one such strategy. It builds on a holistic view of health that recognizes the many factors that 	Public Health Agency of Canada <u>Tel</u> : 1 (866) 225-0709 (ask for Publications) <u>E-mail</u> : publications@hc- sc.gc.ca

<u>Organization</u>	Resources	<u>Contact</u>
	influence population health and well being. These social determinants include, for example, poverty, income inequality, racism and discrimination, and early childhood experiences.	Note Catalogue No. H39-632/ 2002E
	Health Canada initiated this literature review in order to consider HIV/ AIDS in a population health context, to identify those social determinants most closely associated with HIV/ AIDS, and to consider policy directions that will strengthen the Canadian response to the epidemic.	Also available for download at: http://www.spigelman.c om/Rpt-Pop_Health.pdf
Saskatchewan Health, Population Health Branch, Communicable Disease Control Unit	HIV/AIDS in Saskatchewan (2003) This epidemiological report profiles HIV and AIDS in Saskatchewan from the commencement of documented surveillance activities in 1984 to the end of December, 2003.	<u>Website</u> : http://www.health.go v.sk.ca/mc_hiv_aids_a nnual_rep_2003.pdf
Saskatchewan Health, Provincial Strategy Team on HIV, Blood- borne Pathogens and Injection Drug Use	At Risk: Recommendations for a Strategy on HIV, Blood-borne Pathogens and Injection Drug Use (2002) This report provides the background for the recommendations of the Provincial Strategy Team. Its mandate was to investigate the transmission of HIV and other blood-borne pathogens through injection drug use and make recommendations to the Chief Medical Health Officer. The report recommends a non-judgmental, public health approach in order to address the complex issues of HIV, blood-borne pathogens and injection drug use. It respects the wide range of alternative prevention and intervention options. An essential step to understanding the message of this report is recognizing injection drug use as, first and foremost, a health and social issue.	<u>Website</u> : http://www.health.go v.sk.ca/mc_dp_skhlth_ at_risk_booklet.pdf
Saskatchewan Health, Saskatchewan Subcommittee on HIV/AIDS	Guidelines for the Management of Potential Exposures to hepatitis B, hepatitis C, HIV and Recommendations for Post-Exposure Prophylaxis (2004) Prevention and Management of hepatitis B, hepatitis C, HIV and Blood borne Pathogens. The document consisted of recommendations to assist	<u>Website</u> : http://www.health.go v.sk.ca/rr_cdc_guideli nes.pdf

<u>Organization</u>	<u>Resources</u>	<u>Contact</u>
Public Health Agency of Canada	health service organizations and direct care providers in the development of policies and procedures for reducing the risk of transmitting hepatitis B (HBV), hepatitis C (HCV), Human Immunodeficiency Virus (HIV) and other blood borne pathogens (BBP) as a result of exposures in the health care setting. Guidelines for post-exposure prophylaxis were included. Antiretroviral medications were recommended and made available in 3-day kits that were located in several sites throughout the province. In April 2002, a working group comprised of a number of interested stakeholders met to review and update the guidelines in response to the availability of improved antiretroviral medications and in order to make the guidelines consistent with practices across the province. This document replaces the former. <i>Canadian HIV Statistical Reports</i> This report is part of a semi-annual series providing a review of available HIV and AIDS surveillance data in Canada. The HIV/AIDS Surveillance section is part of the Surveillance and Risk Assessment Division, at the Centre for Infectious Disease Prevention and Control. This section is responsible for data collection. In addition, this section continues to improve data quality, define and set surveillance standards, as well as support the use of these data to influence programmatic and policy action.	Surveillance and Risk Assessment Division Centre for Infectious Disease Prevention and Control Public Health Agency of Canada Tunney's Pasture, AL 0602B Ottawa, ON, K1A 0K9 <u>Tel</u> : (613) 954-5169 <u>Fax</u> : (613) 957-2842 <u>Website</u> : http://www.phac- aspc.gc.ca/hast-
AVERT	AVERT is an international AIDS charity providing information on HIV/AIDS. Resources include: quizzes, booklets/posters, statistics, care and treatment, STD information, etc Some other resources include:	vsmt/public_e.html AVERT 4 Brighton Road Horsham West Sussex RH13 5BA
	 Lesson Plans for HIV/AIDS Education with Young People: http://www.avert.org/lessons.htm HIV/AIDS Lesson Plans & Instructions for Teachers: http://www.avert.org/media/pdfs/hivaidslessons.pdf 	United Kingdom <u>E-mail</u> : info@avert.org <u>Website</u> : http://www.avert.org

<u>Organization</u>	Resources	<u>Contact</u>
UNESCO (United Nations Educational, Scientific and Cultural Organization):	 UNESCO functions as a laboratory of ideas and a standard-setter to forge universal agreements on emerging ethical issues. The Organization also serves as a clearinghouse – for the dissemination and sharing of information and knowledge – while helping Member States to build their human and institutional capacities in diverse fields. Resources include: Culture and HIV/AIDS Program – this is a joint UNAIDS and UNESCO project which takes an anthropological perspective on HIV/AIDS issues. For more information on projects they are involved in across the world, consult their extensive website at: http://portal.unesco.org/culture/en/ev.php-URL_ID=12409&URL_DO=DO_TOPIC&URL_SECTION =201.html (or type 'culture and HIV' into the 'Search' option on the main UNESCO website at: www.unesco.org) 	UNESCO 7, place de Fontenoy 75352 Paris 07 SP France UNESCO general <u>Tel:</u> +33 (0)1 45 68 10 00 <u>Fax:</u> +33 (0)1 45 67 16 90 <u>Website</u> : www.unesco.org
UNAIDS	The Joint United Nations Programme on HIV/AIDS, UNAIDS, is the main advocate for global action on the epidemic. It leads, strengthens and supports an expanded response aimed at preventing transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to HIV/AIDS, and alleviating the impact of the epidemic.	UNAIDS 20, avenue Appia CH-1211 Geneva 27 Switzerland <u>Tel</u> : +41.22.791.3666 <u>Fax</u> : +41.22.791.4187 <u>E-mail</u> : unaids@unaids.org <u>Website</u> : www.unaids.org



Resource	<u>Contact</u>
Journey Home: First Nations Living with HIV/AIDS (1994) Abstract: Video intended to assist Aboriginal families and communities providing supportive response to persons with HIV/AIDS. Suitable as an educational resource for a wide audience, including the general public and health educators. 38 minutes; available in English and French with a discussion guide. Gryphon Production.	STD/AIDS Resource Centre BC Centre for Disease Control 655 West 12th Avenue, Room 1123 Vancouver, BC, V5Z 4R4 <u>Tel</u> : (604) 660-2090 <u>Fax</u> : (604) 775-0808 <u>Website</u> : http://www.bccdc.org/content.php? item=40 Or from: Gryphon Productions Ltd. P.0. Box 93009, 5331 Headland Dr. West Vancouver, BC, V7W 3C0 <u>Tel</u> : (604) 921-7627 <u>Fax</u> : (604) 921-7626 <u>E-mail</u> : videos@gryphonproductions.com
Chance for Change <u>Abstract:</u> is a half-hour drama depicting a young native man caught between the fast-paced world of the city streets, and his culture and family. Returning home to a rural Indian reserve after some time in prison and on the streets, Mike is persuaded by his wife to attend an AIDS information workshop. Realizing the seriousness of his past high-risk behaviour, Mike decides to go for an AIDS test. With the support of his grandfather, a nurse and his wife Doreen, Mike begins to understand the need for a change in his life. In a "Chance for Change" we learn that there is more to AIDS prevention than the correct use of condoms; individuals must examine their own lifestyles and sexual practices and determine what changes might be necessary to ensure good health in their lives.	STD/AIDS Resource Centre BC Centre for Disease Control 655 West 12th Avenue, Room 1123 Vancouver, BC, V5Z 4R4 <u>Tel</u> : (604) 660-2090 <u>Fax</u> : (604) 775-0808 <u>Website</u> : http://www.bccdc.org/content.php? item=40 Or from: Gryphon Productions Ltd. P.0. Box 93009, 5331 Headland Dr. West Vancouver, BC, V7W 3C0 <u>Tel</u> : (604) 921-7627 <u>Fax</u> : (604) 921-7626 <u>E-mail</u> : videos@gryphonproductions.com

Resource	<u>Contact</u>
Kecia, Words to Live By <u>Abstract:</u> "Kecia" is an emotional 24 min. documentary about a young Native Indian girl from a small community on Vancouver Island and events, which led up to her becoming infected with the HIV (AIDS) virus. The video follows Kecia Larkin on a tour of native communities throughout Ontario as she delivers strong messages to young people about their bodies and the AIDS virus. Featured on several Canadian national news broadcasts, Kecia is a powerful speaker and in addition to AIDS, addresses such issues as: sexual abuse, alcoholism, drug addiction, street life and the realities of growing up in a small native Indian community.	Canadian AIDS Clearing House 400-1565 Carling Avenue Ottawa, ON K1Z 8R1 <u>Toll Free</u> : 1 (877) 999-7740 <u>Tel</u> : (613) 725-3434 <u>Fax</u> : (613) 725-1205 <u>E-mail</u> : aidssida@cpha.ca <u>Website</u> : http://www.aidssida.cpha.ca Or from: Gryphon Productions Ltd. P.0. Box 93009, 5331 Headland Dr. West Vancouver, BC, V7W 3C0 <u>Tel</u> : (604) 921-7627 <u>Fax</u> : (604) 921-7626 <u>E-mail</u> : videos@gryphonproductions.com
Her Giveaway: A Spiritual Journey With AIDS (1988) <u>Abstract:</u> The common misconceptions around AIDS and the aboriginal community are dispelled and basic AIDS information is provided. The personal story and insights of an aboriginal person who has AIDS is also shared. (20:00 min.)	STD/AIDS Resource Centre BC Centre for Disease Control 655 West 12th Avenue, Room 1123 Vancouver, BC, V5Z 4R4 <u>Tel</u> : (604) 660-2090 <u>Fax</u> : (604) 775-0808 <u>Website</u> : http://www.bccdc.org/content.php? item=40 Or from distributor: Women Make Movies Order Department 462 Broadway, Suite 500WS New York, NY, 10013 <u>Tel</u> : (212) 925-0606 x360 <u>Fax</u> : (212) 925-0606 x360 <u>Fax</u> : (212) 925-2052 <u>E-mail</u> : orders@wmm.com <u>Website</u> : http://www.wmm.com/

Resource	<u>Contact</u>
Feather of Hope (1991)Abstract: Cardinal, Gil (Director); Radford, Tom (Producer)Ken Ward was the first Native person to go public as a carrier of the AIDS virus. Feather of Hope is the deeply felt, revealing story of Ken's commitment to use his personal tragedy to create healing and awareness among his people. (24:00 min.)	STD/AIDS Resource Centre BC Centre for Disease Control 655 West 12th Avenue, Room 1123 Vancouver, BC, V5Z 4R4 <u>Tel</u> : (604) 660-2090 <u>Fax</u> : (604) 775-0808 <u>Website</u> : http://www.bccdc.org/content.php? item=40
First Nations and HIV: Linking the Evidence (2003) Wood, Evan; Spittal, Patti. (60:00 min.)	STD/AIDS Resource Centre BC Centre for Disease Control 655 West 12th Avenue, Room 1123 Vancouver, BC, V5Z 4R4 <u>Tel</u> : (604) 660-2090 <u>Fax</u> : (604) 775-0808 <u>Website</u> : http://www.bccdc.org/content.php? item=40
British Columbia Aboriginal AIDS Awareness Program (BCAAAP) (2000) <u>Abstract:</u> A description its program and issues on aboriginal community services and health care. (54:00 min.)	STD/AIDS Resource Centre BC Centre for Disease Control 655 West 12th Avenue, Room 1123 Vancouver, BC, V5Z 4R4 <u>Tel</u> : (604) 660-2090 <u>Fax</u> : (604) 775-0808 <u>Website</u> : http://www.bccdc.org/content.php? item=40
Let Me Tell You a Story of Love (1997) <u>Abstract:</u> This video is aimed at Inuit communities. It features interviews with AIDS experts, social workers, and person living with HIV/AIDS. Puppets are used to tell a story of how a woman was infected by her boyfriend while living in the south, and how he was unknowingly infected by sharing a needle with his friends some year prior. (27:00 min.)	Canadian AIDS Clearing House 400-1565 Carling Avenue Ottawa, ON, K1Z 8R1 <u>Toll Free</u> : 1 (877) 999-7740 <u>Tel</u> : (613) 725-3434 <u>Fax</u> : (613) 725-1205 <u>E-mail</u> : aidssida@cpha.ca <u>Website</u> : http://www.aidssida.cpha.ca

Resource	<u>Contact</u>
AIDS: A Gitksan Point of View (1994) Abstract: The story of John from contracting the HIV virus to his acceptance of responsibility for the choices he made in his life. (9:00 min.)	STD/AIDS Resource Centre BC Centre for Disease Control 655 West 12th Avenue, Room 1123 Vancouver, BC, V5Z 4R4 <u>Tel</u> : (604) 660-2090 <u>Fax</u> : (604) 775-0808 <u>Website</u> : http://www.bccdc.org/content.php? item=40
AIDS One Time (2002) <u>Abstract:</u> This video was created from excerpts of the "Twelve-Foot Puppets Promote HIV/AIDS Prevention Project" to develop community awareness about HIV/AIDS. It encourages all people to learn the facts about HIV/AIDS and invites individuals and communities to acknowledge their grief and their hope. (1100 min.)	STD/AIDS Resource Centre BC Centre for Disease Control 655 West 12th Avenue, Room 1123 Vancouver, BC, V5Z 4R4 <u>Tel</u> : (604) 660-2090 <u>Fax</u> : (604) 775-0808 <u>Website</u> : http://www.bccdc.org/content.php? item=40
<i>First Story (1999)</i> <u>Abstract:</u> Several HIV-positive Aboriginals living in Vancouver Downtown Eastside talk about the health issues and problems they are facing and the service provided by the Vancouver Native Health Society. (29:55 min.)	STD/AIDS Resource Centre BC Centre for Disease Control 655 West 12th Avenue, Room 1123 Vancouver, BC, V5Z 4R4 <u>Tel</u> : (604) 660-2090 <u>Fax</u> : (604) 775-0808 <u>Website</u> : http://www.bccdc.org/content.php? item=40
Silent Love: A Video on the Emotional Side of AIDS Depicts the love and support a young Native who has AIDS received from his family in a small First Nation community. Ends with the message that AIDS can affect anybody and staying safe is the only way to prevent it. (18:34 min.)	STD/AIDS Resource Centre BC Centre for Disease Control 655 West 12th Avenue, Room 1123 Vancouver, BC V5Z 4R4 <u>Tel</u> : (604) 660-2090 <u>Fax</u> : (604) 775-0808 <u>Website</u> : http://www.bccdc.org/content.php? item=40

Resource	<u>Contact</u>
Open Heart, Open Minds: Living with AIDS/HIV in Indian Country <u>Abstract:</u> Nelson, David (Producer); Lujan, James (Director) A glimpse of those infected and affected by HIV/AIDS with a view to create awareness, compassion and understanding toward the disease. (41:00 min.)	STD/AIDS Resource Centre BC Centre for Disease Control 655 West 12th Avenue, Room 1123 Vancouver, BC, V5Z 4R4 <u>Tel</u> : (604) 660-2090 <u>Fax</u> : (604) 775-0808 <u>Website</u> : http://www.bccdc.org/content.php? item=40
I Will Not Cry Alone (1999) Abstract: A video about HIV/AIDS and the crisis facing Aboriginal communities across Canada. According to Health Canada available evidence suggests that the aboriginal population is being infected with HIV at an earlier age than the non-Aboriginal population. And because of the transience of Aboriginal people between inner cities and rural areas, even the most remote communities are not excluded from HIV contact. (25:00 min.)	Duval House Publishing 18228 102 Avenue Northwest, Edmonton, AB, T5S1S7 <u>Tel</u> : (780) 488-1390. <u>Website</u> : http://www.duvalhouse.com/video.h tml Or from: STD/AIDS Resource Centre BC Centre for Disease Control 655 West 12th Avenue, Room 1123 Vancouver, BC, V5Z 4R4 <u>Tel</u> : (604) 660-2090 <u>Fax</u> : (604) 775-0808 <u>Website</u> : http://www.bccdc.org/content.php? item=40
 HIV/AIDS Support Strengthen Unity In Our Families, Our Communities, Our Nations (1995) <u>Abstract:</u> This video is aimed at Native communities and families. It looks at HIV/AIDS through personal stories of Aboriginal people who are infected and affected by the disease. (20:45 min.) Keeper, Joy. 	Canadian AIDS Clearing House 400-1565 Carling Avenue Ottawa, ON, K1Z 8R1 <u>Toll Free</u> : 1 (877) 999-7740 <u>Tel</u> : (613) 725-3434 <u>Fax</u> : (613) 725-1205 <u>E-mail</u> : aidssida@cpha.ca <u>Website</u> : http://www.aidssida.cpha.ca

al Indian and Inuit Community Representatives Organization bx 1019, 1 Roy Montour Lane wake, QC, J0L 1B0 50) 632-0892 50) 632-2111 niichro@niichro.com re: www.niichro.com/2004/ n: DS Resource Centre ntre for Disease Control est 12th Avenue, Room 1123 buver, BC, V5Z 4R4 04) 660-2090 04) 775-0808 re: www.bccdc.org/content.php?
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bowace Educational binment Co. k 190, Broadview, SK, SOG 0K0 b) 696-2303 cec.dev@sk.sympatico.ca htact: chewan Learning, Jum Distribution Services /ascana Parkway, Regina SK 7 b) 787-9747 b) 787-5987 Jum.orders@sasked.gov.sk.ca sed in Health Education: A Jum Guide for the Middle Grades 6-9)(1998) te: www.saskjobs.ca/curr_inst/iru/

Resource	<u>Contact</u>
HIV/AIDS Presentation from the Aboriginal Nurses Association's First National Teaching Conference "Keeping Our Children Safe". 1997.	Publication Resource Centre First Nations and Inuit Health Branch 20th Floor, Jeanne Mance Bldg. Tunney's Pasture, Postal Locator 1920A, Ottawa, ON, K1A 0L3
	Or, fax your order to: (613) 954-8107
	Or available from:
	Canadian AIDS Clearing House 400-1565 Carling Avenue Ottawa, ON, K1Z 8R1
	<u>Tel</u> : (613) 725-3434 <u>Toll Free</u> : 1 (877) 999-7740 <u>Fax</u> : (613) 725-1205 <u>E-mail</u> : aidssida@cpha.ca <u>Website</u> : http://www.aidssida.cpha.ca
A Long Walk - Journey of an AIDS Activist (1998) Abstract: Video documentary of Native Canadian Ken Ward and his advocacy for HIV prevention and treatment and work with First Nations peoples. 49 minutes; available in English.	Canadian AIDS Clearing House 400-1565 Carling Avenue Ottawa, ON, K1Z 8R1 <u>Toll Free</u> : 1 (877) 999-7740 <u>Tel</u> : (613) 725-3434 <u>Fax</u> : (613) 725-1205 <u>E-mail</u> : aidssida@cpha.ca <u>Website</u> : http://www.aidssida.cpha.ca Or from:
	National film Board of Canada Sales and Customer Service, D-10 PO Box 6100, Station Centre-Ville Montreal, QC, H3C 3H5 <u>Toll Free</u> : 1 (800) 267-7710 <u>Fax</u> : (514) 283-7564 (Attention: Sales and Customer Service) <u>Website</u> : http://www.nfb.ca
	Or from:
	Duval House Publishing 18228 102 Avenue Northwest, Edmonton, AB, T5S1S7 <u>Tel</u> : (780) 488-1390 <u>Website</u> : http://www.duvalhouse.com/

Resource	<u>Contact</u>
Be Aware [Music video]	Duval House Publishing 18228 102 Avenue Northwest,
<u>Abstract:</u> Brainchild of Aboriginal AIDS activist Ken Ward. This music video follows the story of a young	Edmonton, AB, T5S1S7
woman on the powwow trail who enjoys the parties and the tipi creeping, but doesn't know how to protect	<u>Tel</u> : (780) 488-1390.
herself from HIV. Using traditional and modern symbols and storytelling, the video depicts her anguish about who will raise her young daughter when she's gone.	<u>Website</u> : http://www.duvalhouse.com/
Open Your Eyes and Be Aware : A Resource for HIV- and AIDS-Awareness Workshops (1999)	Canadian AIDS Clearing House 400-1565 Carling Avenue Ottawa, ON, K1Z 8R1
Abstract: "Open Your Eyes and Be Aware" video and booklet are intended to be used as resources for HIV/AIDS awareness workshops for teens between the ages of 13 and 19. This music video is based on the rap song "Be Aware", which tells the story of a young woman who becomes infected with HIV/AIDS, and pregnant due to a one-night stand. The companion guide answers many basic questions young people may have about HIV and AIDS, and suggests workshop activities that will promote discussion and understanding. Audience: Aboriginal peoples / Educators / Adolescents / Young adults. (6 min., 24 sec).	<u>Tel</u> : (613) 725-3434 <u>Toll Free</u> : 1 (877) 999-7740 <u>Fax</u> : (613) 725-1205 <u>E-mail</u> : aidssida@cpha.ca <u>Website</u> : http://www.aidssida.cpha.ca
Point of Death. [Video] (1999)	Fort Smith Métis Council
<u>Abstract:</u> Fort Smith Métis Nation (Northwest Territories) produced a video by and for youth stressing the	P.O. Box 1107 Fort Smith, NT X0E 0P0
dangers of HIV transmission and injection drug use. This was an acclaimed video, which won an international documentary award. 30 minutes, compact disc (all NWT Aboriginal languages, English and French) and workshop materials (English only) on HIV/AIDS and IV drug use.	<u>Tel</u> : (867) 872-2643 <u>Fax</u> : (867) 872-5225 <u>E-mail</u> : metiscouncil@gardtal.com Or from:
	STD/AIDS Resource Centre BC Centre for Disease Control 655 West 12th Avenue, Room 1123 Vancouver, BC V5Z 4R4
	<u>Tel</u> : (604) 660-2090 <u>Fax</u> : (604) 775-0808 <u>Website</u> : http://www.bccdc.org/content.php? item=40

Resource	<u>Contact</u>
Aboriginal Youth Videos Youth Strengthening the Circle Chako, Coming of Age Chako, Coming of Age Guidebook 	Chee Mamuk, Aboriginal Program STD/AIDS Control BC Centre for Disease Control 655 12th Ave. W Vancouver BC V5Z 4R4 <u>Tel</u> : (604) 660-1673 <u>Fax</u> : (604) 775-0808
 YouthCO - hepatitis C Videos Your Awareness of hepatitis C (10 mins.): Created by youth for youth to help increase their safety and awareness. Using an original sound track, storyline, voice-overs and graphics, this video reaches a diverse population of youth with a wide variety of learning styles. Video can be ordered from YouthCO or downloaded off their website (note: very large file). Filter: The Facts About hepatitis C (10 mins.). This video was created by youth for youth with a focus on harm reduction. Using an original soundtrack, gripping graphics and compelling interviews with youth infected with the virus, this video is essential resource for educating young people. Video can be ordered from YouthCO or downloaded off their website (note: very large file). 	YouthCO AIDS Society #205-1104 Hornby Street Vancouver, BC, V6Z 1V8 <u>Tel</u> : (604) 688-1441 <u>Toll Free</u> : 1 (877) youthco <u>Fax</u> : (604) 688-4932 Confidential support phone number: (604) 808-7209 <u>E-mail</u> : information@youthco.org <u>Website</u> : www.youthco.org

UNIVERSITY THESES

<u>Title</u>	Summary
HIV/AIDS and Aboriginal Women in Saskatchewan: Colonization, Marginalization and Recovery. [MA] <u>Year</u> : 2003 <u>Author</u> : Romanow, Carol-Anne Gloria <u>Source</u> : University of Saskatchewan	This research was conducted in an attempt to understand why Aboriginal women in Saskatchewan remain marginalized in their continuing struggle against HIV/AIDS and hepatitis C. Through the use of in-depth ethnographic profiles and personal histories, twenty-two Aboriginal women from Saskatchewan candidly shared their life histories. The women were asked a range of questions, including their knowledge about HIV/AIDS and hepatitis C, and their attitudes and behaviours concerning sexual activities, alcohol and drug use, education, health, and lifestyle. The majority of the respondents were found to be prostitutes who continued to be involved in street prostitution, even after they had been diagnosed with HIV and/or hepatitis C.
	The key issues for Aboriginal women with HIV/AIDS and/or hepatitis C focus on the fact that they sustain 'triple jeopardy,' in that they are discriminated against for having HIV/AIDS and/or hepatitis C, for being a minority population by virtue of their Aboriginal ancestry, and for being women. Any analyses of what makes Aboriginal women vulnerable to HIV and hepatitis C infection must take into account the role of poverty, independent of any risk factors, in leading to infection, illness, and in some instances, death.
	The results of this research indicate that the incidence of both HIV and hepatitis C is high in Aboriginal communities in Saskatchewan, due largely to low condom use, high rates of STDs (sexually transmitted diseases), low self-esteem, a lack of self-identity, increasing intravenous drug use, violence, sexual abuse, and high representation in street prostitution. This thesis serves to fill some of the research gaps in knowledge about the relationship between race, gender, social class, sexual behavior and HIV/AIDS and/or hepatitis C infection.
Two-spirit men in Winnipeg and the experience of HIV/AIDS (Manitoba). [MA] <u>Year</u> : 2003 <u>Author</u> : Jackson, Randall Craig. <u>Source</u> : University of Manitoba	This exploratory study describes the everyday life concerns of seven HIV-positive two-spirit men living in Winnipeg, Manitoba. The focus of this study is on the intersection between presenting oneself as gay and Aboriginal, and the reconstruction of identity following a positive diagnosis for HIV disease. Guided by standpoint epistemology, notions of "the other"; phenomenology and use of the medicine wheel, qualitative methods were utilized to collect and analyze the

<u>Title</u>	Summary
	data. Findings revealed a coalescing of themes around four discrete categories that express the essence of participants' experience of HIV infection and AIDS. This study highlights (1) how these men experienced life prior to diagnosis, (2) how they dealt with the initial knowledge of HIV infection, (3) what everyday life with HIV entails, and (4) how they cope with future representation of HIV as illness. In examining these themes, this study reveals how these men imbue their on-going struggles with HIV/AIDS with a sense of spirit, focus, and emotional strength using cultural resources.
HIV in Aboriginal women in northern Alberta (Immune deficiency). [MSc.] <u>Year</u> : 2002 <u>Author</u> : Shokoples, Sandra Elaine <u>Source</u> : University of Alberta	Although only 8.4% of the population of northern Alberta are Aboriginal, 46% of women with human immunodeficiency virus (HIV) in northern Alberta who were seen by the Northern Alberta HIV Program are Aboriginal. The highest numbers of HIV-positive women were in the 15-34 year age groups. Of the two major risk factors for women for contracting HIV – heterosexual contact and intravenous drug use (IVDU), more HIV-positive Aboriginal women had used IV drugs. There was no statistically significant difference between HIV-positive Aboriginal women and non-Aboriginal women in terms of the proportion who had received anti-retrovirals (ARV) or the proportion who had experienced outcomes of low CD4 count, death, or acquired immunodeficiency syndrome (AIDS). HIV - positive Aboriginal and non-Aboriginal women continue to become pregnant after being diagnosed as HIV positive. Aboriginal leadership and participation in programs that address the issues of women and of Aboriginal people are necessary to prevent the spread of this epidemic.
Storied moments: A visual narrative inquiry of Aboriginal women living with HIV (Immune deficiency). [MN] <u>Year</u> : 2002 <u>Author</u> : Caine, Vera Franziska Julianne. <u>Source</u> : University of Alberta	This visual narrative inquiry tells the stories of five urban Aboriginal women living with HIV and in telling their story tells part of our story and part of my story. Throughout this study we attempted to understand the complex, multi-layered stories of despair, struggle, hope and possibility. As well, we tried to make sense of our identity. In these stories there is a continuous shift between the present, past and future, between the known and unknown, between the told and untold, and between the self and others. Visual narrative inquiry combines the use of storytelling with photography to express life experiences. The women utilized disposable cameras during the study to visually document their everyday lives. Visual narrative inquiry helped us explore our life experiences in a relational context whereby the aboriginal women and myself became co-researchers and ultimately co-authors in the writing of stories and visual representation of our lives.
Experiences of Aboriginal HIV/AIDS programs in Calgary: The great teacher of	This is a qualitative study of how the urban Aboriginal population in Calgary, Alberta, Canada faces HIV/AIDS. It strives to understand how a global disease is translated within

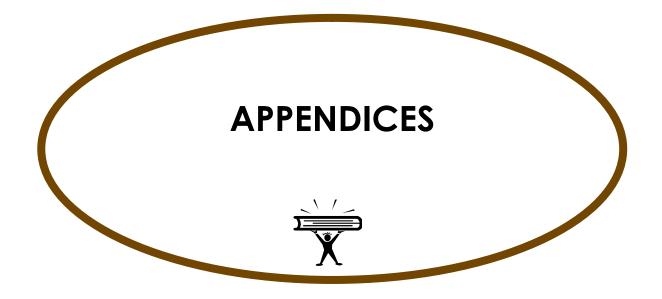
<u>Title</u>	Summary
compassion (Immune deficiency, Alberta). [MA] <u>Year</u> : 2002 <u>Author</u> : Romero Vivas, Isabel Laura <u>Source</u> : University of Calgary	a particular historical and social context. Contemporary Native people face many social challenges, a consequence of colonization, Residential Schools and historical and on- going racism. HIV/AIDS Aboriginal prevention agencies try to combine Western and Native perspectives, but they privilege the western one, since they are planned, implemented and funded by non-Aboriginal initiatives. According to Native people, HIV/AIDS is the Great Teacher of Compassion that "is here to teach the people how to live again as partners, families and communities". A "culturally appropriate" prevention model would acknowledge history and follow a <i>wholistic</i> health approach, involving body, mind, emotions and spirit. It would involve Aboriginals at all stages of the program, since HIV/AIDS is closely related to identity processes, self-esteem, Treaty rights and re-gaining self-control.
Aboriginal women's perspectives on 'culturally appropriate' HIV counselling and testing (Immune deficiency) [MSc.] <u>Year</u> : 2002 <u>Author</u> : Bucharski, Dawn Marilyn <u>Source</u> : University of Alberta	A qualitative study was conducted to determine Aboriginal women's perspectives on "culturally appropriate"; HIV counselling and testing. Data were collected through semi structured individual interviews with seven Aboriginal women, and with six women in a focus group, in a western Canadian city. The data were analyzed utilizing thematic content analysis. Four major categories were explicated: Aboriginal women's life experiences that may increase their risk for HIV infection; barriers to HIV counselling and testing for Aboriginal women; guiding principles of the ideal HIV testing situation; and characteristics of culturally appropriate HIV counselling and testing for Aboriginal women. The need for sensitivity to the hardships and life experiences Aboriginal women may have experienced was a pervasive theme in all of the categories. The study concludes with directions for further research and implications for HIV policy and programming for Aboriginal women.
The many directions of four stories: Aboriginal women's experiences living with addictions and HIV/AIDS (Immune deficiency) [MA] <u>Year</u> : 2000 <u>Author</u> : Ryan, Shannon Amber <u>Source</u> : Simon Fraser University	Stressing the centrality of ordinary human experience by focusing on "what is at stake" for particular participants in particular situations (Kleinman & amp; Kleinman 1991), this exploratory study involved listening, observing, analyzing, documenting and better understanding "things as they are" (Jackson 1996) for four street-involved, HIV-positive Aboriginal women. The particular situation and voices of street-involved Aboriginal women are rarely discussed in reference to policy development in the Downtown Eastside of Vancouver, in BC, in Canada, or within anthropological literature. Accordingly, this thesis contributes to existing knowledge, grounded in the voices and experiences of the four women who discuss "what is at stake" for them as HIV-positive Aboriginal women residing in Canada's most impoverished neighborhood. The thesis highlights the particular situations and circumstances in which four Aboriginal women live that contribute to their vulnerability

<u>Title</u>	Summary
	not just to HIV/AIDS, but to a number of constraining social factors that affect their overall health, safety and quality of life. To understand and better appreciate the women's lived experiences (Jackson 1996), or their positioned knowledge (Kleinman 1995), an ethnographic perspective that placed primary emphasis on narrative was utilized. Through the use of narrative, within a population health framework that takes a more comprehensive view of Aboriginal women's health to encompass the historical, social, cultural, economic, and physical factors as they interact with race and gender, I examine some of the factors that impinge upon the health of Aboriginal women, directed by the four powerful stories/voices of the women themselves.
Condom use among First Nations people living on- reserve in Ontario. [MSc.] <u>Year</u> : 1997 <u>Author</u> : Burchell, Ann Natalie <u>Source</u> : University of Toronto	Objective. To describe patterns of condom use among First Nations people living on-reserve in Ontario. Methods. Analysis of secondary data from the Ontario First Nations AIDS and Healthy Lifestyle Survey, a cross-sectional survey of 658 men and women living in eleven reserve communities. Individuals who had sexual intercourse in the last twelve months were included (n = 400). Descriptive statistics and multiple logistic regression were used to analyze condom use in the last twelve months. Results. Eight percent always, 31% sometimes, and 61% never used condoms. Of those who used condoms, 8% used them for sexually transmitted disease (STD) prevention only, 10% used them for birth control only, and 82% used them for both purposes. Multiple logistic regression revealed that age, gender, familiarity with the traditional way of life, having a steady sex partner, number of sex partners, worry about pregnancy, knowledge about HIV, knowing someone with AIDS, and embarrassment obtaining condoms had significant effects on condom use. Conclusions. The results have implications for the promotion of condoms for HIV/STD prevention among First Nations people living on-reserve in Ontario.
HIV infection in aboriginal women (immune deficiency, Alberta) [MN] <u>Year</u> : 1996 <u>Author</u> : Mill, Judith Ellen <u>Source</u> : University of Alberta	The issue of infection with the human immunodeficiency virus (HIV) leading to AIDS (acquired immunodeficiency disease) is both complex and challenging. As the AIDS epidemic has evolved over the past decade, researchers have identified practices and behaviours that influence transmission of the HIV virus. Although a cure for AIDS has not been found, treatments that may lead to long term control of the disease have been identified. Increasingly, health care practitioners have realized the need to understand the context of the behaviours that may place individuals at increased risk of HIV infection. HIV infection is an issue of concern in the Aboriginal community of Canada. Aboriginal women are over-represented in the number of new clients attending HIV clinics in a large urban centre serving northern Alberta. A qualitative research study

<u>Title</u>	Summary
	was designed to explore the cultural factors that relate to HIV infection in these women. The findings are presented in two papers within this thesis. An explanatory model for HIV illness is described in the first paper. Some of the findings relating to etiology and treatment of HIV illness are divergent from common biomedical views of the disease. In the second paper a model is developed to conceptualize the relationships that exist between the women's formative years, their self esteem and the survival techniques they used prior to becoming HIV-positive. These survival techniques may have placed them in situations that increased their risk of infection with the HIV virus.
The perceptions of sex among First Nations people living on- reserve in Ontario [MSc.] <u>Year</u> : 1995 <u>Author</u> : Bullock, Sandra Leah <u>Source</u> : University of Toronto	The objectives of this thesis are to determine: the perceptions of sex among First Nations People living on-reserve in Ontario; the associations between socio-cultural variables and the perceptions of sex; and the association between individuals' perceptions of sex and AIDS-related attitudes. Data from a cross-sectional, descriptive, quantitative survey, were used to meet the objectives. Confirmatory factor analysis verified the grouping of the sex descriptors on three dimensionspositive, negative, and necessity. Multivariate regression showed an association between the positive perception and age, education, familiarity with traditions, sex education from the Native tradition and Elders, and the importance of sex. Negative perceptions of sex are associated with gender, age, language, partner status, sex education from a partner, and the importance of sex. Embarrassment obtaining condoms is associated with the Catholicism, and perception-by-marital status interaction terms. Determinants specifically related to First Nations culture and traditions are found in this analysis to be related to more negative, and less positive perceptions of sex.
Disturbing the comfortable: A qualitative evaluation of workshops conducted by the Atlantic First Nations AIDS task force (immune deficiency) [MA] <u>Year</u> : 1994 <u>Author</u> : Lamon, Martha Ellen <u>Source</u> : Dalhousie University	The purpose of this study was to conduct a qualitative evaluation of the AIDS education workshops sponsored by the Atlantic First Nations AIDS Task Force. Seven AIDS education workshops were observed; the Project Coordinator and 23 workshop participants were interviewed. The respondents ranged in age from 14 years to middle aged adults. Using the Medicine Wheel as a guide I analyzed and interpreted the data to determine: (a) the consistency of the content of the workshops and the factors that influenced workshop implementation, (b) the participants' responses to the content and methodology of the workshops, (c) the respondents' and Project Coordinator's impressions of the content and methodology of the workshops, and (d) the perceived effects of the workshops on the HIV/AIDS-related knowledge, attitudes, skills, and behavioural intentions of participants. Three major findings were revealed. They are: (a) The AIDS

<u>Title</u>	Summary
	education workshops were very effective because the Project Coordinator came from within the population being educated, (b) the way the Project Coordinator conducted the workshops challenged respondents to question the validity of some of their behaviours and the way they thought about a number of issues, and (c) the workshops were effective in increasing knowledge; however, the need for more information, resources that could be easily accessed following the workshops, and for repeated visits by the AIDS educator to reinforce learning was identified.
Conveying Information About HIV/AIDS to a First Nations Community: An Evaluation [MA] <u>Year</u> : 1994 <u>Author</u> : Duncan, Jane E <u>Source</u> : University of Calgary	There are many sociodemographic variable that contribute to the poor health status of First Nations people. These variables taken together with the high rates of sexually transmitted disease, injection drug use, alcoholism and teen pregnancy indicate 1) that First Nations People are at significant risk of contracting HIV and developing AIDS and 2) that once present, the virus will have the opportunity to travel quickly throughout the community. The research question this study seeks to address is: how do First Nations People respond to existing media and messages intended to convey information to them about HIV/AIDS? A review of the literature suggests the effective materials must be culturally appropriate and community specific. This study evaluates the effectiveness of existing materials (videotapes, posters, pamphlets, condom covers, and comics) through the use of focus groups conducted on and around the Stoney Indian Reservation at Morley, Alberta. The data was viewed through three bodies of literature: social marketing, participatory research and the social construction of illness. The data strongly suggests that "culturally appropriate" is neither a simple nor well understood concept. Further, it is possible to have effective materials that not only communicate across Native community boundaries but also across Native-White boundaries. Cultural content is important but in some cases not as important as production quality. This study concludes that the construction of HIV/AIDS as a meaningful issue in Native communities is a precursor to any form of participation or ownership, and this can be facilitated in a pragmatic way through the utilization of the principles of social marketing.
First Nations students' perceptions of the relevancy of an AIDS/HIV curriculum (immune deficiency) [MA] <u>Year</u> : 1993 <u>Author</u> : Lutz, Sherri	The First Nations students' perceptions regarding the relevancy of an AIDS/HIV curriculum were examined. In particular, the presence of familiarity, relevancy and community ownership in the curriculum were explored. The participants were a selected group of First Nations grade 7/8 students who had been involved in a pilot project for First Nations students. Interviews, observations, rating scales and case studies were

<u>Title</u>	Summary
<u>Source</u> : University of Victoria	used to assess the presence of familiarity, relevancy and community ownership in the students' reports of their involvement in a culturally relevant curriculum. The AIDS/HIV curriculum was, in general, not perceived as being culturally relevant for the Saanich First Nations grade 7/8 students because most of the material was unfamiliar, irrelevant and had a low sense of community ownership. Suggestions are made about designing a curriculum for First Nations students that takes into consideration cultural-specific First Nations values, teachings and histories.
HIV and AIDS and aboriginal communities in Canada. A socially accountable participatory study (immune deficiency) [MA] <u>Year</u> : 1992 <u>Author</u> : Peberdy, Sally Ann <u>Source</u> : Carleton University	Using a socially accountable participatory research methodology, this thesis examines the needs of Aboriginal people living with AIDS and HIV (PLWA/HIV) in Canada, and the vulnerability of communities to infection as articulated by PLWA/HIV and Aboriginal AIDS organizations involved in education, awareness and prevention programs and the provision of services and support. The problem is placed in the socio-geographical context of Aboriginal communities, which it is argued, affects the demand for, and the pattern of demand for services and support. At the same time it highlights differences in the needs of people and communities living on and off reserve. The results identify common themes of concern which include: the need for education - for acceptance as well as prevention: income; housing; nutrition and medical treatments; appropriate service delivery; and funding. Overall participants enunciated a need for a holistic approach to education and health which can address the factors influencing risk to communities and the lives of PLWA/HIV and which emphasizes the importance of traditional values and the healing process that is taking place in communities today, as well as a need for communities and PLWA/HIV to be in control of the development of programs for effective culturally relevant and community sensitive education and service provision.
The effect of a comprehensive AIDS curriculum on motivating changes in Northern Canadian college students (immune deficiency) [MEd.] <u>Year</u> : 1990 <u>Author</u> : Moskal, Rosemary Jean <u>Source</u> : University of Alberta	A comprehensive curriculum was designed to allow students the opportunity to learn the facts about AIDS transmission and prevention, discuss personal opinions, clarify values, and develop the skills necessary to practice low risk behaviors. The course was implemented over two months to 123 predominantly aboriginal college students (80%) who were attending the Fort Smith Thebacha Campus of Arctic College in the Northwest Territories. An ANOVA revealed the experimental subjects who received the course, significantly increased their knowledge of AIDS transmission and prevention (p \$<\$.001), their attitude towards low risk behaviors (p \$<\$.01) and their compassionate attitude towards those afflicted with the AIDS virus (p \$<\$.05) over the subjects in the control group who received no course on AIDS.





General Interview Schedule for Face-to-Face Interviews

- 1. To begin, I'd like to know a little bit about you probes:
 - a. how old you are,
 - b. how long you have lived in this community, or elsewhere in the north
 - c. how often you travel to other communities (probe reasons for travel)
 - d. what you enjoy about living here,
 - e. and what you find challenging about living here

As you know, this study is about gathering information on what people have heard about HIV/AIDS or hepatitis C, what they have heard about these diseases in northern Saskatchewan, and what they feel is needed to prevent people in the north from becoming sick with these disease, or to help people who are already sick. These are the types of questions I would like to ask you now.

- 2. How do you think people get HIV? hepatitis C? (People may ask what these are –outline briefly)
 - a. Probes –what causes it? How is it transmitted?
- 3. Which groups of people have been most affected by HIV or AIDS? (probes –around the world, in Canada -ethnicity, age, sex) hepatitis C?
- Studies show that Aboriginal people in Canada are more vulnerable to HIV infection than non-Aboriginal people. Why might that be?
 a. Probes –social circumstances, poverty, behaviours
- 5. How much of a problem do you think HIV or AIDS is in your community? hepatitis C?
- 6. What would be the first thing to come to your mind if you heard that someone in your community had HIV or AIDS? hepatitis C?
 - a. How do you think that would affect the community?
 - b. How would the community respond if it was known that someone had HIV from a blood transfusion? Injection drug use? Homosexual activity? (probes –Same? Differently?) Why?
- How would you feel if one of you family members has HIV or AIDS? hepatitis C? (probes –compared to a sickness like cancer or diabetes, for example)
- 8. How would someone know if they have HIV or AIDS? hepatitis C?

- 9. Where would someone from your village go to find out:
 - a. Information about HIV or AIDS? hepatitis C?
 - b. If they have HIV or AIDS? hepatitis C?
 - c. What might make it harder for people to go to these places? Easier? (e.g. anonymity, fear, trust of service providers)

10. Should people with HIV or AIDS be allowed to (with hepatitis C be allowed to):

- a. Attend community suppers or other social gatherings in the village? Why do you feel this way? What would change the way you feel?
- b. Be allowed to work with food in a restaurant? Why do you feel this way? What would change the way you feel?
- c. Attend/teach school? Why do you feel this way? What would change the way you feel?
- d. Participate in church or other spiritual congregation? Why do you feel this way? What would change the way you feel?
- e. Be in public areas (e.g. Band Office, Health Clinic waiting room)? Why do you feel this way? What would change the way you feel?
- 11. Have you heard rumours of anyone in your community being infected with HIV? hepatitis C?
 - a. How did/would this affect the person the rumour was about?
 - b. How did/would this make you feel about that person?
 - c. What affect did/ would this have in your community?
- 12. Have you known anyone living with HIV or AIDS? hepatitis C?
 - a. What do you think it was/would be like for that person, and their family to live in the community?
 - b. Who would they be able to talk to for support?
- 13. What problems do you feel people from northern Saskatchewan who are HIV-positive (might) face? (probes –lack of privacy or anonymity, isolation, loneliness, others afraid of them/avoiding them) With hepatitis C?
- 14. In which ways is your community vulnerable to HIV coming in? (probes: injection drug use, unprotected sex, frequent travel to/from large urban centers like Saskatoon, alcohol/drug abuse). To hepatitis C coming in?
- 15. What things could be done to make your community a more supportive place for people with HIV or AIDS? hepatitis C?
 - a. What are some of the problems or limitations?

- 16. What things could be done to prevent people in your community from getting HIV infection? hepatitis C?
 - a. What are some of the problems or limitations?
- 17. What do you think should be the most important thing your community should focus on to prepare for HIV prevention and HIV or AIDS support activities?

This next question is not specifically about HIV, AIDS or hepatitis C. This is a more general question about your health needs and the things you do to stay healthy.

- 18. In general, what are some of the things you need or do to stay healthy? Is it difficult for you to get access to any of these things? (e.g. food, medicine, condoms, particular services, avoid alcohol, drugs...)? Why / why not?
 - a. Probes: money, privacy/anonymity, service not available
 - b. Have you ever found it difficult to do something important to your health because you were afraid of or worried about how friends/ partner/ family would react? (Probes –say no to alcohol or drugs, say no to sex, talk about safe sex with a partner)

Now one question about your own possible vulnerability to HIV or hepatitis C, or that of people close to you:

19. Do you consider yourself safe from HIV infection? hepatitis C? Why/why not? What about family members or friends? Why/why not?

We have three more general questions to make sure we haven't left anything out...

- 20. Is there anything you feel it is important for us to understand about HIV or AIDS in your community or in northern Saskatchewan in general that we haven't already talked about? About hepatitis C?
- 21. How do you feel about your community participating in a project like this? How do you feel about your participation?
- 22. Would you be interested in participating in any kind of community working group/ board/ advisory group on HIV and AIDS or hepatitis C?



<u>Front Line Worker Interview Schedule – Health and Social Service</u> <u>Providers</u>

- 1. What is the name of the agency/ organization you work for?
- 2. What areas of the north does this organization serve? (e.g. far north, north central...)
 - a. What areas of the north do you serve?
- 3. How long have you been working with this organization in the north?
- 4. What services does your agency provide?
- 5. Can you describe your job responsibilities?
- 6. What is the profile of your clients age, gender, ethnicity, on or off reserve, etc.,
 - a. What proportion of your clients are Aboriginal?
- Does your organization have any services/programs that relate specifically to HIV or AIDS? hepatitis C?
 - a. Are some of these services part of your job responsibility?
- 8. How do your clients usually find out about your services?
- 9. What do you think are some of the issues relating to HIV or AIDS in Aboriginal communities? hepatitis C?
- 10. What kinds of issues do you feel that your clients, or anyone in this community, are facing in relation to HIV education and prevention? hepatitis C?
 - a. Are the issues different for:
 - i. men and women?
 - ii. Aboriginal or non-Aboriginal people?
 - iii. people with high or low socioeconomic status?
- 11. What kinds of issues do you feel that your clients, or anyone in your community are facing in relation to HIV screening? hepatitis C?
 - a. Are the issues different for:
 - i. men and women?
 - ii. Aboriginal or non-Aboriginal people?
 - iii. people with high or low socioeconomic status?

- 12. What kinds of issues do you feel that your clients, or anyone in your community, are facing in relation to HIV or AIDS treatment? hepatitis C?
 - a. Are the issues different for:
 - i. men and women?
 - ii. Aboriginal or non-Aboriginal people?
 - iii. people with high or low socioeconomic status?
- 13. Do you feel that you are able to adequately address the needs of your clients specific to HIV or AIDS? hepatitis C?
- 14. What are some of the issues that come up for you as a service provider specific to HIV/AIDS or hepatitis C?
- 15. What are some of the major barriers you experience when attempting to deliver HIV or AIDS or hepatitis C services to this geographic area?
- 16. How might these barriers be overcome?
- 17. If a client came to you:
 - a. With questions or concerns about HIV or AIDS, what would you do?
 - b. With questions or concerns about hepatitis C, what would you do?
- 18. What sorts of services/programs do you feel are missing?
- 19. How should education and other prevention activities be carried out? (probes: workshops, networking)
- 20. What information would you like to have that would tell you more about the issues relating to HIV or AIDS in Northern Saskatchewan communities? hepatitis C? How do you think this information can be introduced into the community?
- 21. What steps have been taken/ do you think need to be taken to create a plan to address HIV or AIDS in Northern Saskatchewan communities? hepatitis C?
 - a. Probes: interagency involvement?; community level response?
- 22. Would be you interested in being part of an ongoing community advisory committee/board/taskforce/working group related to HIV and AIDS?
- 23.1s there anything you feel it is important for us to understand about HIV or AIDS in your community or in northern Saskatchewan in general that we haven't already talked about? About hepatitis C?



FOCUS GROUP INTERVIEW SCHEDULES

Elders Focus Group Questions: (separate groups for male and female)

To begin:

Welcome everyone, and thank you for your participation in this discussion group. As you know, this study is about gathering information on what people have heard about HIV/AIDS or hepatitis C, what they have heard about these diseases in northern Saskatchewan, and what they feel is needed to prevent people in the north from becoming sick with these diseases, or to help people who are already sick.

Before we begin discussing these issues, I would like us to take a few moments to introduce ourselves to the group. Could you tell us a little bit about yourself, whatever you feel comfortable sharing (age, how long you have lived in this community, or elsewhere in the north, how often you travel to other communities, what you enjoy about living here, and what you find challenging about living here) and why you decided to participate in today's discussion.

- 1. What would be the first thing that would come to your mind if you heard that someone from your community had HIV or AIDS?
 - a. Have you heard rumours/ known anyone with HIV?
 - b. What effect did this/ would this have in your community?
- How do you think people get HIV or AIDS? hepatitis C?
 b. Probes –what causes it? How is it transmitted?
- 3. What things could be done to prevent people in your community from getting HIV or AIDS? hepatitis C?
- 4. What things could be done to make your community a more supportive place for people with HIV or AIDS? hepatitis C?
- 5. Do you talk to your children/ grandchildren about HIV or AIDS? hepatitis C? Why/why not?
 - a. Where would they go to get information about HIV or AIDS or hepatitis C?

Adult Focus Group Questions: (separate groups for male and female)

Welcome everyone, and thank you for your participation in this discussion group. As you know, this study is about gathering information on what people have heard about HIV/AIDS or hepatitis C, what they have heard about these diseases in northern Saskatchewan, and what they feel is needed to prevent people in the north from becoming sick with these diseases, or to help people who are already sick.

Before we begin discussing these issues, I would like us to take a few moments to introduce ourselves to the group. Could you tell us a little bit about yourself, whatever you feel comfortable sharing (age, how long you have lived in this community, or elsewhere in the north, how often you travel to other communities, what you enjoy about living here, and what you find challenging about living here) and why you decided to participate in today's discussion.

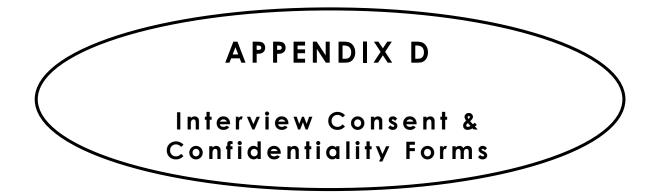
- 1. What would be the first thing that would come to your mind if you heard that someone from your community had HIV or AIDS?
 - a. Have you heard rumours/ known anyone with HIV?
 - b. What effect did this/ would this have in your community?
- How do you think people get HIV/AIDS? hepatitis C?
 c. Probes –what causes it? How is it transmitted?
- 3. What things could be done to prevent people in your community from getting HIV or AIDS? hepatitis C?
- 4. What things could be done to make your community a more supportive place for people with HIV or AIDS? hepatitis C?
- 5. Do you talk to your children about HIV or AIDS? hepatitis C? Why/why not?
 - a. Where would they go to get information about HIV or AIDS or hepatitis C?

Youth Focus Group Questions: (separate groups for male and female)

Welcome everyone, and thank you for your participation in this discussion group. As you know, this study is about gathering information on what people have heard about HIV/AIDS or hepatitis C, what they have heard about these diseases in northern Saskatchewan, and what they feel is needed to prevent people in the north from becoming sick with these diseases, or to help people who are already sick.

Before we begin discussing these issues, I would like us to take a few moments to introduce ourselves to the group. Could you tell us a little bit about yourself, whatever you feel comfortable sharing (age, how long you have lived in this community, or elsewhere in the north, how often you travel to other communities, what you enjoy about living here, and what you find challenging about living here) and why you decided to participate in today's discussion.

- 1. What would be the first thing that would come to your mind if you heard that someone from your community had HIV or AIDS?
 - a. Have you heard rumours/ known anyone with HIV?
 - b. What effect did this/ would this have in your community?
- 2. What behaviours/ situations do you feel make people vulnerable to HIV infection? hepatitis C infection?
 - a. What makes it hard to avoid these situations/ behaviours?
 - b. What would make it easier to avoid these situations/ behaviours?
 E.g. problem solving skills, negotiation skills, making a negative into a positive...
- 3. What kinds of suggestions do you have to raise awareness among your community's youth on issues related to HIV or AIDS? hepatitis C? E.g. videos, drop in center, pamphlets etc
- 4. What services/ programs do you think youth need related to HIV or AIDS and hepatitis C education, prevention, and treatment? E.g. youth sexual health education/treatment center... Are some available now? Are they easy/ difficult to access? Why?





SASKATCHEWAN POPULATION HEALTH AND EVALUATION RESEARCH UNIT, INC.

FOUNDING MEMBERS:

University of Regina

University of Saskatchewan

Health Services Utilization and Research Commission (Sask.)

Saskatchewan Association of Health Organizations

Saskatchewan Health

Interview Consent Form

Project Title: Determining Factors Towards Improving HIV/AIDS Support Structures in Northern Saskatchewan Aboriginal (Métis and First Nations) Communities.

Principal Investigator:

Dr. Sylvia Abonyi SPHERU University of Regina Regina, SK S4S 0A2 306.966.2194 (Saskatoon) Sylvia.abonyi@uregina.ca

Overview: The purpose of this project is to determine what people in northern Saskatchewan think about HIV/AIDS and hepatitis C, the impact that HIV/AIDS and hepatitis C may have (or has already had) on themselves or in their communities, and what they see as effective and appropriate prevention, education, and management initiatives.

Methods: Four communities, including yours, have volunteered to participate in this study. We will be conducting face-to-face interviews and discussion groups with people from each of the participating communities.

We are asking for your participation in an interview to give us your perspectives on HIV/AIDS and hepatitis C in your community. We anticipate that the interview will take no more than one to one and half hours. Please be advised that you do not have to answer any questions you are not comfortable with and that you may change your answers or withdraw from the study at any time. No questions will cause undue physical or emotional stress. All interview data will be kept confidential and only the research group will be aware of your identity. You will have the opportunity to review your transcript, if you wish. All materials pertaining to this interview (tapes, digital recordings, hard copies of transcripts, electronic files on disk), will be stored in the office of the principal investigator in a locked cabinet. Any findings from this project will be reported in such a way that no individual participant is identifiable. Your answers will only be used for the purposes of this project. All original data will be destroyed no later than three years after the end of this project.

> Health Sciences Building, University of Saskatchewan 107 Wiggins Road, Saskatoon, SK, S7N 5E5

If you have any questions or concerns regarding the procedures and goals of the study as they are outlined here, please contact Dr. Sylvia Abonyi at the phone number or e-mail address listed above.

This project was approved by the Research Ethics Board, University of Regina. If research participants have any questions or concerns about their rights of treatment as participants, they may contact the chair of the Research Ethics Board at 306.585.4775 or by e-mail at research.ethics@uregina.ca.

I have read/ or had read to me, and understood the contents of this consent form. I agree to participate in this interview and the study: ____Yes ___No

I have received a copy of the consent form for my files: _____Yes ____No

I agree to have my interview audio taped: _____Yes ____No

I have received a \$_____ honorarium for my participation ______Yes _____No

Participant Printed Name

Participant Signature

Researcher Signature

Date

I wish to review my transcript:

_____Yes _____No

I understand that my address will be used only to arrange for transcript review:

Name:	
Address:	
Phone :	



SASKATCHEWAN POPULATION HEALTH AND EVALUATION RESEARCH UNIT, INC.

FOUNDING MEMBERS:

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Discussion Group Consent Form

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Principal Investigator:

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You will have the opportunity to review the transcript of this discussion, if you wish. All materials pertaining to this discussion (tapes, digital recordings, hard copies of transcripts, electronic files on disk), will be stored in the office of the principal investigator in a locked cabinet. Any findings from this project will be reported in such a way that no individual participant is identifiable. Your answers will only be used for the purposes of this project. All original data will be destroyed no later than three years after the end of this project.

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I have received a copy of the consent form for my files: _____Yes ____No

I agree to have the discussion group audio taped: _____Yes ____No

I have received a \$	honorarium for my	participation	Yes	No
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Participant Printed Name

Participant Signature

Date

I wish to r	review the tr	anscript of this discussion	on, only with respect to my responses:
	Yes	No	
I understa	nd that my a	address will be used only	y to arrange for transcript review:
Name:			
Address:			

Phone :



Saskatchewan Population Health and Evaluation Research Unit

DECLARATION OF ANONYMITY AND CONFIDENTIALITY

PROJECT:

Determining Factors Towards Improving HIV/AIDS Support Structures in Northern Saskatchewan Aboriginal (First Nation and Métis) Communities

Any information and all records gathered during the course of research is privileged information – whether these concern a single interview, or include observations about an individual's home, family, lifestyle, or activities. The same privilege attaches to all records or documents associated with individuals participating in research projects as respondents.

I, _____ (PLEASE PRINT), affirm that I will uphold the general unconditional guarantee of respondent anonymity and confidentiality.

I also affirm that I will uphold personally, and in cooperation with my research colleagues, the following additional guarantees:

- No record will be reproduced in any manner, in full or in part, having potential personal identification capabilities either directly or indirectly;
- No record will be reviewed in any way, including casual reading by anyone without express authorization;
- No directly or indirectly personally identifying information will at any time be disclosed to anyone;
- No records, or reproductions of records, will be removed at any time from the premises normally used by researchers and staff, without the specific approval of the project leader.

YOUR SIGNATURE

YOUR NAME, PRINTED

WITNES	S	
	//	//
DATE	MONTH	YEAR

APPENDIX E

Participant Comments on the Interview Experience and on Participating in this project One of our concerns about conducting this project in the four participant communities was that the project itself not contribute to the creation of rumours about HIV/AIDS or hepatitis C or create fear or panic in communities. The Steering Committee met at length on numerous occasions to develop a process of communicating about the intent of this research and for dealing with emergent negative scenarios. We also decided to ask participants at the end of their interviews how they felt personally about their participation and the project taking place in their communities, as one of the ways of checking that our process was effective. This section summarizes some of the feedback we received.

Overall, most participants felt positive about their participation and about their community's participation.

Reasons why several participants did not rate their experience as 100% positive or comfortable were related to:

- The interview process was a new experience for them.
- Distractions during the interview prevented them from being as open as they wanted to be during the interview.
- Concerns about the confidentiality of their names in the project this participant was O.K. with the interview process once they were reassured that their name would not be used.

These participants, however, did not rate the interview experience as outright negative.

Personal Experiences

Over 90% of face-to-face interview participants said they were O.K. with their participation in the project. Many participants said they were now more aware of these diseases because of the interview. Below is a sample of comments from participants on their interview experience and/or the overall project:

"It was all right, I know a little bit more now (laughs)." – Man, Age 18-29

"I'm glad I can help and I would do it again." – Woman, Age 30-54

"It will probably help out. They'll help people to understand more about disease." – Woman, Age 30-54

"Um, um I feel fine about that study. Something to think about anyway." – Woman, Age 30-54

"I always try to do whatever. Just like this interview, I didn't want to turn it down because I know that you won't have many people turn to you, so I just say yes. And that's why I would participate in anything that would help the community." – Woman, Age 55+

"O.K. I, I, I feel comfortable you know, talking about this. Oh ya." – Man, Age 55+

"I think better. I feel good. This is the first time I have, you know, I wanted to participate in a study like this and I'm glad that you came out here today to, to voice my concerns on some of the issues that are going to face our Native kids in the community." – Woman, Age 55+ "I'd feel comfortable you being here in my home instead of going, having to go over there because a lot of people don't have transportation to go there so it's better that you're going from house to house, you know, even though, you know, you just ask them if you can go there. I think this is the best thing that could be done because it's confidentiality in your own home and nobody's gonna hear it, but still there's gonna be, like doing it during school hours and all that when there's no kids around, you know, so I, I think this is a pretty good start. [... continues] I feel like I, I accomplished something (laugh). Like I finally can let it out, let it all out, you know, about, about all these diseases and everything where, where I'm not gonna hide. Like nobody talks about it, nobody wants to discuss it with you, you know, and me talking about it right now it makes me feel good 'cause I know that what I'm giving you I know you're gonna try and go and do everything to help our community. You know, it's like I'm helping the whole community by talking to you about it so I feel good about it "

– Woman, Age 18-29

"I feel good that I'm able to have to draw on from my personal experience and observations of other communities and how they've treated individuals that have these diseases [...]." – Man, Age 30-54

Community Participation

Over 90% of participants had no issues with their community participating in this project. Many participants felt that the project would create more awareness in their community about HIV/AIDS and hepatitis C issues (and even increase their own awareness about these issues).

"Good because it creates more awareness for people to make it a safe environment." – Man, Age 30-54

"I think it's good, it gives people more knowledge to know about this stuff eh? Like even hepatitis C, I didn't even know there was a hepatitis C (laughs)." – Man, Age 18-29

"I would go for it. Myself I would go for it. In the town we need to understand these things 'cause it's coming this way so. It's early." – Woman, Age 30-54 "I feel real great that, you know, the councilors are finally recognizing us to understand these, these sicknesses that are going around in the north and I know that lot of people are gonna get educated by what you are doing here and that's really great what you are doing." – Man, Age 30-54

"It's a really good approach to find out how to help our people, it's positive." – Woman, Age 30-54

"Another step toward better understanding and preventing people from getting sick." – Man, Age 18-29

"I am happy about the things I did not know about. Now I know about the dangers of being at risk of the diseases. I need to know more about the symptoms/signs of an infected person. I'm very concerned now for other children/youth/and me." – Man, Age 18-29

"I think it, it's good. This is, this is a start. People should know about HIV or hepatitis C and homosexuality and lesbianism and the whole thing. You know, we can't hide forever. Some day we're gonna be, you're gonna be there. You're gonna get one of these things and we shouldn't, we can't hide." – Woman, Age 55+

"I think it's really good. I think kids should know more about this and so [also] the families, the older people. One of these days we might be facing that we have to take care of one of our own. We have to learn more about it." – Woman, Age 55+ "I think it's, I think it's cool." – Woman, Age 18-29

"It feels awesome man." – Man, Age 18-29

"It's great. I like it." – Woman, Age 18-29

"It's good. It's about time." – Man, Age 18-29

"It's pretty good to do these kind of things to get people's input on stuff like this and basically work from here." – Man, Age 18-29