FIRST NATIONS AIDS SOCIETY

HEALING OUR SPIRIT

To: Partners in Aboriginal Health and HIV/AIDS

From: Healing Our Spirit BC First Nations AIDS Society

Re: Building Research Capacity in Aboriginal AIDS Service Organizations – Project Final Report

Greetings! Please find enclosed a copy of the final report for the Healing Our Spirit Building Research Capacity Project. The pilot project was for 1.25 year, and an overview of it is provided in this report. You will also find attached as appendices, two research reports:

1. Healing Our Spirit Report on Results of Aboriginal Knowledge, Attitudes and Beliefs Survey of HIV/AIDS Workshop Participants 1996 – 1998

2. Healing Our Spirit Report on Results of Aboriginal HIV Educational Workshop Evaluation Survey 1996 – 1997 Data

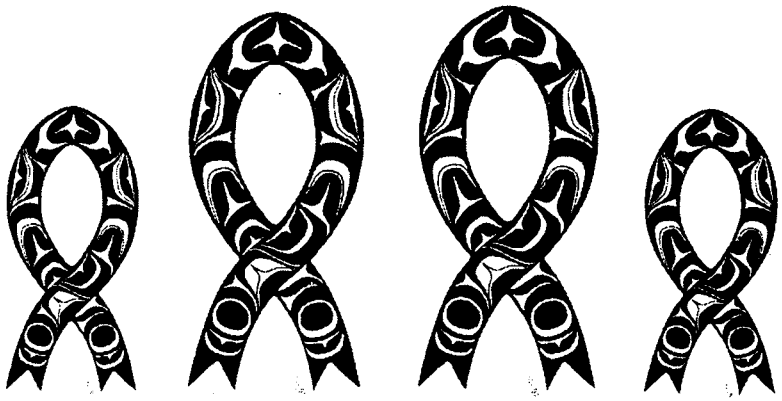
The two reports provide an overview of Aboriginal workshop participants knowledge and attitudes about HIV/AIDS, what they have gained from HIV/AIDS education, and anticipated behaviour changes. As our workshop participants are a self-selected sample, we do not endorse the use of this data to be representative of Aboriginal people in BC.

We encourage you to use, learn from, and borrow the information provided here, particularly those who are interested in Aboriginal HIV/AIDS prevention, program evaluation and planning.

Healing Our Spirit will have two articles published this summer in the Native Journal of Social Work, Special Aboriginal HIV/AIDS Issue. For more information call the Native Journal of Social Work, 705-675-1151 ext. 5049.

HEALING OUR SPIRIT B.C. First Nations AIDS Society
319 Seymour Boulevard, North Vancouver, BC Tel: (604) 983-8774 Fax: (604) 983-2667
MAILING ADDRESS: 415B West Esplanade, North Vancouver, BC V7M 1A6

Healing Our Spirit BC First Nations AIDS Society
Building Research Capacity Project
Final Report
April, 2000



Healing Our Spirit BC First Nations AIDS Society
"Honouring and Caring for our Nations Affected and Infected With HIV/AIDS"

Funded by
Prevention & Community Action Programs,
HIV/AIDS Health Promotions and
Programs Branch,
Health Canada

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Table of Contents

1.0 What is Healing Our Spirit BC First Nations AIDS Society?

Healing Our Spirit BC First Nations AIDS Society (HOS) was founded and incorporated as a non-profit society in 1992. The co-founders Leonard Johnston, and Frederick Haineault were both of the Cree Nation. They perceived the need to provide awareness of HIV/AIDS through prevention services to First Nations and Aboriginal communities in BC. Both Leonard and Frederick have passed on to the Spirit world, but the legacy of their work in HIV/AIDS lives on. Today, Healing Our Spirit provides a wide range of prevention, care, treatment, support, research, and evaluation services to Aboriginal communities across BC. Three important components of Healing Our Spirit are the education program, the outreach office and the annual Aboriginal HIV/AIDS conference held in BC.

The HOS Education program provides holistic and culturally appropriate HIV/AIDS prevention workshops to health professionals, students, communities, youth, incarcerated Aboriginals, Elders and chiefs and councilors. The Education program trains and brings speakers living with HIV/AIDS to Aboriginal communities and organizations to share their life experiences. The program works with communities and organizations to ensure that those who need to hear the prevention message are encouraged to attend the workshops in the community. Workshop audiences range from community members, to chief and council, health professionals, youth, incarcerated persons, job training programs and children in school. Workshops are held in communities of a few hundred residents, to urban centres across BC.

The Outreach office in Vancouver offers services for Aboriginal people living with HIV/AIDS. Peer support, volunteer programming, social support and activities, emergency funds, housing and human rights advocacy, referrals, healing circles, and counselling in residential school syndrome are offered to Healing Our Spirit Lifetime members and clients. Lifetime membership with HOS is free for Aboriginal people living with HIV/AIDS.

The annual Aboriginal HIV/AIDS conference is hosted by Healing Our Spirit, in partnership with Aboriginal communities across the province. Delegates and presenters attend from across Canada and the United States. The conference brings together - funders, health workers, health professionals, Aboriginal people living with HIV/AIDS, and community members.

The focus of the conference is to honour Aboriginal people who are infected and affected by HIV and AIDS. Workshop topics range from prevention, to self care, harm reduction, physical, mental, spiritual and emotional growth, community awareness and development, access to care issues for women and children, and palliative care. In previous years, the conference has been held in Vancouver, Prince George, Nanaimo and Cranbrook in March of 2000.

2.0 Background and rationale for the HOS building research capacity project

2.1 Challenges to conducting community based HIV/AIDS research

Development of the field of community based research is ongoing. Community based research is as diverse as the communities who undertake it. There are many challenges to conducting research outside of academic institutions, one example being the issue of ethical approval for research projects. There are barriers to obtaining ethical approval of research grant proposals by community based organizations. Universities have concerns about legal liability issues of approving research conducted outside the institution. In some cases, these barriers have not posed a problem. For example the Kootenay/Boundary Community Health Services Society obtained ethical review from the Ethics Committee of the Greater Trail Community Health Council to conduct an HIV/AIDS Needs Assessment in 1999. Community based organizations applying for ethical review through a local or neighbouring university must have a university staff researcher involved in the research as a co-investigator.

In addition, communities and organizations do not often have the resources or infrastructure to initiate and conduct research. Principal investigators cannot be paid salary or compensation from research project funds. There are also issues of legitimacy of research conducted outside of research institutions. Community based research and particularly Aboriginal community based research may not be viewed as credible as traditional academic research.

2.2 Is Aboriginal community-based research different?

Aboriginal approaches to community based research can differ from non-Aboriginal community based research in distinct ways. The methodology and research design reflect a greater level of community involvement in the research process. There are fundamental differences in the underlying beliefs and principles that shape how research is carried out. The principles of ownership, access and control (OCA) are key for Aboriginal communities engaging in research. Non-Aboriginal community based research encourages the incorporation of community needs, as long as they do not compromise academic standards. However, Aboriginal community values can often be at odds with academic standards or needs. The Aboriginal research principles, OCA, pose a fundamental shift in the concept of research. The shift returns power to Aboriginal communities who are currently disempowered by the lack of recognition of Aboriginal knowledge; token involvement of Aboriginal peoples in research that affects them; and minimal involvement in research informing policy change that affects Aboriginal peoples, and is controlled from outside Aboriginal communities.

For Aboriginal communities who have been 'informants' or 'subjects' of research since the time of contact, obtaining control of the research process is key. Issues of data ownership and stewardship are key aspects of OCA Aboriginal research principles. At the community and national level, Aboriginal communities are in the process of re-defining the traditional relationship they have had with non-native academics, academic institutions, and research funding bodies. In areas of research that involve Aboriginal individuals and communities, Aboriginal people seek to gain an equal place in these areas:

- Ownership of data collected from and/or by Aboriginal people, and research that involves and has involved Aboriginal people.
- Control of the research process, beginning with defining the questions, methodology, process for participation, and interpretation of the results.
- Access to completed and current research that involves and affects Aboriginal people. Access to institutions, funding bodies and opportunities for supporting Aboriginal research career development.

In Aboriginal HIV/AIDS research, these areas require a need for not only an Aboriginal driven research process, but also meaningful involvement of Aboriginal people living with HIV/AIDS in the decision making process.

2.3 Background to the HOS building research capacity project

A needs assessment survey was conducted over a three year period with Healing Our Spirit HIV/AIDS prevention workshop participants. The questionnaire used by HOS educators assesses the knowledge, attitudes and beliefs of workshop participants, and is administered at the beginning of the prevention workshop. There were over thirteen hundred questionnaires and workshop evaluations that needed to be analyzed. HOS did not have the capacity to complete the analysis in house. Instead of contracting a consultant to complete the analysis, HOS approached researchers at the Department of Health Care & Epidemiology, UBC to partner in the development of a project that would train Aboriginal people to undertake HIV/AIDS research initiatives.

There is an acknowledged need for Aboriginal health researchers, and for increased capacity of Aboriginal organizations and communities to conduct community based research. This project aimed to address this lack of research capacity, and also to provide the Aboriginal community with a resource to build the capacity of other organizations.

3.0 What is the building research capacity project?

3.1 The university and community partnership model

The model that was used for the HOS building research capacity project was to form a partnership with university based and independent research consultants to transfer skills to the Aboriginal community. The partnership with researchers and universities is one approach that is being utilized by Aboriginal groups, and organizations to address the need for increased research capacity. The formation of partnerships is an interim measure that further community development, and increased numbers of Aboriginal people with post-secondary experience will increase Aboriginal research capacity over time.

3.2 What are the goals of the HOS building research capacity project?

The overall goal of the project was to increase and develop Aboriginal research capacity in regards to Aboriginal HIV/AIDS. Healing Our Spirit initiated the project to:

- Develop research capacity of Healing Our Spirit BC First Nations AIDS Society
- Develop research capacity of Aboriginal AIDS Service Organizations (or AIDS service organizations serving large Aboriginal clientele)
- Develop research skills of project and Healing Our Spirit staff
- Support capacity building of Aboriginal people in regards to Aboriginal HIV/AIDS research
- Develop further the linkages between university based researchers and the Aboriginal community, specifically for partnership initiatives and research skills transfer
- Enhance HIV/AIDS Resource Library and enhance community access to resources
- Provide opportunities, through linkages and partnership, for non-Aboriginal researchers to develop understanding and skills around issues of cultural sensitivity and cultural competency

4.0 How did HOS increase Aboriginal research capacity?

The building research capacity project identified ways to develop research capacity in the Aboriginal community in regards to Aboriginal HIV/AIDS. Specifically, these areas are:

- Training of Aboriginal people in research skills
- Capacity building of the organization, to independently, or in partnership with Aboriginal AIDS service organizations, conduct Aboriginal HIV/AIDS research
- Development of partnership and linkages to further development of Aboriginal HIV/AIDS research
- Conducting research in the Aboriginal community on HIV/AIDS
- Sharing the results and learnings of research projects on an international, national and local scale, and in particular with the Aboriginal community
- Collection of research reports, resources, enhancement of HOS resource library, enhancement of resource dissemination strategy

Sections 4 to 8 describe in greater detail how research capacity development in the Aboriginal community was addressed in these areas. The development of non-Aboriginal cultural capacity, though not a documented aspect to the project, is an important goal and benefit to the capacity building process. Through the process of partnership and relationship building, an education process of non-Aboriginal people in regards to Aboriginal culture, protocol and customs, and history takes place. Particularly in HIV/AIDS, there are a number of high risk factors for Aboriginal people that can only be understood in a cultural and historical context. The development of Non-Aboriginal capacity to work effectively with Aboriginal people, and provide assistance in increasing Aboriginal autonomy, must be a key aspect in Aboriginal capacity building initiatives.

4.1 Staff training & how training enhanced HOS services

Training was provided through the project that benefited a number of areas of Healing Our Spirit service delivery. Formal computer and oral presentation/facilitation training was provided for 3 project staff, and four other HOS staff. The training was provided in areas that would enhance skills for specific job responsibilities. Courses were provided by public and private institutions in these areas:

- database design, maintenance and use
- use of powerpoint for presentation design
- statistics - data analysis
- statistics - questionnaire design
- facilitation and presentation
- use of STATA - statistical software for tabulation of simple analysis, statistical tests

The training enhanced the skills of the staff and their ability to develop research capacity. This, in turn improved HOS services in the following ways:

- HIV/AIDS prevention education activities – better information collected about workshop participants, better informed program planning, and targeting of specific groups. For example, high numbers of young sexually active participants, and number of participants sharing needles indicated by our survey highlight the need to focus programming to these groups.
- Administration systems for organizing the annual Aboriginal HIV/AIDS conference were enhanced by database training. A database was created for Aboriginal communities participating in the annual conference. This allows for queries of the data, for example, under-represented regions accessing the annual conference.
- A database created for communities accessing HOS education services was created that improves record keeping, and creates better information on communities accessing HOS services, including types of education being accessed, primary target groups identified by the community.
- A database was created for client intake for Healing Our Spirit HIV positive client services. The database will improves record keeping, which will allow HOS to identify trends, and better serve Aboriginal HIV positive clients.
- An increased capacity to make HOS HIV/AIDS research presentations, and to share learnings from research generated by HOS.
- Improved evaluation forms and database created for the annual Aboriginal HIV/AIDS conference, HOS education services, and advocacy and support for HIV positive clients. Improved and targeted evaluation identifies areas for improvement in program design and delivery to Aboriginal peoples.
- A new capability to analyze data generated by Healing Our Spirit programs and services. Data can now be collected and interpreted by Healing Our Spirit staff, working in partnership with Aboriginal communities, or Aboriginal service organizations.
- A new capability to share research results and experience of developing research capacity with Aboriginal communities, ASOs, Aboriginal ASOs, and the larger HIV/AIDS and health community.

The technical and presentation training assisted Aboriginal staff in the development of their technical expertise. Research is more than technical skills, the development of research tools and data analysis often involves an intensive process oriented approach. Aboriginal project staff received on the job training from research consultants hired for the duration of the building research capacity project. The training that was provided was based on specific needs and projects identified by Healing Our Spirit. The research consultants worked on site training Healing Our Spirit staff, and provided telephone and email consultation. The research consultants also provided assistance in identifying research opportunities and in developing funding proposals.

Training involved the development of the following research skills:

- questionnaire development and design, data collection techniques and methodological considerations
- setting up of data analysis systems before data collection, streamlining data analysis
- data analysis process: data coding, questionnaire database creation, data entry, data cleaning and preparation for analysis of data in statistical software
- creating data graphs and charts
- write-up of research data results, report preparation

These skill sets were developed and applied in a practical manner to research projects that were identified by Healing Our Spirit, with particular emphasis on the Education, Client Outreach, and Resource library programs. The project was integrated into existing programs and services at Healing Our Spirit, which are described in greater detail in Section 1.

5.0 Sharing of research results and learnings of the project

Research results, and learnings from the project were shared at various levels. At the grassroots level with Aboriginal communities and program participants, to the international level where results were presented at the AIDS Impact 1999 conference, and two publications in the Native Journal of Social Work which is available to academics and Aboriginal researchers and frontline workers.

5.1 Research reports

1. Healing Our Spirit BC First Nations AIDS Society Report on Results of Aboriginal Knowledge, Attitudes and Beliefs Survey 1996 - 1998
2. Report on Results of Healing Our Spirit HIV/AIDS Education Workshop Evaluation Survey
3. Attitudes Towards HIV/AIDS Among Aboriginal Peoples Living in BC

5.2 Research Presentations

Poster Presentation and Information Dissemination
Healing Our Spirit Annual HIV/AIDS Conference - Fourth Annual BC Aboriginal HIV/AIDS conference bringing together community members, APHAs, health service providers, youth and elders.

Oral Presentation and Request for Support of NHRDP Application "Economic Costs, Resource Impacts and Access to Care for Aboriginal Persons Living with HIV/AIDS in Rural and On-Reserve Locations in British Columbia"
Chief's Health Committee Meeting - First Nations Summit Health committee that is a voice for, provides direction and policy support to on reserve First Nations

Panel Participant
Red Road HIV/AIDS Network/Pacific AIDS Network "The Circle of Unity in Community Based HIV/AIDS Research" Research Seminar - Partnership of Aboriginal and non-Aboriginal HIV/AIDS networks to provide training in community based research and provide opportunity for networking and dialogue between funders, academics and community based frontline workers.

Oral Presentation on Building Research Capacity Project and results of study, "Attitudes Towards HIV/AIDS Among Aboriginal People Living in BC"
Red Road HIV/AIDS Network Quarterly Meeting - a network of Aboriginal HIV/AIDS service providers and APHAs in BC

Oral Presentation on Building Research Capacity Project and results of study, "Attitudes Towards HIV/AIDS Among Aboriginal People Living in BC"
AIDS Impact 1999 - Annual International HIV/AIDS conference

5.3 Research Paper Submissions

The Native Journal of Social Work is publishing a special issue on Aboriginal People and HIV/AIDS in June, 2000. Healing Our Spirit and researchers from the Dept. of Health Care & Epidemiology, and UBC Centre for Health Services and Policy Research, have two peer-reviewed articles published in the special issue. The articles are titled, "Attitudes and Beliefs Towards HIV and AIDS Among Aboriginal Peoples Living in British Columbia" and "Honouring and Caring for Aboriginal People and Communities in the Fight Against HIV/AIDS".

6.0 Building Research Capacity of Aboriginal and non-Aboriginal ASOs

6.1 Challenges and successes of partnership building

At the outset of the project, all local AIDS Service Organizations were contacted by an introductory letter and follow-up phone call. Some organizations we contacted did not return our follow-up phone calls. Some organizations did return our call, but did not have the time to meet with us.

The organizations that met with project staff were informed of the project goals, and the meeting focussed on the sharing of information about:

- their current client intake system, and research capacity
- HOS research capacity building activities
- their interest in participating in the research capacity building project

For those organizations we met with, some expressed interest in the project, but did not participate for the following reasons:

- lack of staff funds – staff time already stretched to its limit with direct service
- lack of funds to acquire computer equipment necessary to build research capacity
- already have an extensive client intake, data collection system in place
- were too busy to meet with HOS project staff

There were also two organizations that were contacted on numerous occasions because they had an existing data set, or were keen to develop their program evaluation. Both organizations hired consultants to complete the analysis and evaluation.

A database was created that contains information about the research capacity of Vancouver based ASOs. A database was also shared with Healing Our Spirit by the Community Health Research Liaison, a university based community outreach worker that surveyed a large number of Vancouver services. Both databases are available from Healing Our Spirit.

Despite the barriers that frontline organizations identified to increasing their research capacity, the project worked collaboratively with Aboriginal AIDS service organizations in various capacities. Partnerships, community outreach activities, conferences and meetings included:

BC Aboriginal AIDS Awareness Program: information and research tool sharing, collaboration on promotional material development. Partnership to develop Aboriginal research capacity, conduct research.

Red Road HIV/AIDS Network: network member, information and research tool sharing, assistance with research grant proposal development, collaboration on promotional material development. Partnership to develop Aboriginal research capacity and conduct research.

Community Health Worker: project provided information on epidemiology for presentation to band council for HIV/AIDS service development.

Aboriginal Women's Research Committee: participation on committee, information sharing, provided information on ethical review issues for committee members.

Vancouver Richmond Health Board ASO Data Standardization Project: information sharing.

First Nations House of Learning: partnership formed with AASOs to establish an Aboriginal specific university based ethical review body, address research capacity building with Aboriginal people in regards to HIV/AIDS.

NHRDP Aboriginal HIV/AIDS Program: participation in re-design process, sharing of knowledge with Aboriginal participants of BC Aboriginal HIV/AIDS research initiatives

NHRDP Community based HIV/AIDS Program Consultation: participation in final day of consultation.

Organization for Advancement of Aboriginal Health: participation in process of establishing vision and mission of organization. Information sharing.

Gathering of Spirit for Aboriginal Persons Living With HIV/AIDS, 2000: assistance in questionnaire design, administration of population health survey with APHAs.

International Aboriginal Women and Wellness Conference,2000: information dissemination, networking.

Annual BC Aboriginal Health Conference, 1999 : information dissemination, networking.

CAHR HIV/AIDS Research Conference, 1999 : information dissemination.

7.0 Resources and Research Tools Developed

The development of research skills in the Aboriginal community was the primary objective, and accomplishment of the project. In addition a number of permanent resources were also enhanced, and developed. These resources are available to Aboriginal communities and organizations.

These resources listed in the following chart can assist the Aboriginal community to develop their capacity to conduct and understand research, and to develop programs and evaluation. These are in addition to the research reports attached as appendices, and the two articles published in the Journal of Native Social Work.

Resource Name	What the Resource Is	Value of Resource
Reference Manager	Database software to create bibliographies, insert references in research papers	Can be used in development of funding applications, writing research papers, reports
Education and Community Development Database	Database that contains information on communities accessing HOS services	Information on communities using HOS services, gaps and overlaps with local ASOs
Pre and Post HIV/AIDS Workshop Knowledge Assessment Survey Database	Database that contains knowledge assessments of workshop participants	Assess effectiveness of HIV/AIDS education, identify trends
HIV/AIDS Resource Library	Resource library with books, reports, videos, games, internet access	Improve community access to information for program development, and on Aboriginal HIV/AIDS
HIV/AIDS Questionnaires	Binder containing numerous questionnaires, needs assessments, surveys	Can assist organizations, communities to develop local research with examples of previous work
HIV Positive Client Database	Confidential database containing information on HOS clients	Enhanced ability to identify trends, develop programs for APHAs
Data Collecting and Processing software, Human resources to Analyze Data and Write-up results	HOS staff skills to analyze data, links to professional researchers, softwares: STATA, Excel, Filemaker, Access and Reference Manager	Capacity to process and analyze data, partner with ASOs and communities to assist in research

If you are interested in accessing any of these resources, please do not hesitate to contact Healing Our Spirit, 604-983-8774, toll free 1-800-336-9726, or on the web at www.healingourspirit.org.

8.0 Next steps

8.1 Research funding submissions

A funding application was submitted to NHRDP to conduct a three year research project that would examine issues of cost and access to health services of Aboriginal people living with HIV/AIDS in rural and remote areas of British Columbia. The application was submitted with support and partnership of the Dept. of Healthcare & Epidemiology, UBC, First Nations House of Learning, UBC, Vancouver Native Health Society, Red Road HIV/AIDS Network and BC Aboriginal AIDS Awareness Program

The application has been approved for funding, and is currently undergoing ethical review. Healing Our Spirit also applied for development monies for two letters of intent that would enhance knowledge of effectiveness of HIV/AIDS prevention strategies in Aboriginal communities in BC. These applications were turned down for funding.

8.2 Community requests for assistance in building research capacity

Just prior to completion of the project, Healing Our Spirit was approached for assistance in developing research capacity. As the sustainability of funding was not guaranteed, HOS did not have the resources to partner with these organizations. Assistance was requested for:

- analysis and write-up of a pilot project
- establishment of a program evaluation system for HIV/AIDS harm reduction services

Healing Our Spirit is developing other approaches to working with communities and organizations to develop their research capacity. An Aboriginal HIV/AIDS Community Developer has been hired, and assistance in research development is a part of this new initiative for Aboriginal communities. Communities and organizations interested in accessing these services can contact Healing Our Spirit.

8.3 Sustainability issues

As is the case with many short-term projects, and in particular capacity building projects, there are concerns about sustainability. Specifically the loss of capacity built, which is directly affected by the nature of project funding. The investment of training people is high, and continuity of project development is dependent on available funding to bridge staff between completion and initiation of new projects. Often valuable project staff are lost in the interim of projects finishing, and the delay in funding of projects in the application process for the following fiscal year.

This is a concern for community based organizations that do not have extra funds to fund research development between funded projects. Research projects in this case depend on the commitment of staff developing projects on top of a full workload.

8.4 Next steps and other Resources

The skills and knowledge that were acquired in the building research capacity project are significant to the work that must be done in HIV/AIDS. The building of research capacity of Healing Our Spirit and project staff was a very exciting and challenging process, and has contributed to the overall capacity building of Aboriginal ASOs in Vancouver. There remains much work to be done, and there are many gaps in our knowledge. There is very little data on Aboriginal mobility, unprotected sex and needle sharing on reserve. There is also very little data on Aboriginal women, a group that is being affected by HIV/AIDS at an alarming rate.

The National Health Research and Development Program (NHRDP) will soon cease to exist in its current form. Aboriginal people from across Canada came together in July, 1999 to provide input on the re-design of the NHRDP Aboriginal HIV/AIDS research program. Aboriginal people and Aboriginal ASOs must continue to advocate and lobby for culturally sensitive and respectful funding processes and bodies.

The Laboratory for Disease Control has an Aboriginal Working Group on HIV/AIDS Surveillance and Research. They have developed an ethical review checklist for support or approval of research proposals on Aboriginal people. The checklist covers principles of a code of ethics, and ethical issues specific to Aboriginal communities. An annual Aboriginal HIV/AIDS Surveillance Meeting is held to disseminate and review current HIV/AIDS Aboriginal research. The first meeting was held in March, 1996. CAAN and the LCDC Aboriginal Working Group has recently released "The ABCs of Epidemiology", to assist Aboriginal people in understanding epidemiological terminology and research issues around Aboriginal HIV/AIDS.

Progress towards building Aboriginal research capacity continues to develop, however there are many areas that we can identify as priorities if the momentum is to continue. A first step would be to develop a source of flexible funding that could help bridge gaps between projects. Improved continuity and long-term stability would prevent the loss of the skilled personnel, by providing community based organizations with resources to bridge during time between projects.

A viable and culturally appropriate ethical review process must be established for Aboriginal community based research projects to access. Healing Our Spirit initiated, in partnership with Aboriginal AIDS service organizations based in Vancouver, discussions with UBC Research Services and the First Nations House of Learning, UBC, to establish an

Aboriginal specific ethical review process. The process requires funding, which is currently not available. Progress in this area should be pursued by Aboriginal organizations in partnership with universities.

Funding has recently been made available for Aboriginal research capacity building, and scholarships for graduate work in HIV/AIDS from Health Promotions and Programs, Health Canada. Specific information on research funding sources for Aboriginal communities and organizations will be available in manual form from the Red Road HIV/AIDS Network. The manual will also be available through Healing Our Spirit and BC Aboriginal AIDS Awareness Program.

Appendix A

Healing Our Spirit Report on Results of Aboriginal Knowledge, Attitudes and Beliefs Survey of HIV/AIDS

Report Contents

1.0 Healing Our Spirit BC First Nations AIDS Society

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The focus of the conference is Honouring Aboriginal people who are infected and affected by HIV and AIDS. Workshop topics range from prevention, to self care, harm reduction, physical, mental, spiritual and emotional growth, community awareness and development, access to care issues for women and children, and palliative care. In previous years, the conference has been held in Vancouver, Prince George, Nanaimo. The Fourth Annual conference is being held in Cranbrook in March of 2000, where children and families will be honoured

2.0 Education Program Needs Assessment and Evaluation

The Healing Our Spirit Education program targets prevention education at Aboriginal people who are at risk of being infected or affected by HIV/AIDS. The

Education program works with communities and organizations to ensure that those who need to hear the prevention message are encouraged to attend the workshops in the community. Workshop audiences range from community members, to chief and council, health professionals, youth, incarcerated persons, job training programs and children in school.

In some cases, those who choose to attend the workshops perceive that HIV/AIDS could become a problem in their community. They go to gather information to share with their family and friends. Others may be seeking support for themselves, or someone they know infected of affected by HIV/AIDS. Some may be on their personal healing journey and seek empowering information and support.

At the beginning of the workshop, a questionnaire is administered to the participants. The two page questionnaire takes approximately 5 - 10 minutes to complete (Appendix 1). The questionnaire is used by educators to assess the knowledge, attitudes and beliefs of workshop participants. The questionnaire is voluntary, and the facilitator assists participants by verbalizing the questions. Individuals with low literacy are assisted on a one- on- one basis.

The analysis provided in this report covers August 1, 1996 - December 31, 1998. The Education program is currently using a revised version of this questionnaire. The analysis of the questionnaires was performed in Excel and Stata - a statistical analysis software application.

3.0 Education Survey Results 1996 - 1998

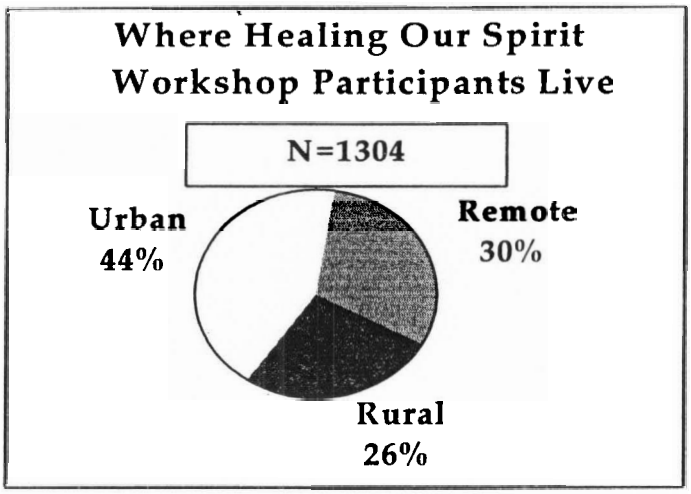
3.1 Where Healing Our Spirit Workshop Participants Live

Workshops are held in communities of a few hundred residents, to urban centres across BC. For the purposes of this study, three categories are used to define community size: urban, rural and remote. Urban communities are defined as large centres, not restricted to the Lower Mainland, including Prince George and Prince Rupert. Prisons are defined as urban.

Communities are defined as remote if they had limited or no road access. For example Alert Bay, Watson Lake, and Gitanyow. Rural is defined as communities that are not urban, nor remote. Rural is midsize, or small communities in close proximity to larger communities, and easily accessible. For example Boston Bar, Penticton, and Ft. St. James.

The percentage breakdown of where the workshop participants live is roughly equal between rural and remote, and urban. There are 1304 respondents from the HIV/AIDS workshops.

Figure A



3.2 Age, Gender, and Age of Workshop Participants When First Sexually Active

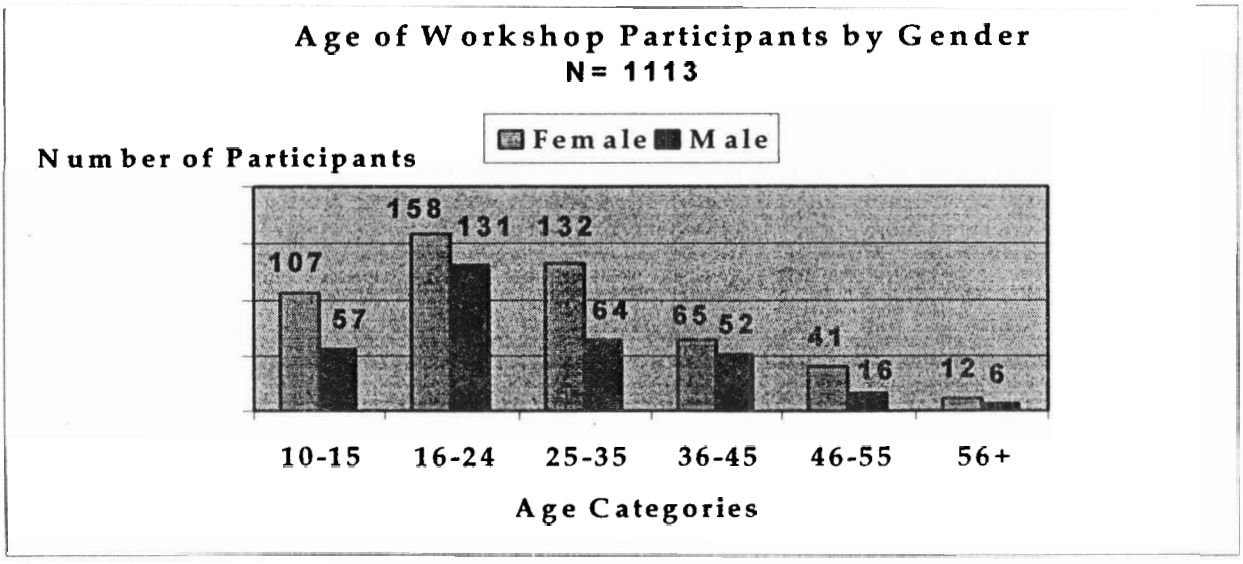
Figure B1 – Gender of Survey Respondents

Male	Female	Other	Total
462 (41%)	651 (58%)	5 (Less than 1%)	1118 (100%)

In the questionnaire, respondents were given three options for gender, "male", "female", and "other." Other was given as an option for respondents that do not self identify with the gender of male or female.

The majority of Healing Our Spirit workshop participants are female - 58%. 41% of Healing Our Spirit workshop participants are male. This may indicate a need to explore strategies with host communities to get more males out to HIV/AIDS workshops. Those working in prevention may want to explore alternative prevention strategies to reach groups not accessing workshops. For example, getting prevention messages out through existing community venues such as sports, hobby clubs or entertainment functions.

Figure B2



Those in the 16 – 24 age range make up the largest portion of workshop participants for both men and women, followed by those in the 25 – 35 age range. It is important that prevention education reaches youth and young adults, as Aboriginal youth and young adults are the fastest growing population infected with HIV. Figure B3 shows the majority of HOS workshop participants are having sex between the ages of 10 and 15. Clearly, prevention needs to reach Aboriginal youth before they become sexually active, and before they begin experimenting with drugs.

Figure B3

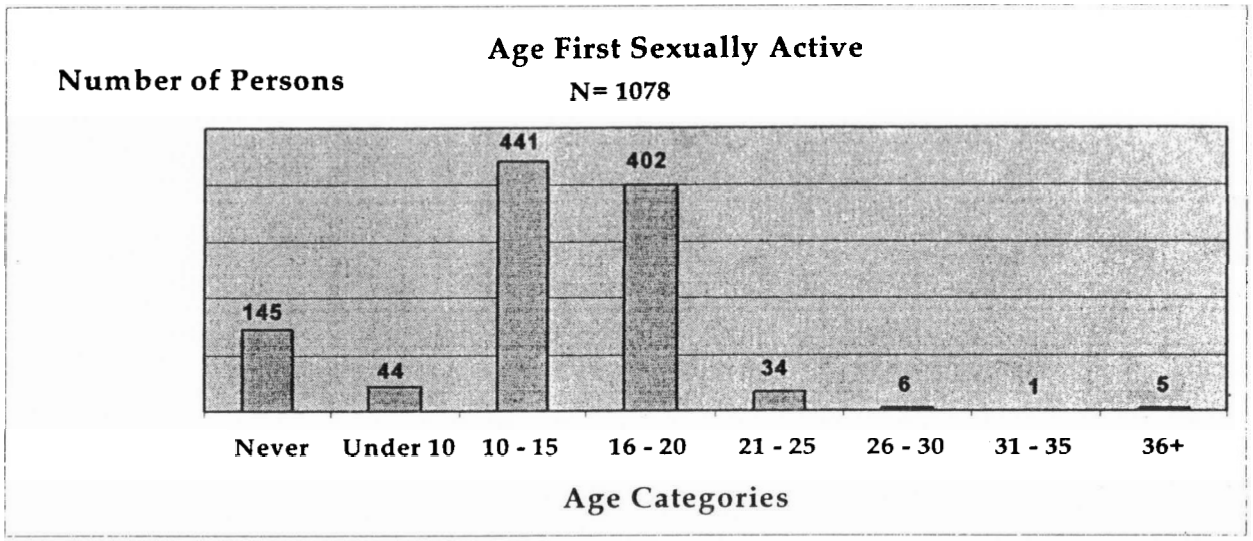
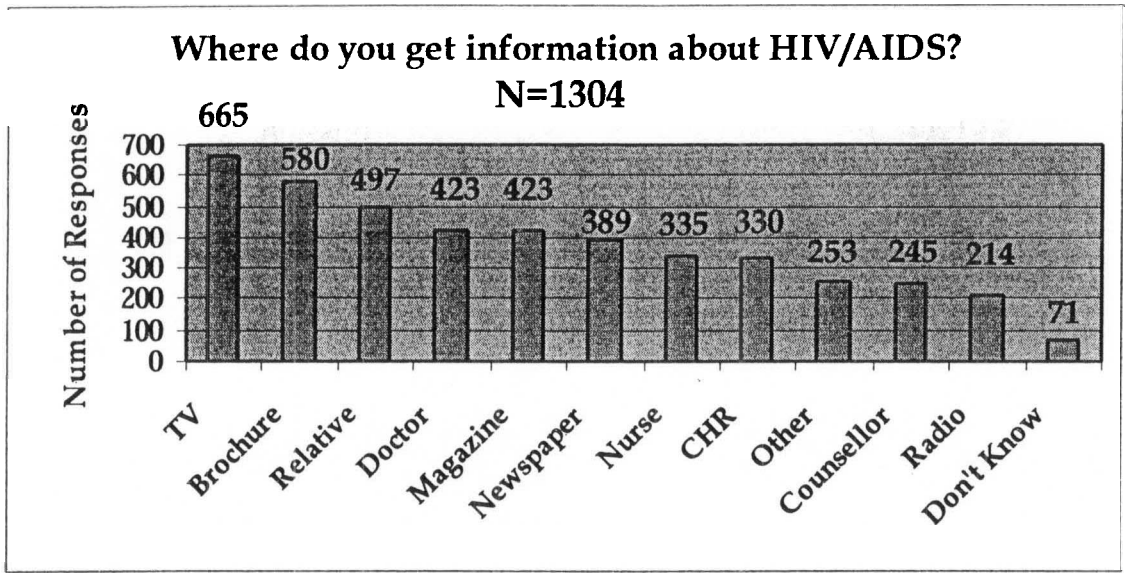


Figure B3 shows out of 1078 workshop participants, 44, or 4% have had their first sexual experience before the age of 10. The legacy of residential schools - the physical, emotional and sexual abuse in Aboriginal communities in Canada, presents challenges for HIV/AIDS prevention. Working with communities in addressing issues that are interconnected with HIV/AIDS is an important aspect of assisting communities prevent the further spread of HIV/AIDS.

3.3 What Sources of Information for HIV/AIDS are Being Accessed?

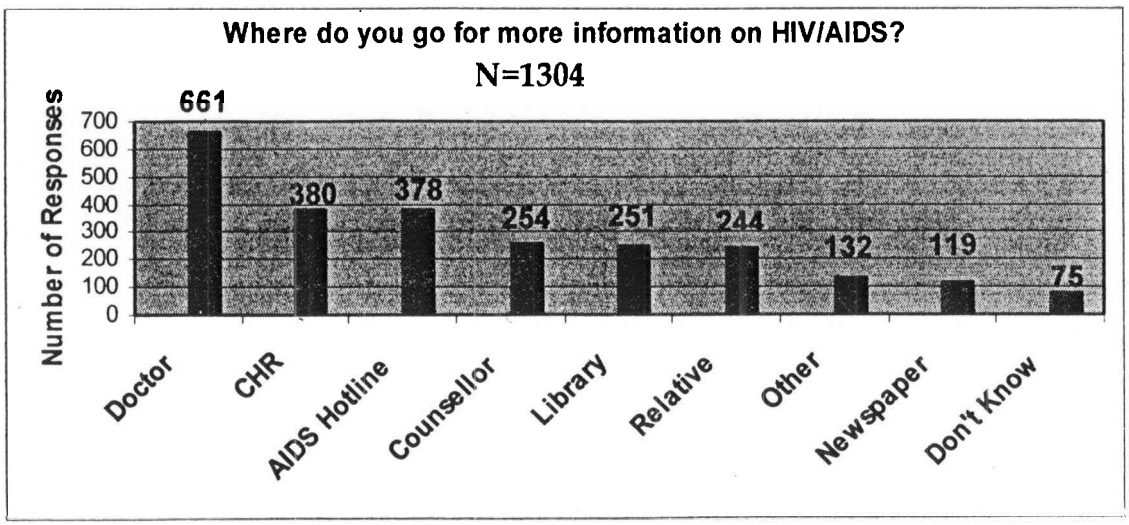
Figure C1



We asked workshop participants, "Where do you get information about HIV/AIDS" - the responses are shown in Figure C1. We asked "If you want more information about HIV/AIDS, where do you go?" the responses are shown in Figure C2.

The media, relatives and the medical system are the most accessed sources of information about HIV/AIDS, of Healing Our Spirit workshop participants. Television is currently a medium that is not being utilized extensively for HIV/AIDS prevention, it is clear that mainstream and Aboriginal forms of media should be identified as mediums to educate communities about HIV/AIDS.

Figure C2



Although most participants get their information through media, when they want *more* information about HIV/AIDS, they will access it from their doctor, community health representative (CHR), or an anonymous source such as a hotline. As the internet becomes a more popular source for accessing information anonymously, the potential is there for reliable and accurate prevention information to be disseminated through websites. Healing Our Spirit has basic information about HIV/AIDS, transmission, and testing on it's website - www.healingourspirit.org.

Figure C2 gives us an indication of what people might do to access more information about HIV/AIDS. It is possible there may be other barriers to accessing more information. Respondents may also answer as they think they should rather what they might actually do. Despite this, it is clear that HOS workshop participants have identified health professionals as a potential further source of HIV/AIDS information.

3.4 HIV/AIDS Knowledge and Beliefs

We asked workshop participants a series of questions about their knowledge of HIV/AIDS transmission, and availability of vaccines and treatment. A vaccine has been developed and is in clinical trials to determine if the vaccine will work. This questionnaire was developed prior to the development of vaccine for HIV.

The limitations of this series of questions is that it was not re-designed to reflect changes in language in HIV/AIDS. For example, the terms such as "AIDS virus" and "HIV" are not used consistently. The questionnaire does not assess knowledge of available HIV/AIDS treatments, which have been shown to improve the longevity of persons living with HIV/AIDS.

Figure D1

Question: A person can have the HIV virus and not have the disease AIDS

Yes	No	Don't Know	Total
902	165	208	1275
71%	13%	16%	100%

The correct answer is "Yes", a person can have the HIV virus and not have the disease AIDS. The majority of HOS workshop participants responded correctly to this question.

Figure D2

Question: You can tell if people have the AIDS virus by just looking at them.

Yes	No	Don't Know	Total
68	1121	98	1287
5%	87%	8%	100%

The correct answer is "No". Nearly 90% responded correctly to this question.

Figure D3

Question: Any person with the AIDS virus can pass it on to someone else through sexual intercourse.

Yes	No	Don't Know	Total
1202	39	49	1290
93%	3%	4%	100%

The correct answer to, any person with the AIDS virus can pass it on someone else through sexual intercourse is "Yes". 93% responded correctly. The perception that AIDS is a "gay white man's disease", is still common among Aboriginal people. Prevention education dispels this belief by educating individuals and communities that certain *behaviours* put one at risk of contracting HIV/AIDS, certain *lifestyles* do not.

Figure D4

Question: A pregnant woman who has AIDS can pass it on to her baby.

Yes	No	Don't Know	Total
1052	85	148	1285
82%	7%	11%	100%

The correct is answer is "Yes", a pregnant woman who has AIDS can pass it on to her baby. Over 80% responded correctly to this question.

Figure D5

Question: There is a vaccine(medicine) available to protect a person from getting HIV.

Yes	No	Don't Know	Total
169	763	349	1281
13%	60%	27%	100%

The correct answer is "No". Although the majority did answer this question correctly, nearly 30% did not know, and over 10% believe there is a vaccine available for HIV.

Figure D6

Question: There is a cure for AIDS at the present time.

Yes	No	Don't Know	Total
67	978	227	1272
5%	77%	18%	100%

The correct answer is "No", there is no known cure for AIDS. 77% answered correctly. Nearly 20% did not know if there is a cure for AIDS, which is quite a high percentage. The promise of antiretrovirals can mislead some to believe that they are a cure for HIV. This perception is dangerous, as there is no known cure for AIDS.

Figure D7

Question: Indians can get AIDS

Yes	No	Don't Know	Total
1205	36	36	1277
94%	3%	3%	100%

The correct answer is "Yes", Indians can get AIDS. This question has the highest number of correct responses - 94%.

Figure D8

Question: Only gay men get AIDS.

Yes	No	Don't Know	Total
58	1068	57	1183
5%	90%	5%	100%

The correct answer is to the question, only gay men get AIDS is "No". 90% responded correctly, with only 5% responding "Yes" and 5% responding "Don't Know".

Figure D9

Question: Only drug users get AIDS .

Yes	No	Don't Know	Total
61	1016	42	1119
5%	91%	4%	100%

The correct answer to the question, only drug users get AIDS, is "No". Again, the number of people responding correctly is high - 91% for this question.

On the whole, workshop participants have answered very well on the series of questions relating to HIV/AIDS knowledge. There is little research or information on how HIV/AIDS knowledge and prevention, affects one's personal decisions and risk behaviours. It is known informally among HIV/AIDS educators, and those living with HIV/AIDS, that a person with good knowledge of HIV/AIDS transmission may continue to discriminate against and fear those who live with HIV/AIDS. Stigma and fear against people living with HIV/AIDS prevents individuals from acknowledging and addressing their own risk behaviours and making necessary changes in their lives. This area that requires further work and attention, to effectively prevent further transmission of HIV/AIDS.

3.5 Attitudes Towards HIV/AIDS , Aborginal People Living With HIV/AIDS

What follows are the results of a study titled " Attitudes Towards HIV and AIDS Among Aboriginal Peoples Living in BC", which was presented at the International AIDS Impact Conference 1999, and will be published in special HIV/AIDS issues of the Native Journal of Social Work. The study is based on data collected in Healing Our Spirit HIV/AIDS prevention education workshops administered from 1996 to 1998.

3.5a What Questions Did We Ask?

Our study is based on responses to four questions we asked in the questionnaire distributed at the beginning of HIV/AIDS prevention workshops. Five response choices are given: Strongly Agree, Agree, Not Sure, Disagree, Strongly Disagree. The questions are:

1) People with AIDS should be allowed to attend pow-wows and other social gatherings.
2) People who get AIDS through sex or drug use deserve the disease.
3) People with AIDS should be allowed to work with food in restaurants?
4) People with AIDS should be allowed to go to public school?

3.5b How Did We Analyze the Data?

The responses were given scores of one to five based on a positive or negative response. Added together, the score range is from 4 - 20. A score of 4 is the most positive score, and 20 is the most negative score. Because 12 is halfway between 4 and 20, this was made the score that divided all responses into two categories. A score of less than 12 is a positive score, meaning you have positive attitudes towards HIV/AIDS. A score of 12 or more is a negative score, meaning you have less positive, or negative attitudes towards HIV/AIDS.

Using a statistical analysis tool called a logistic regression, the responses were analyzed to find any correlation or relationship between the way people responded, and other variables. The variables used in the analysis are: location of the workshop - urban,

rural, remote, gender, and age categories. The age categories are: 10-15, 16-24, 25-35, 36-45, 46-55, and 56+.

3.5c What Did We Learn About the Attitudes of our Workshop Participants Towards HIV/AIDS?

Three groups emerged as being less likely to have positive attitudes towards HIV/AIDS. They are:

- those who live in rural or remote areas of BC, workshop participants from rural and remote areas of BC are about 1/2 as likely to have positive attitudes towards HIV/AIDS.
- those in the 10-15 age category, workshop participants who are 10 to 15 years of age are about 1/4 as likely to have positive attitudes towards HIV/AIDS.
- men are less than 1/2 as likely to have positive attitudes towards HIV/AIDS.

3.5d What do These Results Mean for HIV/AIDS Prevention in BC's Aboriginal Communities?

The results represent a self selected sample of participants of HIV/AIDS workshops, from the time period of August 1996 - December 1998. The people attending the workshops reflect those wanting to learn more about HIV/AIDS. Knowing this, one might infer that the attitudes towards HIV/AIDS be worse in the larger Aboriginal community. And in particular, among young men living in rural and remote areas.

This indicates to those working in rural and remote communities to be aware of opportunities to target HIV/AIDS prevention to men, and in particular, young men. As the majority of the workshop participants also begin sexual activity between the ages of 10 and 15, it is important to begin teaching about sexuality, drug use, safer sex and self esteem *before* they become sexually active, and begin experimenting with drugs.

3.6 Personal Behaviours

The questionnaire contained three questions concerning risk behaviour:

1. Have you ever had an STD (sexually transmitted disease)?
2. Have you ever shared needles?
3. Have you ever had unprotected sex while under the influence of alcohol?

Figure F1a

Gender of participants who answered "Yes" to have you ever had an STD (sexually transmitted disease)? N=1044

Male	Female	Gender Missing	Total
60	113	47	220
27%	51%	21%	100%

70% responded "No" to have you ever had an STD, and 9% responded "Don't Know". A total of 220 HOS workshop participants, or 21% of those who answered this question responded, "Yes" they have had an STD. Of those who have had an STD, 51% were female, 27% male, and 21% did not indicate their gender.

Figure F1b

Age and gender of participants who answered "Yes" to have you ever had an STD ? N=220

	Age 10-15	Age 16-24	Age 25-35	Age 36-45	Age 46-55	Age 56+	Age Missing
Male	2	8	16	17	3	1	13
Female		32	32	17	11	1	20

The majority of those who did have an STD are younger, between the ages of 16 and 45, with age missing for 33 responses.

Figure F2a

Gender of participants who answered "Yes" to have you ever shared needles? N=641

Male	Female	Gender Missing	Total
37	27	19	83
45%	32%	23%	100%

87% of the 641 workshop participants who answered this question, answered "No" to have you ever shared needles. 13% of those who responded to this question responded "Yes". The gender breakdown of those who have shared needles, is 45% are male, 32% female, and gender is missing for 23%. Those who have shared needles make up 6% of the total sample of 1304 respondents.

Figure F2b

Age and gender of participants who answered "Yes" to have you ever shared needles ?

	Age 10-15	Age 16-24	Age 25-35	Age 36-45	Age 46-55	Age 56+
Male	4	3	8	10	2	1
Female	1	4	7	8	1	1
Gender Missing		1	5	8	2	1

Of those workshop participants who have shared needles, the highest number is in between the ages of 25 - 45, making up 55% of the 83 participants who have shared needles.

Figure F3

Participants who responded "Yes" to have you ever had unprotected sex while under the influence of alcohol/drugs? N= 1037

Male	Female	Gender Missing	Total
185	260	98	543
34%	48%	18%	100%

52% (543) of 1037 who answered this question, responded "Yes" they have had unprotected sex while under the influence of alcohol/drugs. 48% (494) responded "No".

Figure F4

Age and gender of participants who responded "Yes" to have you ever had unprotected sex while under the influence of alcohol/drugs? N= 1037

	Age 10-15	Age 16-24	Age 25-35	Age 36-45	Age 46-55	Age 56+
Male	5	62	39	32	9	2
Female	7	72	80	36	19	6
Gender Missing	2	4	21	30	15	4

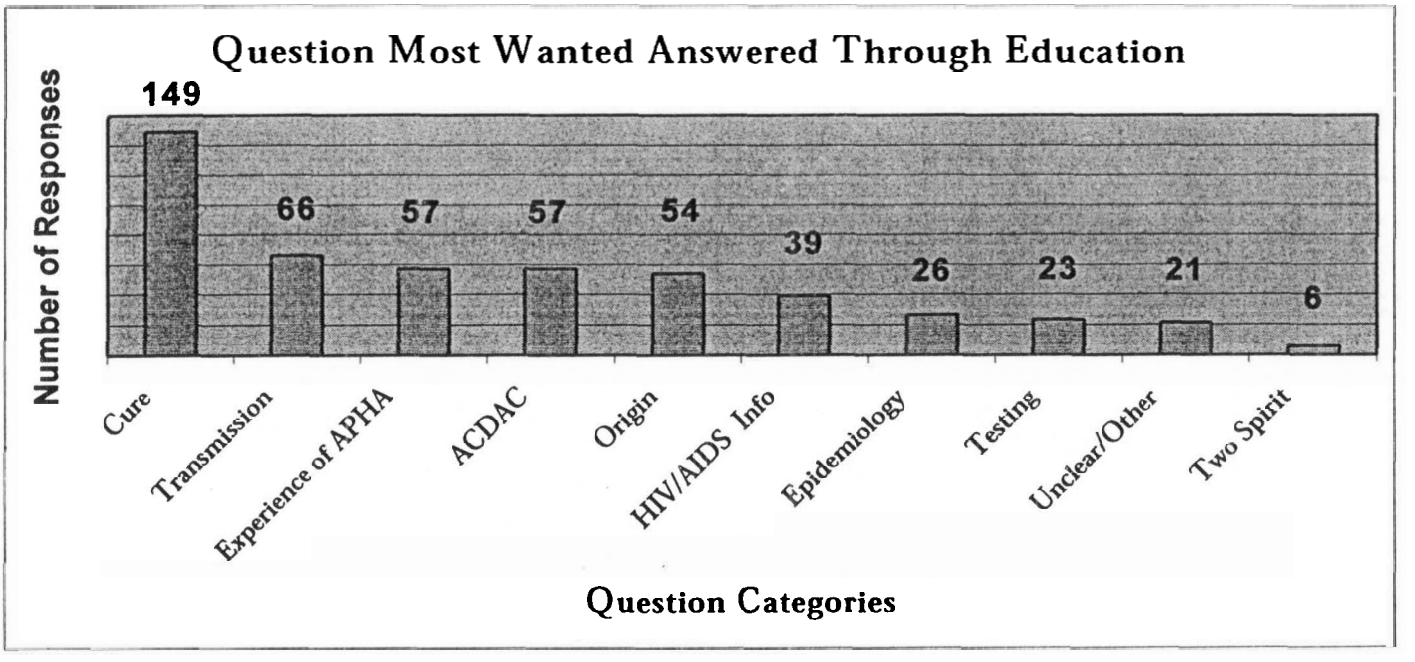
69% (543 out of 1037) who responded "Yes", they have had unprotected sex while under the influence of alcohol/drugs, are between the ages of 16 - 45.

3.7 Question Most Wanted Answered

This question was an open question and responses were coded into categories for analysis. "ACDAC" is short for the category, community awareness and community development in Aboriginal communities. "Unclear /Other" refers to questions that did not fall into any category, or it was unclear what the participant was asking. 'HIV/AIDS Information' encompasses general questions regarding HIV/AIDS, and includes questions about the scientific aspects of HIV/AIDS.

Overwhelmingly, workshop participants want to know if there is a cure for HIV/AIDS. There is equal percentage of requests for information on transmission of HIV/AIDS; what are the physical, emotional, spiritual, and mental aspects of living with HIV/AIDS; where does HIV come from, and the need for awareness and community development in Aboriginal communities.

Figure G



5.0 Conclusions and Discussion

Despite prevention education efforts, and knowledge of HIV/AIDS transmission, some Aboriginal individuals and communities remain in fear of, and hold discriminatory attitudes towards HIV/AIDS, and those who live with the disease. On the whole, respondents to this survey had good knowledge of HIV/AIDS. As indicated in the study of Attitudes and Beliefs Towards HIV/AIDS (Section 3.5), there are groups in this self selected sample that have emerged as requiring more education, these are the young men, living in rural and remote areas of BC. Because of the fear and prejudice that still exists around HIV/AIDS, we assume that our workshop participants, in general may tend to have better attitudes towards HIV/AIDS, than those who choose not to attend Healing Our Spirit workshops.

Healing Our Spirit BC First Nations AIDS Society has recently redesigned the HIV/AIDS workshop questionnaire and evaluation. The current forms address pre and post HIV/AIDS knowledge so there may be comparison and a clearer picture of the effectiveness of prevention workshops. The new questionnaires assess knowledge and attitudes prior to and following completion of participation in HIV/AIDS workshops. As they are administered together, they are individually linked and will provide information on retention of information and change in attitudes of individuals receiving HIV/AIDS education.

At this point Healing Our Spirit does not have the funds to administer a follow up questionnaire with participants past a one or two day time interval. There is also need for a broad based survey of knowledge of HIV/AIDS, and behaviours that are putting Aboriginal people at greater risk for transmission of HIV/AIDS, in rural and reserve areas. The retention of HIV/AIDS prevention information, and the effect of education on behaviour change, is also an area of importance that could be addressed by a long term evaluation strategy. At Healing Our Spirit, through the Building Research Capacity Project, efforts have been made to build a base that would help facilitate a project undertaking of this nature in the future.

As the Red Road Pathways to Wholeness: An Aboriginal Strategy for HIV and AIDS in BC is implemented in Aboriginal communities, local needs assessment initiatives will be linked provincially, and evaluation of Aboriginal HIV/AIDS program development linked and standardized provincially.

The results of the Healing Our Spirit education needs assessment survey cannot be generalized to the broader Aboriginal population living in British Columbia. However, the information in this report is useful for those working in health promotion, and for community health workers who are developing programs and services for HIV/AIDS in the Aboriginal community.

Appendix 1
Assessment Survey For HOS HIV/AIDS Workshop Participants

ASSESSMENT SURVEY

MALE ( ) FEMALE ( )

10-15 16-24 25-35 36-45 46-55 56+

SINGLE ( ) MARRIED ( ) DIVORCED ( ) WIDOWED ( ) COMMON-LAW ( ) OTHER ( )

How old were you when you first became sexually active?

Under 10 10-15 16-20 21-25 26-30 31-35 36+ Never

1 Where do you get information about HIV/AIDS?

Television ( ) Newspaper ( ) Magazines ( ) Radio ( ) Relatives & Friends ( )
Brochures/Flyers pamphlets ( ) Doctor/Clinic ( )Counsellor ( )
Community Health Representative ( ) Health Nurse ( ) Other ( ) Don't know ( )

2 If you want more information about HIV/AIDS, where do you go?

Family/Friends ( ) Counsellor ( ) Newspaper ( ) Doctor/Clinic ( ) Library ( )
AIDS Hotline/Info Line ( ) Community Health Rep. ( ) Don't know ( ) Other ( )

3. Check one answer that best matches what you know about HIV/AIDS.

Most of the people who have AIDS now, will die from it.	YES ( ) NO ( ) Don't know ( )
A person can have the HIV virus and not have the disease AIDS.	YES ( ) NO ( ) Don't know ( )
You can tell if people have the AIDS virus by just looking at them.	YES ( ) NO ( ) Don't know ( )
Any person with the AIDS virus can pass it on to someone else through sexual intercourse	YES ( ) NO ( ) Don't know ( )
A pregnant woman who has AIDS can pass it to her baby	YES ( ) NO ( ) Don't know ( )
There is a vaccine (medicine) available to protect a person from getting HIV.	YES ( ) NO ( ) Don't know ( )
There is a cure for AIDS at the present time	YES ( ) NO ( ) Don't know ( )
Indians can get AIDS.	YES ( ) NO ( ) Don't know ( )

Only gay men get AIDS YES ( ) NO ( ) Don't know ( )

Only drug users get AIDS YES ( ) NO ( ) Don't know ( )

4 **Check which items match what you believe about HIV/AIDS.**

A) People with AIDS should be allowed to go to public school.

Strongly agree ( ) Agree ( ) Not Sure ( ) Disagree ( ) Strongly Disagree ( )

B) People with AIDS should be allowed to work with food in restaurants.

Strongly agree ( ) Agree ( ) Not Sure ( ) Disagree ( ) Strongly Disagree ( )

C) People with AIDS should be allowed to attend pow-wow's and other social gatherings.

Strongly agree ( ) Agree ( ) Not Sure ( ) Disagree ( ) Strongly Disagree ( )

D) People who get AIDS through sex or drug use deserve the disease.

Strongly agree ( ) Agree ( ) Not Sure ( ) Disagree ( ) Strongly Disagree ( )

E) Homosexual behaviour (gays/lesbians) is acceptable in our community.

Strongly agree ( ) Agree ( ) Not Sure ( ) Disagree ( ) Strongly Disagree ( )

F) Someday AIDS will be a big problem in the community where I live.

Strongly agree ( ) Agree ( ) Not Sure ( ) Disagree ( ) Strongly Disagree ( )

5 Do you have or have you had one or more sexual partners YES ( ) NO ( )
Do you or have you ever used needles YES ( ) NO ( )
If yes: Have you ever shared needles YES ( ) NO ( )
Have you ever had unprotected sex while under the influence of alcohol/drugs YES ( ) NO ( )
Have you ever had an STD (sexually transmitted disease YES ( ) NO ( ) Don't know ( )
The last time you had sex, did you use a condom YES ( ) NO ( )

6. **What is the one question you would most like to have answered about HIV/AIDS?**

_____

_____

_____

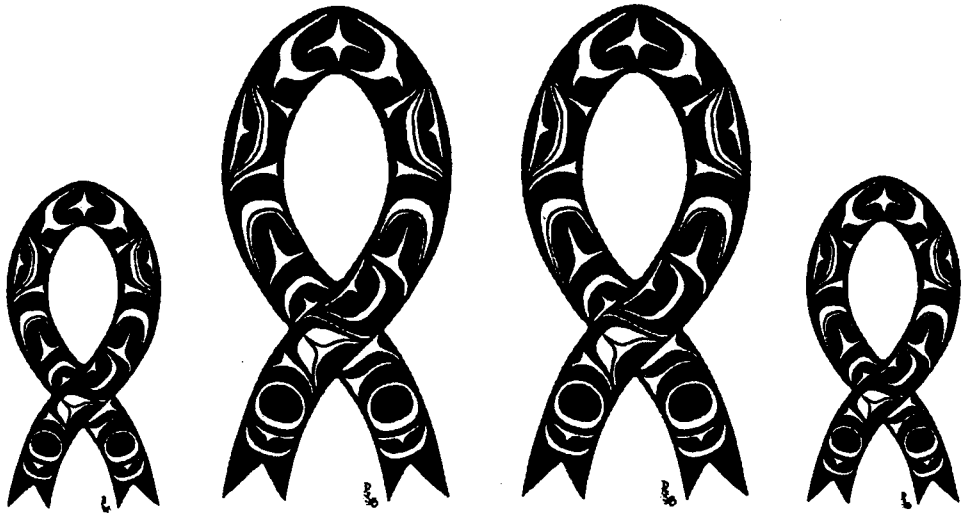
_____

_____

Appendix B

Healing Our Spirit Report on Results of Aboriginal Evaluation Survey of HIV/AIDS Workshop Participants

Healing Our Spirit
BC First Nations AIDS Society



Report on Results of Aboriginal HIV Educational Workshop Evaluation Survey

1996 - 1997 Data

Ivy Bell, Tobin Copley, Suzanne Newman
David Schneider, and Namaste Marsden

March, 2000

Funded by HIV/AIDS Prevention and Community Action Programs

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1. Healing Our Spirit BC First Nations AIDS Society

Healing Our Spirit BC First Nations AIDS Society was founded and incorporated as a non-profit society in 1992. The co-founders Leonard Johnston, and Frederick Haineault were both of the Cree Nation. They perceived the need to provide awareness of HIV/AIDS through prevention services to First Nations and Aboriginal communities in BC. Both Leonard and Frederick have passed on to the Spirit world, but the legacy of their work in HIV/AIDS lives on. Today, Healing Our Spirit provides a wide range of prevention, care, treatment, support, research, and evaluation services to Aboriginal communities across BC.

The Education program provides holistic and culturally appropriate HIV/AIDS prevention workshops to health professionals, students, communities, youth, incarcerated Aboriginals, Elders and chiefs and councillors. The Education program trains and brings speakers living with HIV/AIDS to Aboriginal communities and organizations to share their life experiences.

The Outreach office in Vancouver offers services for Aboriginal people living with HIV/AIDS. Peer support, volunteer programming, social support and activities, emergency funds, housing advocacy, referrals, human rights advocacy, healing circles, and counselling in residential school syndrome are offered to Healing Our Spirit Lifetime members and clients. Lifetime membership with Healing Our Spirit is free for Aboriginal people living with HIV/AIDS.

The annual Aboriginal HIV/AIDS conference is hosted by Healing Our Spirit in partnership with communities across the province. The conference has previously been held in Vancouver, Prince George, and Nanaimo; the Fourth Annual conference is being held in Cranbrook. The conference brings together funders, health workers and professionals, Aboriginal people living with HIV/AIDS, community members. There are delegates and presenters from across Canada and the United States. The focus of the conference is Honouring Aboriginal people who are infected or affected by HIV/AIDS. Workshop topics range from prevention, to self care, harm reduction,

physical, mental, spiritual and emotional growth, community awareness and development, access to care issues for women and children, and palliative care.

2. The Aboriginal HIV Educational Workshops

This report present findings from evaluation surveys completed by participants of Aboriginal HIV/AIDS educational workshops conducted by Healing Our Spirit BC First Nations AIDS Society (HOS). The HOS education program targets prevention education at Aboriginal people who are at risk of being infected or affected by HIV/AIDS.

The program works with communities and organizations to ensure that those who need to hear the prevention message are encouraged to attend the workshops in the community. Workshop audiences range from community members, to chief and council, health professionals, youth, incarcerated persons, job training programs and children in school. Attendance at these workshops is voluntary in all cases. In some cases, those attending the workshops may perceive that HIV/AIDS could become a problem in their community and are there to gather information to share with their family and friends. Others may be seeking support for themselves, or someone they know infected of affected by HIV/AIDS. Some may be on their personal healing journey and are seeking empowering information and support.

While the content of specific workshops can vary according to the age, pre-existing knowledge level, and background of workshop participants, or may be customized in response to specific requests by the sponsoring organization, core content components are common to all workshops conducted through HOS. These core workshop components include discussion of the causes of HIV, HIV epidemiology, the impact of HIV on Aboriginal peoples, techniques for harm reduction or prevention of sexual and intravenous HIV transmission, and issues facing Aboriginal people living with HIV and AIDS. Frequently, on request of Aboriginal communities, an Aboriginal person living with HIV is a guest speaker at the workshop.

Workshop length can range from two hours to three days or more. HOS provides these workshops to interested groups throughout the province of British Columbia, in both rural and urban communities, both on and off reserve.

3. The Workshop Questionnaires

Soon after HOS began conducting HIV education workshops, we recognized a need to systematically gather information from workshop participants to assist us in ongoing refinement of the workshop content. Toward this end, we developed a series of two questionnaires.

The pre-workshop or "assessment" questionnaire was designed to collect baseline information about participants' knowledge, beliefs, and attitudes towards HIV and AIDS. Workshop participants completed the assessment questionnaire immediately before the workshop commenced. Results from this questionnaire are reported in the "Report on Results of Aboriginal Knowledge, Attitudes and Beliefs Survey" by Marsden and Bell.

The post-workshop or "evaluation" questionnaire was designed to solicit information about the key messages participants are taking away with them, the changes to sexual or injection behaviors they anticipate making as a result of the information provided in the workshop, how they might tell others about what they learned in the workshop, and what additional things they would like to learn about HIV and AIDS. The evaluation questionnaire was completed by participants at the end of the workshop. Information from the evaluation questionnaire is the subject of the present report.

The evaluation questionnaire is one page long and typically took less than five minutes to complete. Like the assessment questionnaire, the evaluation questionnaire was voluntary, and the facilitator assisted participants by verbalizing the questions and assisting individuals with low literacy one on one. All questions were in an open-ended format. A sample evaluation questionnaire is contained in Appendix A.

The assessment and evaluation questionnaires were not administered in a way that allows them to be individually linked; that is, it is not possible to compare a specific individual's pre-workshop and post-workshop responses. This fact, combined with the fundamental difference in questionnaire content, prevents us from attempting any direct pre/post intervention evaluation. However, we felt that analysis of the evaluation questionnaires separate from the assessments was a worthwhile undertaking in its own right.

4. Methods

The evaluation questionnaire was administered from 1996 to 1999. Over this four-year period, several revisions were made to the content of the questionnaire. A review of the completed questionnaires revealed a total of six versions had been distributed and completed by workshop participants since 1996. These versions generally substantially differed from one another in terms of question topic and phrasing, thus making comparisons between responses from the different versions impractical. We identified one widely used version for analysis. We refer to this as the "Type II" questionnaire.

A careful review of all workshop files identified 1,021 completed Type II questionnaires. The analysis in this report includes these 1,021 Type II questionnaires, which were completed between March 18, 1996 and December 11, 1997 inclusive.

Because all the questions in the survey instrument are in an unstructured, open-ended format, it was necessary to undertake a structured content analysis approach to questionnaire coding. A random sample of 75 questionnaires was selected and reviewed in two stages by two reviewers. Each reviewer analyzed all 75 questionnaires independently. In the first stage, the sampled questionnaires were reviewed and used to construct a content-driven coding classification. The reviewers then met, compared each other's preliminary content codes, then reconciled differences between the two classification schemes to create one common set of codes. In the second stage, the same 75 questionnaires were independently reviewed a second time, this time using the "common" coding classification. Inter-rater reliability using the common classification

was good, and some additional refinements were made to the classification scheme. The resulting content coding scheme is included as Appendix B. A researcher was recruited and trained how to code questionnaires using the coding scheme and enter the results into a database. The database used was a FileMaker Pro application developed specifically for entry of these data.

Data for analysis were exported from FileMaker Pro into Stata, a statistical analysis application. Because many individuals may not have been coded for certain content areas, the number of people responding to a question by giving information in a specific content area will be indicated at the top of each table or chart using the notation, "N=."

5. Results

This analysis concerns the 1,021 Type II (Appendix A) questionnaires completed between March 18, 1996 and December 11, 1997 and coded using the coding scheme in Appendix B.

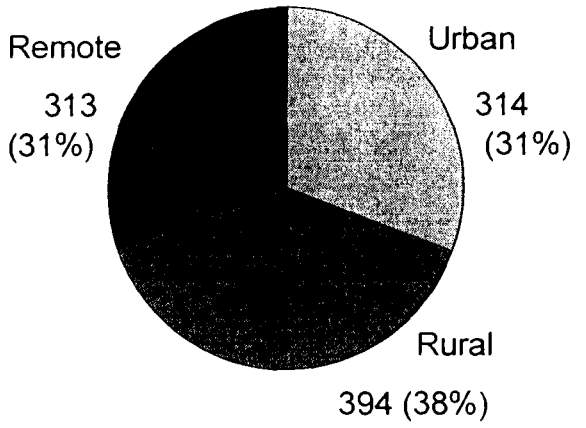
5.1. Distribution by community and location type

Communities throughout the province are represented here (Table 1). Communities were coded as either "Urban," "Remote," or "Rural." "Urban" communities are defined as large centres, not restricted to the Lower Mainland, including Prince George and Prince Rupert. Prisons are also defined as urban. Communities are defined as "Remote" if they had limited or no road access. This includes Alert Bay, Telegraph Creek, and Gitwinksihlkw. "Rural" is applied to communities that are not urban, nor remote. They are midsize, or small communities in close proximity to larger communities, and easily accessible. Rural communities include Boston Bar, Enderby, and Ft. St. James. As Figure 1 shows, the number of completed questionnaires is evenly distributed between these three types of communities. Analysis of responses from each question shows no association between location type (Urban, Rural, or Remote) and coded responses to any of the items in the questionnaire.

TABLE 1: COMMUNITIES BY LOCATION TYPE (N=1,021)

Community	Type	N	%
Alert Bay	Remote	26	2.55
Alexis Creek	Remote	11	1.08
Bella Bella	Remote	66	6.46
Bella Coola	Remote	15	1.47
D'arcy	Remote	22	2.15
Gitanyow	Remote	10	0.98
Gitwinksihlkw	Remote	7	0.69
Hartley Bay	Remote	29	2.84
Kingcome Inlet	Remote	16	1.57
Kitkatla	Remote	1	0.1
Kuper Island	Remote	36	3.53
Port Alice	Remote	2	0.2
Seton Lake	Remote	30	2.94
Takla Lake	Remote	25	2.45
Telegraph Creek	Remote	17	1.67
Agassiz	Rural	7	0.69
Ashcroft	Rural	7	0.69
Boston Bar	Rural	17	1.67
Canoe Creek	Rural	5	0.49
Chilliwack	Rural	8	0.78
Enderby	Rural	8	0.78
Fort Ware	Rural	27	2.64
Ft. St. James	Rural	54	5.29
Ft. St. John	Rural	5	0.49
Hope	Rural	3	0.29
Lillooet	Rural	44	4.31
Mcleod Lake	Rural	4	0.39
Merritt	Rural	28	2.74
Mission	Rural	32	3.13
Penticton	Rural	9	0.88
Powell River	Rural	63	6.17
Salmon Arm	Rural	22	2.15
Sardis	Rural	8	0.78
Seabird Island	Rural	10	0.98
Squamish	Rural	8	0.79
Tobacco Plains	Rural	5	0.49
Tsawwassen	Rural	10	0.98
Yale	Rural	11	1.08
Burnaby	Urban	9	0.88
Delta	Urban	10	0.98
Musqueam	Urban	3	0.29
New Westminster	Urban	15	1.47
North Vancouver	Urban	37	3.62
Surrey	Urban	70	6.86
Vancouver	Urban	169	16.55
Total		1021	100.00

CHART 1: DISTRIBUTION OF LOCATION TYPE (N=1,021)



5.2. MOST IMPORTANT THING REMEMBERED FROM WORKSHOP

Question 1 asked, "What is the most important thing that you remember about today's workshop?" As shown in Appendix B, responses to this question were coded along one general and six specific dimensions. The first (general) dimension captured comments related to general topic or program areas. Responses are summarized in Table 2. Because the survey instrument contained only unstructured open-ended questions, two categories captured non-specific comments regarding the program ("General, unspecified" and "Workshop in general"). The presentation materials used (54%) and the HIV positive speaker (11%) was the most frequent specific responses.

TABLE 2: MOST IMPORTANT THINGS REMEMBERED, GENERAL (N=1,021)

Response	n	%
Missing	3	0.3
General, unspecified	99	9.7
Workshop in General	209	20.5
Have attended AIDS workshop before	4	0.4
Facilitator	6	0.6
Speaker	115	11.3
Materials	547	53.6
Cultural Appropriateness	10	1.0
All was important	27	2.6
Other Workshop	1	0.1
Total	1021	100.0

The six specific dimensions identified during content analysis were:

1) "Biomedical": Disease causes, epidemiology, treatment options, etc.
2) "Behavioral": Behaviors affecting risk of transmission of HIV
3) "HIV Services": Discussion of clinical or support services related to HIV/AIDS
4) "Social": Social issues related to HIV/AIDS
5) "Psychosocial": Psychological and interpersonal issues related to HIV/AIDS
6) "Other": A catch-all category for responses not fitting in the above categories

Nearly three in ten participants indicated biomedical issues were the most important things they remembered from the workshop. HIV pathogenesis dominated these responses, with focus in the areas of HIV transmission, the HIV illness process or trajectory, and the epidemiology of the epidemic. Interestingly, less than one percent of respondents indicated either information on HIV testing or therapeutic options were the most important thing they remembered. Also worthy of note in the relatively low profile of coinfection issues such as STDs, Hepatitis, or other illnesses among responses. HIV coinfection with HCV or certain STDs is a rapidly growing problem in recent years, and these results may indicate an opportunity for HOS to review their workshop programming in this area.

TABLE 3: MOST IMPORTANT THINGS REMEMBERED, BIOMEDICAL (N=1,021)

Response	n	%
Missing	727	71.2
General, unspecified	9	0.9
Transmission	99	9.7
Testing	7	0.7
Infection - process (HIV in cells)	17	1.7
Illness - process (Continuum of HIV/AIDS)	93	9.1
Origin of HIV	1	0.1
Epidemiology (spread of virus)	30	2.9
HIV + other illnesses	10	1.0
New info/ research - treatment,cure	7	0.7
STD's	8	0.8
Hepatitis/TB - other illnesses	8	0.8
Other Biomedical	5	0.5
Total	1021	100.0

As Table 4 shows, participant responses in the "behavioral" dimension were dominated by safer sex messages (23.3%). Safer injection practices were certainly represented among the responses (6.4%), but the relatively low frequency of these responses is not surprising given that the surveys were completed in a group setting were the confidentiality of the responses could not be ensured.

TABLE 4: MOST IMPORTANT THINGS REMEMBERED, BEHAVIORAL (N=1,021)

Response	n	%
Missing	742	72.7
General, Unspecified	14	1.4
How to - safer sex	44	4.3
Use safer sex	146	14.3
How to - safer injection	14	1.4
Use safer injection	3	0.3
Safer sex and safer injection	48	4.7
Universal precautions	6	0.6
Other behavioral	4	0.4
Total	1021	100.0

While few participants indicated that information about HIV-related services was the most important thing they remembered from the workshop, information about where to obtain additional HIV prevention information among those who did give responses in this dimension (Table 5).

TABLE 5: MOST IMPORTANT THINGS REMEMBERED, HIV SERVICES (N=1,021)

Response	n	%
Missing	958	93.8
Availability of prevention information	52	5.1
Availability of counselling - general	1	0.1
Availability of counselling - testing	3	0.3
Availability of services/support for people with HIV	4	0.4
Would like to offer help	1	0.1
Other HIV services	2	0.2
Total	1021	100.0

As with HIV services, few participants indicated that discussion about HIV social issues was the most important thing they remembered. Of those who did, social stigmatization and human rights issues dominated. Interestingly, only two individuals specifically identified Aboriginal issues (Table 6).

TABLE 6: MOST IMPORTANT THINGS REMEMBERED, SOCIAL (N=1,021)

Response	n	%
Missing	926	90.7
General, unspecified	1	0.1
Social Stigma/Human rights	86	8.4
Funding for HIV/AIDS	1	0.1
Aboriginal issues	2	0.2
Other social	5	0.5
Total	1021	100.0

Gaining a better understanding of the experience of living with HIV/ADS and learning how to talk to, support, or live with people with HIV stood out in the psychosocial dimension (Table 7). Further analysis reveals that these responses are highly associated with the HIV-positive workshop speaker rating (in the "general" dimension, Table 2), suggesting that for these individuals, the speaker was successful in personalizing HIV and making the experience of becoming infected with HIV immediate for workshop participants.

TABLE 7: MOST IMPORTANT THINGS REMEMBERED, PSYCHOSOCIAL (N=1,021)

Response	n	%
Missing	891	87.3
General	2	0.2
Personal empowerment	15	1.5
How to live with/support/talk to APHAs	19	1.9
Experience of living with HIV/AIDS	91	8.9
Other Psychosocial	3	0.3
Total	1021	100.0

5.3. WORKSHOP KNOWLEDGE AND ANTICIPATED CHANGE IN SEXUAL BEHAVIOR

About eighty percent of participants responded to the question regarding anticipated changes in one's sexual behavior (Table 8). Interpretation of these responses, particularly ones like "no change" or "not applicable", is difficult since it is not known whether participants were sexually active. Despite the problems associated with this question, it is clear many participants have clearly identified and can articulate the safer sex message, and the accompanying message promoting self-respect. It is important to note, however, that this question is asked in a hypothetical context—and immediately following an HIV education workshop— so questions of participant's

ability to retain the information correctly over a longer time period and translate stated intentions into action remains unanswered.

TABLE 8: ANTICIPATED CHANGE IN SEXUAL BEHAVIOR (N=1,021)

Response	n	%
Missing	2	0.2
No change	38	3.7
Abstain from sex	42	4.1
Safer Sex/use condoms	393	38.5
Stay in monogamous/stable relationship	54	5.3
Testing	5	0.5
Avoid having sex while drunk/high	1	0.1
Self respect/generally be careful	121	11.9
Am more aware	53	5.2
Never had sex	20	2.0
N/A	39	3.8
No	23	2.3
Don't Know	12	1.2
Other	16	1.6
Did not respond	202	19.8
Total	1021	100.0

5.4. WORKSHOP KNOWLEDGE AND ANTICIPATED CHANGE IN INJECTING BEHAVIOR

Fewer participants responded to the question regarding injection drug use. As the responses to the question clearly indicate there was considerable ambiguity and confusion regarding a participant's eligibility to answer the question. Over 40 percent of participants did not respond to the question (indicating a self-selection by non-IDUs to not respond), yet upward of 10 percent of the responses would suggest the respondent is not a user. Such confusion makes interpretation of all the responses for this question difficult, since we cannot know if a respondent is a member of the target audience (injection drug users) or not. In spite of these difficulties, question responses indicate that appropriate prevention messages are being understood in relation to injection drug use. Two main messages can be identified in the responses: harm reduction (use new needles, clean one's needle, avoid sharing, etc.), and avoidance (do not use needles, etc.).

TABLE 9: ANTICIPATED CHANGE IN INJECTING BEHAVIOR (N=1,021)

Response	n	%
Missing	2	0.2
No change	1	0.1
Don't use needles (unclear – do not personally use, or stating – do not use)	189	18.5
Always use new needle/use needle exchange	8	0.8
Always use clean needle/clean before	80	7.8
Do not share needles	69	6.8
Shouldn't use needles	12	1.2
Self respect/generally be careful	9	0.9
I will stop using needles/won't use	4	0.4
I have quit using needles	13	1.3
I never/ don't use needles	62	6.1
N/A	92	9.0
No	50	4.9
Don't Know	5	0.5
Other	11	1.1
Did not respond	414	40.6
Total	1021	100.0

5.5. WORKSHOP KNOWLEDGE AND ANTICIPATED METHOD OF EXPLAINING HIV RISKS TO SEXUAL PARTNER

Almost 70 percent of participants responded to the question asking how they "would explain the dangers of risky behaviours" to their [sexual] partner. This question was specifically directed to individuals who considered themselves to be in a "committed relationship." While respondents gave a fairly wide range of responses (Table 10), the responses indicated that a large proportion of participants (43.0%) valued open discussion about sexual transmission of HIV with one's partners. Responses within this theme included suggestions to be "straight-forward", "open," or "honest", to express a mutual concern for one another, and to engage in a discussion of risky versus safer behaviours. Some participants felt that the materials or information provided in the workshop would help with these discussions, and six participants indicated they would like to bring their partners to future workshops.

Other responses for this question included promotion of condoms use (and for some, refusing sex without a condom), and maintaining monogamous relationships. Regarding testing, 34 participants (3.3%) would ask their partner to be tested for HIV

or show the results of a recent HIV test, while one participant would not disclose the results of a (presumably positive) HIV test to their partner. Only three individuals explicitly stated they would not discuss the issue with their partner.

TABLE 10: ANTICIPATED APPROACH TO EXPLAINING RISKS TO SEXUAL PARTNER (N=1,021)

Response	n	%
Missing	16	1.6
stay monogamous	34	3.3
No change	3	0.3
Partner already knows/I'm not at risk	12	1.2
Would not discuss issue with partner	3	0.3
Would not disclose HIV status to partner	1	0.1
Ask partner to test/result of test	34	3.3
Be straight-forward/direct/explain	87	8.5
Honesty/openness/expression of mutual concern	158	15.5
Explanation of risky vs. safer behaviours	132	12.9
Use workshop materials/information/knowledge	55	5.4
Provide literature/materials in general	7	0.7
Bring partner to workshop	6	0.6
Issue ultimatum/no sex w/o condom/	13	1.3
Tell /ask partner to wear condom	29	2.8
I practice safe sex - no change	1	0.1
Response does not explain how they will change	39	3.8
N/A	52	5.1
No	8	0.8
Don't Know	12	1.2
Other	11	1.1
Did not respond	308	30.2
Total	1021	100.0

5.6. DESIRE FOR ADDITIONAL INFORMATION ABOUT HIV/AIDS

Question 3 asked, "What more would you like to know about HIV/AIDS?" This is a parallel question to Question 1: whereas Question 1 asked what participants felt was the most important thing they remember about the workshop they had just completed, Question 3 follows up to ask what more information they would like to learn. The question coding reflects the close relationship between these two questions. As shown in Appendix B, responses to this question were coded along the same six specific dimensions as used in Question 1.

About one third of workshop participants included biomedical issues among the things they would like to learn more about (Table 11). While issues related to HIV

pathogenesis and epidemiology (which dominated in Question 1), were represented in about 10 percent of responses, interest was focussed on learning more about progress in new treatment options or finding a cure. As in Question 1, coinfection issues or the impact of HIV on Aboriginal peoples were mentioned very infrequently.

TABLE 11: DESIRE FOR ADDITIONAL KNOWLEDGE, BIOMEDICAL (N=1,021)

Response	n	%
Missing	682	66.8
General, unspecified	3	0.3
Transmission	10	1.0
Testing	11	1.1
Infection - process (HIV in cells)	8	0.8
Illness - process (Continuum of HIV	49	4.8
Origin of HIV	20	2.0
Epidemiology (spread of virus)	21	2.1
HIV + other illnesses	4	0.4
New info/ research - treatment,cure	199	19.5
Nutrition	3	0.3
Impact on First Nations	1	0.1
STD's	1	0.1
Hepatitis/TB - other illnesses	3	0.3
OI's - opportunistic infections	1	0.1
Beyond AIDS 101	1	0.1
Other Biomedical	4	0.4
Total	1021	100.0

As Tables 12 and 13 show, very few participants indicated an interest in obtaining more information in either the "behavioral" or "social" dimensions. The low response rates in these categories suggests that the safer sex/injection messages captured in the "behavioral" dimension and the human right and stigmatization issues captured in the "social" dimension were covered by the workshop facilitators unambiguously and provided enough content to satisfy the immediate interests of the audience.

TABLE 12: DESIRE FOR ADDITIONAL KNOWLEDGE, BEHAVIORAL (N=1,021)

Response	n	%
Missing	1014	99.3
How to - safer sex	2	0.2
Use safer sex	1	0.1
How to - safer injection	3	0.3
Safer sex and safer injection	1	0.1
Total	1021	100.0

TABLE 13: DESIRE FOR ADDITIONAL KNOWLEDGE, SOCIAL (N=1,021)

Response	n	%
Missing	1004	98.3
General, unspecified	1	0.1
Social Stigma/Human rights	5	0.5
Politics of HIV/AIDS	1	0.1
Funding for HIV/AIDS	1	0.1
Aboriginal issues	4	0.4
Other social	5	0.5
Total	1021	100.0

Few participants also responded they would like more information about HIV-related services, suggesting this material was either well covered within the workshop, or was an area that held little interest for participants. Responses were more or less evenly distributed between desiring more information about HIV prevention, about where to get HIV counselling, and where to find support services for people infected or affected by HIV (Table 14). Seven individuals responded with indications they would like to offer help in providing HIV-related services in their communities.

TABLE 14: DESIRE FOR ADDITIONAL KNOWLEDGE, HIV SERVICES (N=1,021)

Response	n	%
Missing	943	92.4
General, unspecified	6	0.6
Availability of prevention information	22	2.2
Availability of counselling - general	9	0.9
Availability of counselling - testing	6	0.6
Availability of services/support for PHAs	13	1.3
Would like to offer help	7	0.7
Other HIV services	15	1.5
Total	1021	100.0

While few participants' responses were in the psychosocial dimension, gaining a better understanding of the experience of living with HIV/ADS and learning how to talk to, support, or live with people with HIV stood out within this dimension. As with similar Question 1 responses, further analysis reveals that responses in Question 3 are highly associated with the HIV-positive workshop speaker rating (in the "general" dimension, Table 2). This suggests that for these individuals the speaker's success in personalizing HIV may have created the basis for a sustaining interest in developing a deeper understanding of the personal and social impact of HIV and AIDS.

TABLE 15: DESIRE FOR ADDITIONAL KNOWLEDGE, PSYCHOSOCIAL (N=1,021)

Response	n	%
Missing	973	95.3
Personal empowerment	2	0.2
How to live with/support/talk to APHAs	20	2.0
Experience of living with HIV/AIDS -	25	2.5
Other Psychosocial	1	0.1
Total	1021	100.0

5.7. HOW PARTICIPANTS WOULD TELL OTHERS ABOUT SAFER SEX

While a wide variety of suggestions were offered by workshop participants in response to the question asking how they would teach their partner, friend, or children about safer sex methods, the responses can be groups into three general themes. The first theme concerns condom use. Responses show the largest proportion of participants felt promotion of condom use and other safer sex practices, teaching how to use condoms properly, and increasing the availability of condoms were important (Table 16). Secondly, emphasis on abstinence or the importance of staying in a stable monogamous relationship also figured prominently. Thirdly, respect for oneself and others was frequently identified by respondents.

TABLE 16: SUGGESTIONS FOR SAFER SEX METHODS (N=1,021)

Response	n	%
Missing	3	0.3
Would not suggest anything	2	0.2
Abstain if possible, if not use condoms	79	7.7
Abstain from sex	30	2.9
Safer Sex/use condoms	311	30.5
Teach how to use condoms/do safer sex	69	6.8
Safe sex/sex education should be taught in schools	13	1.3
Condoms should be freely available/free	2	0.2
Stay in monogamous/stable relationship	22	2.2
Testing	11	1.1
Talk/Ask partner about STD's/IDU	2	0.2
Avoid getting/engaging in sex while drunk/high	1	0.1
Self respect/generally be careful	152	14.9
Will discuss these issues with my family	34	3.3
Have already discuss these issues	1	0.1
General/All workshop learnings	72	7.1
N/A	9	0.9
Yes	5	0.5
No	5	0.5
Don't Know	8	0.8
Other	16	1.6
Did not respond	174	17.0
Total	1021	100.0

5.8. PARTICIPANTS' INTEREST IN FUTURE WORKSHOPS

About 80 percent of participants responded to the last question. Nearly all respondents expressed a desire to attend future workshops. While participants listed a variety of content areas which they would like future workshops to address (Table 17), the responses can be broken down into three areas. First, there was a commonly expressed desire simply for more information (often expressed generally), or a complaint that there just had not been enough time to cover all the issues the participant would like to have discussed. Secondly, specific content areas of personal interest to the participant were mentioned. Thirdly, a number of participants specifically stated that they would like more workshops so that the information they had just learned could be provided to others in the community (e.g., others need to learn more; we need to educate our children; I want to learn more so I can teach others). Only 55 individuals stated that they did not wish to attend more workshops;

14 of these individuals explained that they felt that everything had been covered in the workshop.

TABLE 17: PARTICIPANTS' INTEREST IN FUTURE WORKSHOPS (N=1,021)

Response	n	%
Missing	5	0.5
Enjoyed the workshop	16	1.6
Not enough time	3	0.3
Need to learn more	206	20.2
Want to learn more re: safe sex	3	0.3
Community needs to learn more/others	117	11.5
Need to educate children/ future generations	63	6.2
Want to learn more so I can help others	22	2.2
Ongoing reinforcement needed/need help	26	2.6
Would like to keep up with new/updates	92	9.0
So I can be more supportive/to reduc	6	0.6
Would like opportunity for more debriefing	1	0.1
Go beyond AIDS 101	1	0.1
Yes, more on STD's/Hep/TB	4	0.4
Yes, very good information to know	60	5.9
Yes, I would like to bring partner/friend	2	0.2
No, all was covered	14	1.4
N/A	3	0.3
Yes	102	10.0
No	41	4.0
Don't Know	20	2.0
Other	11	1.1
Did not respond	203	19.9
Total	1021	100.0

6. CONCLUSIONS

The findings of this analysis of completed evaluation forms demonstrate that Healing Our Spirit has been effective in engaging Aboriginal participants about HIV/AIDS issues. Core components of the education program, such as the HIV illness process, how HIV is spread, disease epidemiology, and—importantly—the importance of taking effective steps to reduce the likelihood of HIV transmission all are well represented among participants' responses on the questionnaire. While these basics of HIV appear to have made an impression on many participants, many of these respondents also have indicated they would like more information about HIV and AIDS. Much of this interest is in regard to new developments in HIV research, particularly HIV therapies. Interestingly, issues surrounding coinfection were not well

represented, although coinfection (particularly with certain STDs and Hepatitis C) are becoming an increasing concern both from a public health perspective and for the therapeutic implications for coinfected individuals.

It is clear the safer sex / safer injecting messages were well understood by workshop participants. While participants may have chosen to focus of different routes to achieving reduction in the risk of HIV transmission, they clearly had an understanding of what the most important risky behaviours are, and of effective options for minimizing the risk of infection for oneself or one's partner.

While analysis of the data contained in the evaluation forms has proven to be informative for educators and researchers at Healing Our Spirit, we recognized a number of significant shortcomings in the questionnaire. For example, the open-ended format proved to be very difficult to code and analyze. However, the semi-structured questionnaire design worked well at this early stage insofar as it permitted participants the latitude to identify and comment upon workshop elements or issues that were of importance to them without steering or limiting the direction of the questionnaire's inquiry. We have been redesigning all questionnaire instruments used in workshops with the aim of creating a more structured and rigorous instrument capable of focussing on specific issues of interest. Furthermore, the new questionnaires will also solicit basic information to allow standard demographic description of the surveyed population (missing from the "Type II" evaluation forms), and will allow for individual linkage of pre- and post-workshop questionnaire responses. The latter feature will allow direct measurement of items such as knowledge or attitude scores, comparing score change on a per-individual basis between the assessment (pre-workshop, or "baseline") questionnaire and the evaluation (post-workshop) questionnaire. Additional opportunities exist to assess participants' capabilities to retain the workshop information many months after the workshop; the logistical design and confidentiality considerations that would be involved in such a participant re-contact exercise are all now being considered by Healing Our Spirit staff.

Evaluations will become a more important area for Aboriginal HIV/AIDS programming both at Healing Our Spirit and at Aboriginal AIDS service organizations (AASOs) in general. Healing Our Spirit has begun to look at evaluation, and continues to assess the potential of routinely employing formal evaluations to inform education program planning. We hope to be able to apply the techniques and knowledge we learn through this process to other programs, and to share results and expertise with our partner organizations and other AASOs and Aboriginal HIV/AIDS programs in BC.

Appendix A:

Sample HOS "Type II" Evaluation Questionnaire

Healing Our Spirit *B.C. First Nations AIDS Society*

Evaluation Form

Date: _____ **Community:** _____

1. **What is the most important thing that you remember about todays' workshop?**

   _____

   _____

   _____

2. **What you learned today - How will you change your;**
   A) Sexual behaviour? _____

   B) or if you use needles? _____

   C) or if you are in a committed relationship- how would explain the dangers of risky behaviours to your partner?

   _____

   _____

   _____

3. **What more would like to learn about HIV?AIDS?**

   _____

   _____

4. **What is your suggestion for safer sex method? What would you teach your partner, a friend, or your children?**

   _____

   _____

   _____

5. **Would you like to have more workshops and why?** _____

Appendix B:
Content Coding for HOS "Type II" Evaluation Questionnaire

Originally prepared by Tobin Copley Feb 13, 1999
Revised, September 07, 1999

Q1) What is the most important thing you remember about today's workshop?

Question 1 and 3 use the same coding categories. To reduce analytical problems with multiple coding, seven broad themes were identified from the reviewed forms, and more detailed codes were defined for use within each thematic area

Workshop	
1	General, unspecified
2	Workshop in general
3	Have attended workshop before
10	Facilitator
20	Speaker
30	Materials
40	Cultural appropriateness
50	All was important
98	Other workshop

Biomedical	
1	General, unspecified
5	Transmission
6	Testing
10	Infection - process (HIV in cells)
11	Illness - process (continuum of HIV to AIDS)
12	Origin of HIV
13	Epidemiology (spread of virus)
15	HIV + other illnesses
20	New info/research - treatment, cure
30	Nutrition
35	Impact on First Nations
40	STD's
50	Hepatitis/TB - other illnesses
60	OI's - opportunistic infections
70	Beyond AIDS 101
98	Other biomedical

Behavioural	
1	General, unspecified
10	How to - safer sex
11	Use safer sex
20	How to - safer injection
21	Use safer injection
23	Safer sex + safer injection
30	Universal precautions

... Question 1 coding, continued

HIV/AIDS Services	1	General, unspecified
	1	General, unspecified
	10	Availability of prevention information
	20	Availability of counselling - general
	21	Availability of counselling - testing
	30	Availability of services - support for APHAs
	40	Would like to offer help
	98	Other HIV services
Social/Society		
	1	General
	10	Social stigma/human rights
	20	Politics of HIV/AIDS
	30	Funding for HIV/AIDS
	40	Aboriginal issues
	98	Other social
Psychosocial		
	1	General
	10	Personal empowerment
	20	How to live with/support/ talk to APHAs
	30	Experience of living with HIV/AIDS - APHAs
	98	Other psychosocial

Coding, Question 2.

Q 2a) Anticipated sexual behaviour change	
0	No change
10	Abstain from sex
11	Safer sex/use condoms
17	Stay in monogamous
20	Testing
30	Avoid having sex while drunk/high
40	Self respect/generally be careful
50	Am more aware now
91	Never had sex
94	N/a
96	No
97	Don't know
98	Other
99	Did not respond

Q2b) Anticipated injection drug use change	
0	No change
10	Don't use needles (unclear, do not, or I do not)
11	Always use new needle/needle exchange
13	Always use clean needle/clean before use
17	Do not share
18	Shouldn't use needles
20	Testing
40	Self respect/generally be careful
50	I will stop/won't use
51	I have quit using
91	I never/don't use needles
94	N/a
96	No
97	Don't know
98	Other
99	Did not respond

... Question 2 coding continued

Q 2c) How would explain dangers of risky behaviours to sexual partner	
0	No change
1	Partner already knows/I'm not at risk
2	Would not discuss issue with partner
3	Would not disclose HIV status to partner
4	Would be difficult/hard to explain to partner
5	Ask partner to test/test result
10	Be straightforward/direct/explain dangers
12	Honesty/openess/express mutual concern
15	Explain risky vs. safer behaviours
20	Use workshop materials/information
21	Provide pamphlets/materials
23	Bring partner to workshop
30	Ultimatum - no condom/no sex/leave relationship
31	Tell/ask partner to wear condom
40	Don't fool around/stay monogamous
90	I practice safe sex - no change
91	Does not explain how
94	N/a
96	No
97	Don't know
98	Other
99	Did not respond

Q3) What more would you like to learn about HIV/AIDS?

Biomedical	
1	General, unspecified
5	Transmission
6	Testing
10	Infection - process (HIV in cells)
11	Illness - process (continuum of HIV to AIDS)
12	Origin of HIV
13	Epidemiology (spread of virus)
15	HIV + other illnesses
20	New info/research - treatment, cure
30	Nutrition
35	Impact on First Nations
40	STD's
50	Hepatitis/TB - other illnesses
60	OI's - opportunistic infections
70	Beyond AIDS 101

Behavioural	
1	General, unspecified
10	How to - safer sex
11	Use safer sex
20	How to - safer injection
21	Use safer injection
23	Safer sex + safer injection
30	Universal precautions
98	Other behavioural

HIVAIDS Services	
1	General, unspecified
10	Availability of prevention information
20	Availability of counselling - general
21	Availability of counselling - testing
30	Availability of services - support for APHAs
40	Would like to offer help
98	Other HIV services

Social/Society	
1	General
10	Social stigma/human rights
20	Politics of HIV/AIDS
30	Funding for HIV/AIDS
40	Aboriginal issues
98	Other social

... Question 3 coding continued

Psychosocial	
1	General
10	Personal empowerment
20	How to live with/support/ talk to APHAs
30	Experience of living with HIV/AIDS - APHAs
98	Other psychosocial

Q4) Suggested safer sex method	
0	Would not suggest anything
1	Abstain if possible, if not use condom
10	Abstain from sex
11	Safer sex/use condom
12	Teach how to use condoms/safer sex
13	Safe sex/ sex education should be in schools
14	Condoms must be available/free
17	Stay in monogamous/stable relationship
20	Testing
25	Ask if partner has STDs/talk about it
30	Avoid having sex while drunk/high
40	Self respect/ generally be careful
43	Will discuss with my family
45	Have already discussed issues with my family
50	General/All workshop learnings
91	Never had sex
94	N/a
96	No
97	Don't know
98	Other
99	Did not respond

Q5) Would you like more to have more workshops and why?	
1	Enjoyed workshop
2	Not enough time
20	Need to learn more
21	Want to learn more - safe sex
22	Want to learn more - needle use
23	Community needs to learn more/education
24	Need to educate children, future generations
25	Want to learn more so I can help others
26	Need to hear message over time to remember it
27	Would like to keep up with new /changing information
40	So I can be more supportive/reduce stigma of APHAs
50	Would like opportunity for more debriefing - safe sex
51	Would like opportunity for more debriefing - needle use
70	Go beyond AIDS 101
90	More on STDs, Hep, TB
91	Very good info to know
92	Would like to bring partner/family
93	No, it was covered in this workshop
94	N/a
95	Yes
96	No
97	Don't Know
98	Other
99	Did not respond