The Red Road: Pathways to Wholeness, An Aboriginal Strategy for HIV and AIDS in BC

Evaluation Report

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Background

The BC Aboriginal HIV/AIDS Task Force was established in 1996 to bring together on and off reserve organizations and projects dealing with HIV/AIDS. The Task Force has worked to increase the network of those living with HIV/AIDS, the professionals working in the field and those who have an interest in addressing HIV/AIDS in their community. One of the primary achievements of the Task Force has been the development and implementation of the Red Road: Pathways to Wholeness, An Aboriginal Strategy for HIV and AIDS in BC (hereafter referred to as the Strategy).

Prior to completion of the Strategy, consultation sessions were held in eight different communities through out the province. The primary goals of these sessions were:

- to collect ideas, opinions and concerns from participants to support the final draft of the Strategy, and
- to provide an overview of the draft strategy, raise awareness and promote implementation through out the province.

The Strategy, which was officially launched on February 1, 1999, is a pathway to increase the quality of life of all Aboriginal people. This is accomplished by respecting and integrating the traditional and cultural values and beliefs of individuals, families and communities. The Strategy supports the use of those traditions in the treatment of HIV/AIDS in Aboriginal and non-Aboriginal communities.

The Strategy contains 50 recommendations to address Aboriginal HIV/AIDS in BC, which fall under the following categories:

- building healthy communities
- raising awareness of HIV/AIDS
- preventing HIV transmission
- diagnosing HIV infection and starting treatment early
- maintaining the health of Aboriginal people living with HIV
- caring for Aboriginal people living with AIDS
- providing leadership
- securing funding for Aboriginal HIV/AIDS services
- training the necessary personnel
- research to support effective and relevant program planning

An integral component of the implementation of the Strategy is the creation of the Red Road HIV/AIDS Network (hereafter referred to as the Network) which incorporated on May 7, 1999. The purpose of the Network is to:

- reduce or prevent the spread of HIV/AIDS
- improve the health and wellness of Aboriginal people living with HIV/AIDS

- increase awareness about HIV/AIDS and establish a network which supports the development and delivery of culturally appropriate, innovative, coordinated, accessible, inclusive and accountable HIV/AIDS programs and services

Evaluation Objective

In the fall of 1999, the Network put out a Request for Proposals for an evaluation of the Strategy. The objective is to evaluate general knowledge and the initial impact of the Strategy in the Aboriginal communities in BC.

There are four components of the evaluation objective outlined in this report. These are:

1. Overall knowledge and understanding of the Strategy
2. Impact of the Strategy
3. Roles of all community partners related to the Strategy
4. Challenges or barriers to implementation of the Strategy

Evaluation results and findings have been organized based on these four components.

Methodology

It has been just over one year since the official launch of the Strategy. This is relatively early in the implementation phase, so this evaluation may be considered to be the first part of a longer process that will evaluate the actual implementation of the Strategy over the longer term.

The budget for this evaluation did not allow for extensive travel. It was therefore determined that information and data would be collected through the use of a survey that was distributed to Aboriginal communities and organizations throughout the province.

As a first step, the consultant reviewed the Strategy, the verbatim proceedings from the eight community consultation sessions, similar evaluations from other regions and other relevant documentation. This supported the development of the evaluation tools that include a workplan, survey and survey participant list.

The survey participant list was developed to ensure representation of:

- individuals who participated in the consultation sessions
- individuals who did not participate in the consultation sessions
- geographic representation from through out the province (particularly from the eight regions where the consultation sessions were held)
- rural communities, particularly northern and remote communities
- urban communities

- off and on reserve health programs and services
- Aboriginal people living with HIV/AIDS
- family members of Aboriginal people living with HIV/AIDS
- health professionals
- HIV/AIDS advocates

In November 1999, the consultant met with the Red Road Council. The purpose of the meeting was to confirm expectations related to the evaluation, review the initial drafts of evaluation tools, identify any specific concerns, confirm and identify further survey participants and obtain final approval for project time lines.

Surveys were initially mailed and faxed out to 60 different communities and organizations. All mailings included return, self addressed, stamped envelopes for participants to easily return completed surveys in confidence. Upon request and referral, another 27 communities, organizations and individuals received the survey. A total of 87 communities and individuals received copies of the survey.

All potential survey participants were advised of strict confidentiality processes that would be followed by the consultant and the Network (the sponsoring organization). All completed surveys are to be kept as confidential records by the consultant. All data collected was analyzed and summarized by the consultant and submitted in the form of a final report to the Network. No names were to be connected to any specific comments, unless directed by the participant. All comments and participant responses in the report are presented anonymously.

Once the surveys were sent out, the consultant began follow up telephone contact to each of the survey recipients. Recipients were given the choice of completing the survey over the telephone with the consultant (immediately or at a future scheduled time) or completing the survey independently and returning it by facsimile or mail.

In February 2000, the consultant attended a second Council meeting. The purpose of this meeting was to report on the status of the evaluation, provide initial findings and distribute extra copies of the survey. A decision was reached that all members of the Council would receive a copy of the first draft of the evaluation report and have an opportunity to review and provide comments.

In April 2000, the consultant submitted the final report to the Network.

Results/Findings

A total of 87 surveys were distributed through out the province. Over 130 follow up telephone calls were made to the survey recipients. A total of 36 surveys were completed (41% response rate). One survey was completed via an in-person interview with a

participant in the Vancouver area. The greatest number of surveys, 21, were completed over the telephone. The remaining 14 surveys were completed independently by the participants and returned by mail or facsimile.

Only 8 survey recipients, who were contacted by telephone, flatly refused to participate. The reasons cited for non-participation are as follows:

- 5 recipients advised that there was no longer a staffed position responsible for HIV/AIDS support work, and
- 3 recipients advised that their community was not affected by HIV/AIDS and therefore, they had no comment.

Three of the survey participants are aboriginal people living with HIV or AIDS. It is of interest to note that all of these individuals live off reserve. It is also of interest to note that all 3 are actively involved, through volunteerism, in dealing with the disease, acting as advocates and providing peer counseling.

At least 9 survey participants attended one of the 8 consultation sessions hosted by the BC Aboriginal HIV/AIDS Task Force.

Survey Participant Data

Gender

Male	17%
Female	83%

Ethnicity

Aboriginal	86%
Metis	6%
Non-Aboriginal	8%

As with most social programs and services, the greater percentage of employees are female. All of the non-aboriginal participants were health professionals (e.g. Nurses).

Employment

On-reserve	72%
Off-reserve	28%

Residence

On-reserve	67%
Off-reserve	33%

It was difficult to obtain completed surveys from off-reserve organizations, those that did respond were organizations that have specific HIV/AIDS programs and services.

Age

20 – 30 years	22%
31 – 40 years	25%
41 – 50 years	25%
50+ years	28%

Overall Knowledge and Understanding of the Strategy

Survey participants were asked if they were aware of the Red Road: Pathways to Wholeness, an Aboriginal Strategy for HIV and AIDS in BC. Of the 36 respondents, 24 (67%) indicated that they are aware of the Strategy. However, only half of those indicated that they have read the entire Strategy and have a strong working knowledge of its' contents.

Respondents have a fairly good understanding of the primary goals and recommendations of the Strategy. When asked, the survey participants identified a large number of goals and recommendations, which included: to increase access to care and medication; to mobilize action on a greater level to push for change; to promote education and awareness; to lower rates of infection; to develop more awareness programs; to identify program and service overlaps; to recommend a cultural and traditional response to HIV/AIDS amongst aboriginal communities in BC; etc.

Survey participants responded with a high level of confidence when asked why an Aboriginal Strategy is required. Respondents recognize that First Nations people are at an increased risk for infection due to socio-economic circumstances. More importantly, Aboriginal people have different lived experiences and cultural needs and therefore need a different approach to addressing the issue. Survey participants clearly stated that a Strategy for Aboriginal people, by Aboriginal people, has a better chance of being recognized and implemented at the community level.

> *"The Strategy articulates the statistics, challenges, barriers to service delivery and provides direction to communities."*
> Survey Participant

Impact of the Strategy

An excellent measure of the impact that the strategy has had on Aboriginal communities is in the development of new programs and initiatives. Just over half, or 53%, of the survey participants advised that new projects were initiated in their community as a result of the Strategy.

New projects that have been initiated in communities include: HIV/AIDS workshops; community dinners with keynote speakers; the development of community HIV/AIDS plans and protocols; implementation of needle exchange programs; accessing existing services such as Healing Our Spirit; statistics collection; and distribution of condoms, pamphlets and posters.

Survey participants were asked to consider the impact of the Strategy in their community. The following responses were provided by the survey participants regarding their perceptions of the impact of the Strategy related to community awareness about HIV/AIDS and the availability of culturally sensitive programs and services for Aboriginal people.

As a result of the Strategy, awareness has increased about the transmission of HIV/AIDS.

Strongly Agree	6%
Agree	63%
Don't Know	17%
Disagree	11%
Strongly Disagree	3%

This is a very strong and positive response. Almost 70% of survey participants agree that awareness levels have increased.

As a result of the Strategy, awareness of healthy sexuality, healthy relationships and alternatives increased.

Strongly Agree	2%
Agree	40%
Don't Know	34%
Disagree	20%
Strongly Disagree	0%

It is of interest to note that according to the HIV Surveillance System of the BC Centre for Disease Control, the number of Aboriginal people that were newly diagnosed with HIV in 1999 dropped by 46% from the previous year.

There is an increased awareness and sensitivity in the non-Aboriginal community regarding Aboriginal cultures, beliefs and values.

Strongly Agree	9%
Agree	34%
Don't Know	29%
Disagree	20%
Strongly Disagree	8%

Traditional treatment and rehabilitation methods have been developed and access to mainstream medicine has improved.

Strongly Agree	3%
Agree	26%
Don't Know	34%
Disagree	31%
Strongly Disagree	6%

Sensitive social support systems and services to Aboriginal people living with HIV/AIDS and their families has been developed and provided.

Strongly Agree	6%
Agree	11%
Don't Know	31%
Disagree	49%
Strongly Disagree	3%

This statement had the strongest negative response. Participants, particularly from northern communities, state that cultural sensitivity is still a very big challenge in program and service delivery.

Roles of Community Partners Related to the Strategy

Survey participants that work within First Nations government or Aboriginal organizations have a fairly clear understanding of their role related to the Strategy. Community partners advise that they are responsible for: increasing access to care; ensuring education and awareness about HIV/AIDS through the coordination of community workshops; facilitating access to assessment and diagnosis; ensuring awareness of Strategy; implementing the Strategy at the community level; etc.

Many respondents indicated that they wish more work could be done in this area. However, a lack of human and financial resources simply does not allow for it.

> *"We really need a way to exchange ideas/models that are working in our communities."*
> Survey Participant

Some survey respondents inquired about the roles of the various provincial organizations. They indicated that it would be very helpful to know exactly what services are provided by each of these organizations.

Challenges or Barriers to Implementation of the Strategy

The most common barrier cited by community members and service providers is a lack of human and financial resources.

Strategies can not be implemented and services can not be provided without the resources to carry them out successfully. Some respondents indicated that they have found creative ways to address the funding issue. Most often community fund raising events such as bingo and raffles are used to fund community programs and services.

There are very few communities and organizations that actually have an HIV/AIDS coordinator or designated staff. Responsibility for these activities often falls to the Community Health Representative, Community Health Nurse or other health or social program staff.

Another common barrier to implementation of the Strategy is fear. Survey participants indicated that an overall lack of awareness about HIV/AIDS and embarrassment leads to fear and denial. Many respondents indicated that there is a very high level of denial in their community related to HIV/AIDS. Many asked for help or information on how to move past this barrier in a respectful way.

Respondents from the off-reserve, urban setting noted that there is still a considerable amount of prejudiced and stereotyping of Aboriginal people.

> *"It is really tough to go in and ask for help when you feel like they are looking at you and judging you."*
> Survey Participant

Northern and remote communities have considerable isolation issues. There are often few, if any, HIV/AIDS programs and services directly in the community. Community members are required to leave home to access services. Respondents from northern and remote communities also indicated that it is quite difficult to get resource people to visit their community. Many noted that when resource people visit, they are often not able to stay long enough ensure community members develop a level of trust and confidence to approach them with questions and needs.

Survey participants provided an extensive list of the resources that are needed in their community and/or organization to address HIV/AIDS service needs. These include:

- a strategy implementation model(s)
- money for research and support
- information on what's working in other communities
- information on how to support families and people living with HIV/AIDS
- lots of pamphlets and posters and teaching materials
- an HIV/AIDS worker that is Aboriginal, trained and skilled
- more full time health professionals in community, especially doctors
- videos and guidebook or "how to" manual
- addictions counselors and mental health workers
- Aboriginal people living with HIV/AIDS as community speakers
- programs and materials for elders to help prepare them to act as support, guidance and counsel
- age appropriate materials

Essentially, survey participants indicated that they are extremely interested in any information and resources related to HIV/AIDS. In some communities, distribution of information pamphlets is the only service they are able to provide.

> *"We need to find a way to increase the willingness to listen about HIV and AIDS in the community. People just don't want to realize the seriousness."*
> Survey Participant

Many respondents indicated that they would like to see more services in communities outside lower mainland. Although they did note that organizations such as Healing Our Spirit and Red Road are excellent resources. In some cases, the only resources communities are able to access with any success.

Many service providers noted that they often feel as though they are working in isolation. These, however, were primarily those who were not aware of the Strategy and had not had the opportunity to attend any HIV/AIDS workshops or conferences.

> *"It would be nice if a workshop on HIV/AIDS could be held in each and every community in BC."*
> Survey Participant

For a more detailed listing of all survey participant responses, please see Appendix C.

Analysis

One of the primary challenges for Aboriginal people related to HIV/AIDS is the lack of funding for programs and services (provincially and at the community level). This issue was present as a barrier and concern in response to several of the survey questions.

Despite the lack of funding issue, awareness of the Strategy in the Aboriginal community in BC is quite good. 67% of the survey participants confirmed that they are aware of the Strategy and have a general understanding of its' purpose. This may be directly correlated with the fact that 69%, or roughly two thirds, of the survey participants advised that they have participated in an Aboriginal HIV/AIDS conference or workshop. It should not be considered a coincidence then that 69% of the respondents also confirmed that they were aware of 1 or more HIV/AIDS services/organizations that are available to

their community. And finally, 67% of the respondents confirmed that HIV/AIDS training had been access by their community or organization.

There is a trend in the statistics that would seem to connect attendance at Aboriginal HIV/AIDS conferences or workshops with higher levels of awareness about the Strategy and various HIV/AIDS programs and services.

While there is a relatively high level of awareness of the Strategy in Aboriginal communities, people are less familiar with the actual contents of the document. There seems to be a disconnect between the initial introduction and review of the document and the actual integration of its' recommendations and goals into an overall workplan for a community or an organization.

Some survey participants advised that the Strategy was difficult to read and therefore they needed to read parts of the document more than once. Others confirmed that they simply never seemed to find the time to read the entire Strategy. Current workloads simply do not allow for it.

It is important to note that 33% of the survey participants indicated that they are not aware of the Strategy at all. This may be directly correlated with that fact that 31%, or roughly one third, of the participants have not had an opportunity to participate in any Aboriginal HIV/AIDS conferences or workshops.

One of the goals of this evaluation was to ensure that some of the individuals that participated in the community consultation sessions in the fall of 1998 were targeted as survey participants. This was particularity challenging due to the high turn over of staff in health professions. High staff turn over seems to occur due to:

- under valuing of HIV/AIDS educator/worker/advocate positions so that their salaries and benefits are not enticing enough to keep them in the positions, and
- funding cuts causing staff positions to be discontinued.

As per the responses provided by survey participants, there is a serious lack of awareness and participation of First Nation's leadership in the area of HIV/AIDS. Awareness and support from Chief and Council is imperative to successful program implementation.

Of the communities that have access to Aboriginal HIV/AIDS services, they are rated quite well. But many communities still don't have access to any type of service, making rating for effectiveness impossible.

Overall, provincial organizations such as the Red Road HIV/AIDS Network have done an exceptional job of raising awareness related to the Strategy. With relatively limited resources they have managed to establish a 70% awareness rate in Aboriginal communities in less that one year.

Recommendations

The following is a list of recommendations that flow directly from the feedback and responses provided by the survey participants. These recommendations are not listed in any order or priority.

1. Another mass mail out of the Strategy is required. Many individuals expressed an interest in having their own copy of the Strategy, rather than one copy for the entire organization or community. Others also expressed that being able to distribute the Strategy to community members and leadership would go a long way to raising awareness.

2. Within the Strategy, there is reference to an Implementation Guide. It is highly recommended that a guide is developed to accompany the Strategy. The Strategy does an excellent job of connecting strategic goals with community objectives. However, it is clear that community members could benefit from samples of policies and procedures for implementation of the Strategy. Some useful tools may include:
    - sample community workplans which are holistic in nature and include HIV/AIDS activities and policies
    - workshop outlines with planned activities, discussion topics and lists of available resources (books, internet sites, people, etc.)
    - plain language "How to write proposals" packages, including a list of potential funding sources
    - evaluation plans which can be built into all projects, programs and services
    - a look at those communities which have had some success making HIV/AIDS a priority with highlights of what they have done (e.g. a "best practices" guide – what works – successes in program and community health planning)
    - fact sheets, such as tips on how to motivate community members, an active and dedicated community forces leadership to pay attention to the issue

3. Additional funding is required to allow for training of Aboriginal Educators, whose responsibility is to travel through out the province and provide services in all First Nations communities, despite their size and remoteness.

4. Additional funding is required to support Aboriginal PHA's who are advocates, speakers, trainers and educators. Survey participants overwhelmingly confirmed that the most profound impact on communities occurs through the involvement of an Aboriginal PHA.

5. There is a need for further clarification regarding the roles of the provincial Aboriginal HIV/AIDS organizations. There is some confusion about what services are available from which organizations. The Red Road HIV/AIDS Network Resource Directory is an excellent document. It is available in hard copy and on the Network website. In addition to the current information which is provided (staff, mailing

address, street address, telephone, fax, e-mail, services and costs) in the directory, the Network should consider adding:

- eligibility (who can access services – e.g. on or off-reserve, or both),
- service area (provincial, regional, community specific), and
- grants (budget, deadlines, eligibility).

6. The use of electronic technology in the dissemination of information should be continually pursued. More communities are obtaining internet access. The production of materials that promote the use of the internet as a tool for research, data collection and networking may prove quite useful to communities and organizations. Currently 72% of the survey participants have access to the internet, yet only 54% of those actually use the internet to gather information and network.

7. Training of HIV/AIDS professionals and volunteers must be made a priority. A survey of these individuals should be conducted in order to determine what the actual training priorities are in the province. Once those priorities are determined, every effort should be made to lobby all levels of government to address those training needs. All training opportunities must be accessible and culturally sensitive to Aboriginal people.

8. Every effort should be made to attract new delegates to all Aboriginal HIV/AIDS workshops and conferences. It is clear from the results of this evaluation that attendance at these events can be directly correlated with increased community awareness about HIV/AIDS, the Strategy and the various programs, services and training opportunities that are available.

9. Provincial and federal governments must make HIV/AIDS a higher priority issue.

10. Evaluations of current Aboriginal and non-Aboriginal HIV/AIDS programs and services would be very useful. There is a need to determine what is working for Aboriginal people and what is not. This would allow for the potential re-allocation of the limited resources to programs and services that are working. Or possibly the development of new programs and services that may better meet the current needs.

11. As a next step, an evaluation of the actual implementation of the Strategy should be considered. The next phase of evaluation should focus on whether the goals and recommendations within the Strategy are actually being implemented in communities throughout the province.

Appendix A

Survey Participant Data Collection Form

Survey Participant – General Information

Date: _____

Start Time: _____am/pm Finish Time: _____am/pm

- ❑ Male
- ❑ Female

- ❑ Aboriginal
- ❑ Metis
- ❑ Non-aboriginal

Age: _____

Employment: _____
_____

Please check one or more appropriate categories for employer:
- ❑ HIV/AIDS related organization
- ❑ Federal government
- ❑ Provincial government
- ❑ First Nations government
- ❑ Aboriginal organization
- ❑ On-reserve
- ❑ Off-reserve
- ❑ Non-profit organization
- ❑ Private sector
- ❑ Other

If working in area of HIV/AIDS, how long: _____years _____months

PHA (person living with HIV/AIDS):
- ❑ Yes
- ❑ No

Residence (city): _____, British Columbia

- ❑ On-reserve (name of community:_____)
- ❑ Off-reserve

Would you be interested in receiving a copy of the final report of this evaluation?
- ❑ Yes
- ❑ No

If yes, complete Participant Mailing List.

Appendix B

Survey

Evaluation Survey/Questionnaire

1. Are you aware of the Red Road: Pathways to Wholeness, an Aboriginal Strategy for HIV and AIDS in BC? Yes No

2. What do you feel are the primary challenges faced by Aboriginal people related to HIV/AIDS?

_____
_____
_____

3. What do you think are the primary goals and recommendations of the Strategy?

_____
_____
_____

4. What do you feel is the role of your community and/or organization related to the Strategy?

_____
_____
_____

5. Please list all the HIV/AIDS services/organizations you are aware of in your community.

_____
_____
_____

6. Have you had the opportunity to participate in any Aboriginal HIV/AIDS conferences/workshops? Yes No

If yes, are you able to utilize the information you receive at these meetings at the community level, and how?

_____
_____
_____

7. What types of resources are needed in your community and/or organization?

_____
_____
_____

8. Do you feel that there are adequate funding resources to meet HIV/AIDS service needs in your community? Yes No

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If not, how have/would you address this issue?

_____
_____
_____

9. Has any training related to HIV/AIDS been delivered to, or accessed by, your community and/or organization? Yes No

If not, why?

_____
_____
_____

10. What type of training is required?

_____
_____
_____

11. Since the release of the Strategy, has there been an increased interest in research related to HIV/AIDS in your community and/or organization? Yes No

12. What type of research do you feel is required at the community and provincial levels related to HIV/AIDS?

_____
_____
_____

13. Do you have internet access in your community? Yes No

If yes, do you utilize the internet to gather information and network? Yes No

14. What are some of the barriers to implementing recommendations within the Strategy in your community?

_____
_____
_____

15. Are there any specific projects that have been initiated in your community as a result of the Strategy?

_____
_____
_____

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16. Why is an Aboriginal Strategy required?

_____
_____
_____

Rating applied to each question.
1. Strongly Agree
2. Agree
3. Don't know
4. Disagree
5. Strongly Disagree

17. As a result of the Strategy:

a. Awareness has increased about the transmission of HIV/AIDS.	1 2 3 4 5
b. Awareness of healthy sexuality, healthy relationships and alternatives increased.	1 2 3 4 5
c. There is an increased awareness and sensitivity in the non-Aboriginal community regarding Aboriginal cultures, beliefs and values.	1 2 3 4 5
d. Traditional treatment and rehabilitation methods have been developed and access to mainstream medicine has improved.	1 2 3 4 5
e. Sensitive social support systems and services to Aboriginal people living with HIV/AIDS and their families has been developed and provided.	1 2 3 4 5

18. For those Aboriginal specific HIV/AIDS programs/services you have worked with please rate their effectiveness. Where appropriate, recommend how they can be improved. Ratings are 1 = Effective to 5 = Ineffective.

a. Information dissemination about HIV/AIDS 1 2 3 4 5

_____
_____
_____

b. Distribution of HIV/AIDS Prevention Resources 1 2 3 4 5
(condoms, needles)

_____
_____
_____

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c. Public education (presentations, etc.) 1 2 3 4 5

d. Counselling and advocacy 1 2 3 4 5

e. Access to support services 1 2 3 4 5

f. Care and treatment 1 2 3 4 5

g. Referrals for treatment 1 2 3 4 5

h. Hospice care/housing 1 2 3 4 5

19. Are there any other comments or feedback you would like to provide about the Strategy or Aboriginal needs related to HIV/AIDS?

Appendix C

Survey Responses

Survey Responses

The following is a summary of the responses that were given to each question on the survey. Please note that where more than one participant gave the same response, it is documented only once in this report. Also, there were some surveys for which certain questions were left unanswered. This explains why there are not exactly 36 responses (as per number of completed surveys) for every question.

1. ***Are you aware of the Red Road: Pathways to Wholeness, an Aboriginal Strategy for HIV and AIDS in BC?***

Yes	24 (67%)
No	12 (33%)
Total Responses	**36**

Of the 24 respondents that are aware of the Strategy, just less than half of them indicated that they have read the entire Strategy and have a strong working knowledge of its contents.

2. ***What do you feel are the primary challenges faced by Aboriginal people related to HIV/AIDS?***

- low income, poverty, homelessness
- susceptibility to illness
- mobility between cities and reserve
- access to quality health care and services
- need for ongoing education
- lack of support services on reserve
- lack of access to in-home care on reserve
- being Aboriginal
- being female
- living on the streets in the city
- lack of education
- low self esteem
- lack of diagnosis and access to services
- stigma attached to disease
- lack of privacy
- PHA's who also suffer from Fetal Alcohol Effect/Syndrome
- lack of resources
- in First Nations communities there is denial, lack of willingness to listen, community members don't realize seriousness
- difficulty helping people change to healthy lifestyles
- lack of materials that reflect British Columbia First Nations culture and diversity, especially in the north
- limited resources off reserve in the north

- geographic specific issues, remoteness an issue for resources
- federal/provincial jurisdiction issues
- lack of aboriginal health care providers
- mainstream services do not always meet needs
- difficulty in accessing culturally supportive medical practitioners
- costs of drugs and alternative treatments
- discrimination
- lack of access to medications
- inability to return home, be accepted and supported
- there are three provincial aboriginal educators and over 200 bands
- need more resource people in communities, they must be willing to travel to schools and conduct home visits
- not enough information on alternative healing methods
- isolation issues, difficult to get to workshops
- confidentiality, especially when information is sent by mail
- individuals don't realize risk due to substance abuse
- fear of getting tests
- lack of adequate home care
- lack of awareness on reserve about HIV/AIDS and homosexuality
- can't get attention of young people
- people don't understand what's available in workshops
- there is a negative community response to the illness
- being an IV drug user and HIV positive
- dealing with stereotypes about IV drug users

This is the question on the survey that was most readily responded to by the participants. All individuals have a very clear understanding of what the challenges and barriers are for Aboriginal people related HIV/AIDS. This is regardless of whether or not, they are aware of, or have read the Strategy.

3. What do you think are the primary goals and recommendations of the Strategy?

- to increase access to care and medication
- to mobilize action on a greater level to push for change
- to promote education and awareness
- to teach differently
- realize the need to keep interest
- health promotion
- look at medication costs for Metis and non-status
- promote education and awareness in prison system
- implement culturally sensitive programs off reserve
- focus on prevention
- acceptance of the disease
- obtaining healthy lifestyles
- lower rate of infection

- assess why First Nations are at higher risk
- address lack of funds
- developing more awareness programs
- networking
- ID program and service overlaps
- increase awareness and decrease stigma
- recommend a cultural and traditional response to HIV/AIDS amongst aboriginal communities in BC
- get to grass roots and find out needs of individuals
- focus on youth
- improve services
- working with government
- looking at issues in prisons
- harm reduction

Given that less than half of the survey participants have a working knowledge of the contents of the Strategy, many of the responses given to this question were simply what the individuals assumed would be the primary goals and recommendations set out in a Strategy. There were 3 respondents who actually quoted goals and recommendations as they are set out in the Strategy.

The above list is an excellent representation of the goals and recommendations set out in the Strategy. They simply lack the technical detail that can be found in the Strategy.

4. What do you feel is the role of your community and/or organization related to the Strategy?

- increase access to care and ensure connection to services
- to be involved – take ownership
- ensure education through workshops
- to be more accepting of PHA's
- Chief and Council need to be listening and supporting the health staff
- get support of influential band members
- get HIV/AIDS worker
- ensure access to assessment and diagnosis
- have condoms in all social service and band offices
- ensure awareness of strategy
- implementation of strategy
- deal with denial in community
- implement goals of strategy in all areas of work, be holistic in approach
- remember respect and trust
- distribution of pamphlets and condoms
- promote healthy lifestyles
- work with ongoing prevention and awareness methods
- address high rates of STD's

- obtain funds to cover all needs in a region (role of Tribal Councils or organizations responsible for working with more than one First Nation community)
- health promotion
- workshops and one to one information dissemination
- get PHA's to help facilitate workshops and speak
- respond to community need as issues are identified
- distribute and coordinate information and services
- distribute Red Road manuals at workshops, refer people to internet site, participate as member of Red Road
- to be a support system
- statistics collection
- provide referrals
- provide peer support
- deal with drug abuse
- participate in community health education
- support any healing processes
- work as a team and provide information
- share information on testing
- networking with others in province
- provide information to dispel myths/misconceptions
- remove embarrassment connected with disease

While many participants had no problem responding to this question, it was difficult to assess the extent to which these responses are actually being realized at the community level. Awareness of the role of the community related to the Strategy is very good.

5. Please list all the HIV/AIDS services/organizations you are aware of in your community.

# of HIV/AIDS Svc./Org.	**# of Responses**
0	11 (31%)
1 - 4	19 (53%)
5 or more	6 (17%)
Total Responses	**36**

69% of all participants are aware of 1 or more HIV/AIDS services/organizations that serve their community. It is important to note that many of the services listed were non-Aboriginal.

31% of the participants either have no services or are not aware that they exist.

These statistics are consistent with the concern that there are simply not enough Aboriginal HIV/AIDS services available through out the province.

6. Have you had the opportunity to participate in any Aboriginal HIV/AIDS conferences/workshops?

Yes	25 (69%)
No	11 (31%)
Total Responses	**36**

If yes, are you able to utilize the information you receive at these meetings at the community level, and how?

- use materials as facilitator in community
- just review studies and statistics for personal edification
- learn what works in other communities from the networking which occurs at the conferences
- put information in the community newsletter
- general knowledge is important in daily work, more specific materials may be used in community workshops in future
- information provided at conferences is too repetitive, it's usually the same people, need to deal with issues of politics and sexual abuse in communities, need to focus on alcohol abuse, women and AIDS, youth, elders and violence
- very specific models of services, facilitator skills, etc. are mirrored in the community
- by sharing with other staff and planning with HIV/AIDS needs in mind
- provide educational workshops at the community level
- share information in circles
- share information with own children to raise their awareness
- share information in workshops for youth
- developing an HIV protocol, a plan for PHA's
- through everyday work with clients
- share information in workshops with elders in own language

There were no unique or interesting responses to this question. This seems to be where a majority of individuals have the most difficulty. Moving from information collection to implementation.

7. What types of resources are needed in your community and/or organization?

- money for research and support
- implementation models
- information on what's working in other communities
- how to support families and people living with HIV/AIDS
- lots of pamphlets and posters and teaching materials
- human resources
- teaching equipment (e.g. Props, A/V equipment)
- HIV/AIDS worker, trained and skilled
- more full time health professionals in community, especially doctors

- TV commercials on HIV/AIDS
- more awareness workshops
- videos and guidebook or "how to" manual
- speakers
- centre for PHA's
- library resource centre
- more gay and lesbian information
- aboriginal hospice
- education
- new treatments
- prevention and information sessions
- needle exchange
- condom distribution
- HIV testing
- addiction counselors
- mental health workers
- support groups
- sexual health workshops every 6 months
- experts that are aboriginal
- aboriginal nurses
- workshops run by cultural and spiritual people
- PHA speakers
- information on Hepatitis C
- healing programs for groups
- long term care workers
- counseling
- elders for support, guidance and counsel
- video with native people in it
- information for talking to children, parents and adults
- HIV and child care information
- pregnancy and breast feeding information
- age appropriate materials
- full time position filled by PHA, bringing reality and lived experience to the job
- more information on addicts, to lessen stigma

Survey participants are very clear about the types of resources they would like to have in their communities/organizations. The primary barrier to accessing these resources seems to be a lack of funds.

8. Do you feel that there are adequate funding resources to meet HIV/AIDS service needs in your community?

Yes	7 (19%)
No	29 (81%)

Total Responses 36

Initially, it was surprising to see the 7 survey participants actually feel that there is adequate funding available to meet HIV/AIDS service need in their community. It is important to note that these communities all operate in such a manner that they only respond to needs as they arise. There are no real preventative activities occurring in these communities.

If not, how have/would you address this issue?

- advocate to MSB
- use funds from other departments
- proposals to government funding services
- use HIV/AIDS support services which have no, or limited, cost (e.g. Healing Our Spirit, BC Ctr. for Disease Control)
- proposals to MSB and Healing Foundation
- lobby federal government
- address piecemeal funding that is provided by government, advocate for a set budget, not just grants
- start fundraising to raise donations, can no longer depend on government (it is important to note that fundraising also helps to raise awareness)
- network
- look at how funding is allocated provincially, more networking of service agencies
- work with other CHR's in area
- look at programs that exist and re-allocate funding to programs that may work better (evaluation)
- work with Council
- try to facilitate one voice to government, rather than organizations fighting over limited budget provincially

Survey participants really seemed to struggle with this question. Many did not respond because they were not connected to, or aware of, the budget process for their community/organization.

9. Has any training related to HIV/AIDS been delivered to, or accessed by, your community and/or organization?

Yes	24 (67%)
No	12 (33%)
Total Responses	**36**

If not, why?

- only awareness workshops are available
- no funding

- never really been addressed in community
- no target population has been identified
- lack of interest
- not enough human resources
- leadership prefers workshops for clients

10. What type of training is required?

- leadership training
- facilitator training
- level 2 – implementation/models
- how to be an agency that families can come to and ask for support
- trained PHA's to work with CHR's
- AIDS 101 from Healing Our Spirit (works well for Chief and Council)
- dealing with PHA children and safety
- dealing with self esteem issues
- counseling
- blood screening
- working with Aboriginal people
- pre and post test training
- train the trainer
- sensitivity of health care workers/providers
- information related to IV drug use
- professional training equivalent to nurse of teacher, longer and more detailed
- how to conduct workshops and how to get information out
- ongoing information on drugs/treatment strategies
- dealing with illness
- health issues and HIV/AIDS
- clarifying misconceptions
- how HIV/AIDS affects blood and more details about the disease
- ensuring confidentiality
- registered nurse
- alternative healing
- health and home care staff training
- universal precautions
- prevention
- health promotion
- supporting the entire family
- how to relate to people
- training to deal with addicts specifically, it is not a mental health issue

11. Since the release of the Strategy, has there been an increased interest in research related to HIV/AIDS in your community and/or organization?

Yes 11 (32%)

No	23 (68%)
Total Responses	**34**

This is one of the weakest areas of the survey. People have a relatively limited interest and understanding of research related to HIV/AIDS. Many participants confuse research and training.

12. What type of research do you feel is required at the community and provincial levels related to HIV/AIDS?

- infection of women and pregnancy
- effective prevention models for First Nations communities
- focus on both urban and rural communities
- assessment of the needs of persons living with HIV/AIDS
- data on First Nations people living with HIV/AIDS
- information in layman's terms about medication
- a cure
- how to live with HIV/AIDS
- nutrition
- what has happened to my body, and why – for PHA's
- dealing with anger
- band members coming back to the community after a lengthy stay in the city or cities
- how to change lifestyles
- why is there still high rates of infection in First Nations, current materials don't work, why
- evaluation
- why do people stay away from home (reserve) until they are ready to die? How can the community help?
- human behavior related to HIV/AIDS, why continue high risk activity
- clarifying misconceptions
- how to reach out to communities
- alternative medicine
- drug and alcohol abuse and residential school syndrome and linkages to HIV
- what services are wanted
- prevention
- research is not a priority, need to focus on services

13. Do you have internet access in your community?

Yes	26 (72%)
No	10 (28%)
Total Responses	**36**

If yes, do you utilize the internet to gather information and network?

Yes	14 (54%)
No	12 (46%)
Total Responses	**26**

Almost 40% of the respondents have internet access and utilize it to gather information and network. This suggests that the internet is a very useful tool for information dissemination and networking. The number of users of this technology continues to grow on a daily basis. As internet companies expand their services, more and more communities become connected.

14. What are some of the barriers to implementing recommendations within the Strategy in your community?

- lack of funding
- fear and ignorance
- stereotyping
- lack of support and awareness
- lack of capacity
- lack of trained staff, human resources
- stigma connected with disease
- need more copies of the strategy to share with community members
- denial in the community and the need to educate
- politics
- finding people connected to traditions
- lack of interest from band members
- time and money
- difficulty accessing Healing Our Spirit and Red Road services
- lack of cultural sensitivity to diverse needs in BC (culture and language), health authorities could hire Aboriginal people from BC
- regionalization of Ministry of Health stops funding from flowing
- jurisdictional issues
- need to get community interest and focus
- smaller communities need to go through Tribal Council
- youth are experiencing information overload
- no training for workers
- needs to be a safe place for PHA's and need to build trust
- community population is too small, never get funds for proposals
- community resistance
- individuals scared to ask
- isolation, need resource people to stay longer when they visit the community to allow community members opportunity to access, remoteness usually means no visits in winter and rushing to get boats/planes out of community to get home
- leadership does not make it a priority
- obtaining appropriate staff interest and support
- community feel they are immune

The most common response to this question was lack of resources. Whether they are human or monetary. On-reserve, this issue is primarily related to HIV/AIDS not being made a priority by leadership.

Off-reserve, there are simply not enough funds available and the government does not seem to acknowledge the importance of Aboriginal specific programs and services.

15. Are there any specific projects that have been initiated in your community as a result of the Strategy?

Yes	18 (53%)
No	16 (47%)
Total Responses	**34**

Most of the projects initiated in communities were workshops, dinners with speakers, HIV/AIDS plans and protocols, needle exchange programs, accessing existing services such as Healing Our Spirit, statistic collection and distribution of condoms, pamphlets and posters.

16. Why is an Aboriginal Strategy required?

- First Nations have a separate identity and are at an increased risk for HIV
- we need a vision for all communities, a map
- Aboriginal people will connect with it, better relate
- we have our own style of communicating, living, isolation issues, jurisdictional issues, need to address barriers, reserves are closed communities, residential school issues
- need more aboriginal specific services
- to create more awareness for Aboriginal people
- promote prevention
- high rates of disease
- First Nations need to work on this together
- Aboriginal needs are different, especially in remote communities
- a Strategy for aboriginal people, by aboriginal people
- Aboriginal people have different lived experiences therefore need different approach, to build trust
- to articulate the statistics, challenges, barriers to service delivery and provide direction
- promote good health and educate
- need to address HIV/AIDS in timely manner, every day counts to PHA

17. As a result of the Strategy:
Awareness has increased about the transmission of HIV/AIDS.

1. Strongly Agree 2 (6%)
2. Agree 22 (63%)

3. Don't know	6 (17%)
4. Disagree	4 (11%)
5. Strongly Disagree	1 (3%)

Awareness of healthy sexuality, healthy relationships and alternatives increased.

1. Strongly Agree	2 (6%)
2. Agree	14 (40%)
3. Don't know	12 (34%)
4. Disagree	7 (20%)
5. Strongly Disagree	0 (0%)

There is an increased awareness and sensitivity in the non-Aboriginal community regarding Aboriginal cultures, beliefs and values.

1. Strongly Agree	3 (9%)
2. Agree	12 (34%)
3. Don't know	10 (29%)
4. Disagree	7 (20%)
5. Strongly Disagree	3 (8%)

Traditional treatment and rehabilitation methods have been developed and access to mainstream medicine has improved.

1. Strongly Agree	1 (3%)
2. Agree	9 (26%)
3. Don't know	12 (34%)
4. Disagree	11 (31%)
5. Strongly Disagree	2 (6%)

Sensitive social support systems and services to Aboriginal people living with HIV/AIDS and their families has been developed and provided.

1. Strongly Agree	2 (6%)
2. Agree	4 (11%)
3. Don't know	11 (31%)
4. Disagree	17 (49%)
5. Strongly Disagree	1 (3%)

18. For those Aboriginal specific HIV/AIDS programs/services you have worked with please rate their effectiveness. Where appropriate, recommend how they can be improved.

a. Information dissemination about HIV/AIDS

Rating	Participant Response
1. Most Effective	**********
2. Effective	******
3. Average	**********

4. Ineffective	**
5. Most Ineffective	*

- there is a need for more posters to be put up at all gathering places in the community

b. Distribution of HIV/AIDS Prevention Resources (condoms, needles)

Rating	Participant Response
1. Most Effective	******
2. Effective	**********
3. Average	*********
4. Ineffective	***
5. Most Ineffective	****

- these services need to be 7 days a week, 24 hours a day and prisons should consider a needle exchange program

c. Public education (presentations, etc.)

Rating	Participant Response
1. Most Effective	******
2. Effective	**********
3. Average	*******
4. Ineffective	
5. Most Ineffective	**

- provincial HIV/AIDS organizations rate quite well in the provision of this service

d. Counselling and advocacy

Rating	Participant Response
1. Most Effective	**
2. Effective	*********
3. Average	*********
4. Ineffective	****
5. Most Ineffective	*****

- good for Vancouver, not as much in rural, remote communities

e. Access to support services

Rating	Participant Response
1. Most Effective	****
2. Effective	**********
3. Average	*******
4. Ineffective	*
5. Most Ineffective	******

f. Care and treatment

Rating	Participant Response
1. Most Effective	****
2. Effective	***
3. Average	**********
4. Ineffective	***
5. Most Ineffective	*****

g. Referrals for treatment

Rating	Participant Response
1. Most Effective	***
2. Effective	*********
3. Average	********
4. Ineffective	****
5. Most Ineffective	***

h. Hospice care/housing

Rating	Participant Response
1. Most Effective	****
2. Effective	****
3. Average	*****
4. Ineffective	****
5. Most Ineffective	*********

- this service was rated the least effective overall due to the fact that there are so few Aboriginal specific services available

***19. Are there any* other comments or feedback you would like to provide about the Strategy or Aboriginal needs related to HIV/AIDS?**

- we really need a way to exchange ideas/models that are working in communities
- services are only available in Vancouver, need more services in communities outside lower mainland
- CHR's need more information on where to send people for services and stronger networking, often feel alone in community working on the issue
- prefer interview on the phone rather than having to complete survey alone and return by mail, the interview allows for more thought and discussion
- Healing Our Spirit is a fantastic organization, they are a primary resource
- need more access to condoms, needles, the strategy, etc.
- wasn't aware of Strategy, could use more information in the community, working in isolation as only aboriginal person in non-aboriginal community off-reserve
- it would be nice if a workshop on HIV/AIDS could be held in each and every community in BC
- need more HIV/AIDS services in northern BC, stop focusing on lower mainland

- HIV/AIDS is not just a gay issue, focus on the needs of the gay community may affect whether an individual will choose to access services
- there are so few people who have the knowledge and abilities to address HIV/AIDS
- people need to be accountable to the community when attending workshops on behalf of the community
- need to focus on prevention
- need to know how to reach community members with HIV/AIDS
- it is difficult to rate effectiveness of services when there are none available in own community
- need help to move from simply reacting to need, to being pro-active
- we are a community that has not faced this problem in 15 years, there is 1 community member who is familiar with HIV/AIDS but that is all, we could use information pamphlets
- it's expensive to do programs in the community, resource people are too far away
- without more education, First Nation are not going to identify with the need
- need First Nations speakers to raise awareness
- need more networking
- need lots more information
- need PHA speakers to reach youth
- need more updated information on treatment
- need to receive information confidentially (e.g. use blank envelopes to send information in the mail)
- resource people need to stay longer so that the community has time for questions and feedback
- traditional medicines should be a focus/priority
- the community needs a healing centre for native PHA's, for counseling, nutrition, cultural sensitivity and traditional medicines
- communities need to support PHA's, no matter where they live
- there should be a stronger emphasis on abstinence, should view as a moral issue
- IV drug users should be a priority