

**Adult Working Group's
Cross-National Consultations
on Health and Learning
Final Report on Adults Living with HIV/AIDS**

Adult Working Group (AWG)
under the auspices of the
Health and Learning Knowledge Centre (HLKC)
and the
Canadian Council on Learning (CCL)

Sue Folinsbee and Wendy Kraglund-Gauthier
with H el ene Gr egoire and Allan Quigley

August 2008

Table of Contents

Acknowledgements	3
I. Introduction	
A. Background Information	4
B. Purpose of the Consultations	5
II. Consultation Methodology	
A. Consultation Plan	6
i. Choosing communities for the consultation	6
ii. Working with local partners.....	6
B. Consultation Format and Questions	
i. Consultation format	7
ii. Focus of the consultation questions	10
iii. Consultation feedback.....	10
iv. Consultation reports	10
C. Consultation Participants	11
D. Limitations of the Consultations.....	11
III. Consultation Outcomes	12
A. Concepts of Health and Being Healthy.....	12
i. Concepts of health.....	12
ii. Strategies for staying in good health.....	13
iii. Barriers to good health.....	14
B. Learning and Getting Information about Health	
i. Most common ways of getting information about HIV/AIDS	17
ii. Barriers to accessing information about HIV/AIDS	18
C. Experiences with Health Services	
i. What is working well	20
ii. Barriers.....	21
IV. Participant’s Recommendations for Strategies to Address Identified Barriers	25
A. Health Literacy.....	25
B. Developing and Sustaining Healthy Communities	26
i. Public awareness.....	26
ii. Sensitivity training for health care professions and other institutions	27

C.	Strengthening the Capacity of Communities, Practitioners, and Public Agencies/Systems	
i.	Public agencies and systems	28
ii.	Community involvement and outreach.....	28
iii.	Health care professionals with HIV expertise	29
V.	Adult Working Group Recommendations for Setting a Knowledge Agenda	30
A.	Supporting Research	30
B.	Knowledge Mobilization	31
VI.	Summary Statement	32
Appendix A:	Adult Working Group Members.....	33
Appendix B:	Sample Consent Questions	37
Appendix C:	Consultation Questions	38
Appendix D:	Participant Profiles.....	40

Acknowledgments

We would first like to acknowledge the contributions of participants for engaging in the consultations held in Montréal, Québec; Edmonton, Alberta, and Truro, Nova Scotia. We thank them for their participation.

Many thanks to Kim Thomas, [Canadian AIDS Society](#) for her assistance in planning and identifying partners and participants for the consultations with adults living with HIV/AIDS.

In Montréal, we thank Baijayanta Mukhopadhyay for organizing and co-facilitating the consultations. Many thanks also to co-facilitator Michèle LeBlanc and note-takers Natasha Gupta (French) and Tatiana Gomez (English).

In Edmonton, we thank [HIV Edmonton](#) and Debra Jakubec, Executive Director, for partnering with us and hosting the consultations. Many thanks and appreciation to Robert Smith, former HIV Edmonton Research Coordinator, for planning and organizing the Edmonton consultations. Thanks also to Jill Delarue, Dolan Badger, and Lynn Sutankayo for facilitating. Much appreciation also goes to Ted Kerr for taking notes for all the sessions.

In Truro, we would like to thank [Northern AIDS Connection Society](#) for partnering with us and hosting the consultations. Many thanks and appreciation to Bonnie Joldersma, Operations Coordinator, and also to founder and chair Al McNutt for their work in organizing the consultations. Thanks also to Cindie Smith for taking notes.

In addition, thanks and appreciation go to Bosire Monari Mwebi for his additional feedback on consultation questions.

We also want to thank and acknowledge the excellent work of Sue Folinsbee and Wendy Kraglund-Gauthier who wrote the final report.

We hope that this work will be useful to a wide range of audiences interested in research. This work was undertaken with support from the Canadian Council on Learning's [Health and Learning Knowledge Centre](#) and the [National Collaborating Centre for Determinants of Health](#), which bear no responsibility for its content.

B. Allan Quigley
Co-Chair, Adult Working Group
Health and Learning Knowledge Centre
Canadian Council on Learning

Hélène Grégoire
Co-Chair, Adult Working Group
Health and Learning Knowledge Centre
Canadian Council on Learning

August 2008

I. Introduction

A. Background Information

In June 2005, the Canadian Council on Learning (CCL) held a Health and Learning Knowledge Centre (HLKC) consultation in Vancouver, British Columbia. At the consultation, participants agreed to establish various working groups to address the work of the HLKC. These working groups address life stages in health and learning and concentrate on settings, places, and communities where health and learning takes place. The HLKC coordinates and organizes its work according to both the life stages and settings. The Adult Working Group (AWG) is now one of 14 working groups addressing learning across the life span. (See the CCL web site for further information at <http://www.ccl-cca.ca/ccl>)

The mandate of each working group is to build a knowledge agenda for the CCL, under whose auspices the HLKC was established. Each working group is to focus its agenda on the three central themes of the HLKC. These themes are:

- health literacy (with a priority on access, equity, and achieving basic health literacy for all)
- developing and sustaining healthy communities of life-long and life-wide learning
- strengthening the capacity of communities, practitioners, and public agencies/systems to implement intertwined health and learning strategies in comprehensive, sustainable, effective ways

In addition, each working group also is expected to address the four primary functions of the CCL in the activities it recommends and undertakes. These four functions are:

1. research
2. data /monitoring/reporting
3. knowledge transfer
4. dissemination/communications

The AWG is developing a knowledge agenda for promoting the health and learning of adults in:

- at the workplace
- in health care settings
- among families
- in communities

In 2006, the AWG identified the priority groups it would focus on at the outset¹ as follows:

- the health and learning of adults with low levels of literacy skills (2006–2007)
- the health and learning of adult immigrants and refugees (2006–2007)
- the health and learning of adults affected by HIV/AIDS (2007–2008)
- health and learning within regions and communities that fall well below national or regional health norms (2007–2008)

In the AWG’s consultation plan, particular attention was paid to issues of gender and racialization² across the identified range of priority areas.

Over the past year, 2007–2008, the AWG priority groups were: (a) adults living with HIV/AIDS and (b) adults living in rural and remote areas. This report addresses the priority group adults living with HIV/AIDS. The AWG’s work involved direct discussion with adults in the identified groups who could be directly supported through an effective knowledge exchange and translation with respect to health and learning.

B. Purpose of the Consultations

From the consultations focusing on adults living with HIV/AIDS, the AWG sought to identify themes, gaps, and needs related to health and learning as experienced by these adults. The consultation outcomes ultimately point to research priorities concerning the learning needed to improve the health of this group and includes a plan to generate, mobilize, disseminate, and translate research-based knowledge into policy and practice change. This, we hope, will result in a greater understanding of the relationship between health and learning, and in initiatives to improve the health status of adults living with HIV/AIDS across Canada.

The expressed views from the consultations are illustrative of the opinions of adults living with HIV/AIDS. We hope their views will ultimately contribute to research, to policy, and to improved access and services for marginalized Canadians.

¹ The priority group of Aboriginal adults was removed from the AWG plan because the Aboriginal Learning Knowledge Centre was established by the CCL in 2006. See

<http://www.ccl-cca.ca/CCL/AboutCCL/KnowledgeCentres/AboriginalLearning/index.htm>

² In this context, the terms “racialization” and “racialized” refers to a categorization or differentiation made of individuals based on race.

II. Consultation Methodology

A. Consultation Plan

The plan for the consultations was developed by the AWG with input from its national Advisory Committee as part of its planning work in 2005–2006 (see Appendix A). The AWG hired Lindsay Angelow, a health promotion student who worked out of [Access Alliance Multicultural Community Health Centre](#) in Toronto, to help develop the consultation plan. The methodology developed was based on the successful experience of Access Alliance in conducting other similar consultations.

i. Choosing communities for the consultations

Consultations were held in three locations: Montréal, Quebec; Edmonton, Alberta; and Truro, Nova Scotia. In Montréal, the consultation with community members and service providers was held together, with two groups splitting off for the bulk of the consultation along language lines (French or English), and coming together to report back and further discuss report backs and recommendations. In Edmonton and Truro, separate consultations were held with community members and service providers.

Consultation locations were chosen from recommendations by AWG Advisory Committee member Kim Thomas, Director of Programs for the Canadian AIDS Society. These recommendations were based on her knowledge of regions that could benefit from the consultations and would be interested in working with the AWG.

ii. Working with local partners

In Montréal, the AWG hired Baijayanta Mukhopadhyay to organize and conduct the consultations. In Edmonton and Truro, the AWG worked with local organizations HIV Edmonton and the Northern AIDS Connection Society to organize and conduct consultations. The tasks of AWG local partners included identifying and inviting participants for the consultations. Recruitment of participants was conducted by the partners (see “selection and recruitment” below), making all the logistical arrangements for the consultations, co-facilitating the consultations, reviewing consultation reports for accuracy, and disseminating consultation outcomes. Our goal was to attract the widest range of participants to the consultations by advertising them widely in the communities where the consultations were to be held and surrounding areas.

For selection and recruitment, our local partner in Edmonton recruited from their own client base. They recruited service providers from organizations that they work with and that also work with their own clients. In Truro, our partner organization recruited participants from their own client base and through other AIDS organizations. In Montréal, Baijayanta Mukhopadhyay approached AIDS service organizations based on his knowledge in the field and based on Kim Thomas's recommended list of organization. For further advertising, partner organizations used a poster provided by the AWG and also relied on word of mouth.

B. Consultation Format and Questions

i. Consultation format

For confidentiality and comfort reasons, the standard format of the consultations was to hold meetings with community members and service providers who work with them separately, except in Montréal.

Montréal

In Montréal, the consultation session was 4 hours long, including one break for dinner, which was provided as part of the consultation. All participants came from the Montréal area. The format of the session was designed to include both community members and providers. The session started with introductions of the consultation team: facilitators, note takers, and participants. This was followed by a review of the ethics and informed consent practices with participants. The group then split into two smaller groups based on language—French or English—not along provider/community member lines—for the bulk of the consultation meeting. The language they were comfortable communicating in was the determinant. The two groups came together again to report back and have a further discussion as a whole group.

Edmonton

In Edmonton, there were three separate sessions: two for community members and one for service providers. Community members were clients of HIV Edmonton. Service providers came from a variety of organizations that worked with people living with HIV/AIDS, including one person from HIV Edmonton.

In Edmonton, there were two separate sessions for community members living with HIV/AIDS. The organizer at HIV Edmonton decided that it was necessary to divide the adults living with HIV/AIDS into two distinct groups. The reasoning was that the population served by HIV

Edmonton is extremely diverse and the different levels of social functionality may have created barriers for some participants.

The first session included a mixed gender group of adults living with HIV/AIDS. This group was made up of individuals who have managed their HIV/AIDS status to the point of maintaining their own residence, involving themselves in community work, and/or returning to full or part time employment. For the most part, they kept to their treatment regime, whether on medication or not.³ The second session was comprised of street-involved individuals, often highly addicted to one or more illicit substances, without homes, reliant on community kitchens for sustenance and in some cases, involved in the sex trade. Most of these individuals suffered from some mental health issues; most had a history as a victim of trauma; and many had learning disabilities. Much of their time was spent meeting their daily needs and putting together the resources to acquire their drug(s) of choice and wandering from agency to agency, accessing the services they provided. Most were not on treatment regimes and their health was monitored only through interaction with key workers at their preferred agency stops.⁴

Both groups of adults living with HIV/AIDS were primarily of Aboriginal and Caucasian descent, with the majority coming from Aboriginal communities. Interestingly, both groups utilized coping mechanisms that may surprise the average individual whose life does not include such despair. They both functioned within the expectations of their socio-economic status, they both exhibited a resilience that kept them going, they all dealt with a disease that could be debilitating and all have had doubts about their future.⁵

Each of the three sessions started with introductions of the facilitators, note takers, and participants. The AWG coordinator explained the purpose of the consultations and reviewed the ethics and informed consent practices with participants. The session with Aboriginal adults began with a smudging ceremony. Confidentiality among the groups and what was said was discussed and agreed upon. In every case, the AWG coordinator and HIV Edmonton research coordinators sat outside the circle of participants and listened to the discussions. This was recommended as a strategy by HIV Edmonton to allow participants to speak freely without any outside influence. This format was discussed with participants before the session began. Each of the three sessions was 2–3 hours long, followed by lunch or dinner.

³ Background information on community members provided by HIV Edmonton.

⁴ Ibid.

⁵ Ibid.

Truro

In Nova Scotia, the organizers from Northern AIDS Connection Society decided that two separate focus groups of community members and providers would work best. The first session included a group of providers and activists working with HIV/AIDS. This group was made up of individuals who are movement leaders in Nova Scotia. They spoke in the session from the point of view of providers and activists.

The second group was comprised of nine adults living with HIV/AIDS from different areas of Nova Scotia including Truro, Halifax, and New Glasgow. This group included four service providers/activists from the first group who, in this session, offered their perspective of an individual living with HIV/AIDS.

Each of the two sessions was approximately 3 hours long with lunch served in between the two sessions.

Each session started with introductions of the facilitators, note takers, and participants. The AWG coordinator explained the purpose of the consultations and reviewed the ethics and informed consent practices and confidentiality with participants.⁶

Additionally, the operations manager of the Northern AIDS Connection Society and the focus groups' co-facilitator interviewed an additional participant after the focus group session. This participant was a woman who thought the focus group was the day after it actually occurred. We interviewed her because she had been part of the original list for the focus group of adults living with HIV/AIDS and because there had only been one woman in the focus group.

Mix of participants

Of the 20 participants we wanted to attract for each consultation, one-third (maximum) were intended to be providers and practitioners who work with community members. We wanted providers to participate in the consultations because of the useful information they could provide related to their experiences around health and learning in terms of the community members they worked with. At the same time, we wanted the voice of community members to be predominant. In all cases, providers made up one-third or less of the entire group of participants in a consultation. In Truro, four of the service providers also came to the community members' session in the afternoon to give the experience of a person living with HIV/AIDS.

⁶ Please see Appendix A for Consent Practices.

ii. Focus of the consultation questions

Following an explanation of ethics protocol, participants responded to questions⁷ in the following categories:

- what health means
- how community members keep in good health
- how they learn about health and get information they need
- their experiences with the healthcare system
- who should learn what
- what else needs to be done

Community members were also asked to complete a one-page, anonymous background information sheet. Participants indicated details such as their gender, age range, employment status, and level of education.

An honorarium of \$40 or more, depending on travel arrangements, was made available to each community member to compensate for their time and out-of-pocket costs. Participants also received lunch or dinner depending on the time of the consultation.

iii. Consultation feedback

People participated in a short, oral evaluation of the consultation—what they liked about it, as well as how it could be improved at the end of each meeting

iv. Consultation reports

The AWG prepared detailed reports on the consultations in each community for a total of three separate reports. Each report was provided to the local partners for review and feedback before being finalized. The final community reports were sent to local partners so they could distribute them to consultation participants.

⁷ Please see Appendix B for Sample Consultation Questions.

C. Consultation Participants

The charts that follow outline the participation in AWG consultations. See Appendix D for participant profiles.

Consultations with Adults Living with HIV/AIDS

Location	Number of consultation participants
Montréal	16 community members 3 providers
Edmonton	13 community members 7 providers
Truro	10 community members 7 providers
All locations	39 community members <u>17 providers</u>
TOTAL	56

D. Limitations of the Consultations

There are several limitations of the consultation outcomes. The number of participants was small and was selected based on the consultation facilitators and host organizations' ability to contact willing participants. The locations selected were based on the informed advice we had from our Advisory Committee and our ability to identify partners to host the sessions.

Based on the informal methods of choosing participants, we caution against generalizing the results of these consultations across contexts. While generalizations cannot be made from the consultation outcomes, the outcomes provide a good deal of insight with respect to areas of health and learning of adults living with HIV/AIDS that need to be explored through systematic research.

III. Consultation Outcomes

This overall report draws from the three individual reports that were prepared for each of the three locations: Montréal, Edmonton, and Truro. This section summarizes the outcomes from all three AWG consultations according to major themes.⁸

A. Concepts of Health and Being Healthy

The idea [of being healthy] is different since I was diagnosed HIV-positive. Now if I were asked to mark myself out of 10, I would give myself 6 or 7. But compared to HIV-negative people, I would put myself at a 4 or 5.

—Community member, Montréal

i. Concepts of health

Across locations, participants emphasized the importance of physical, mental, and sometimes spiritual health. They indicated that physical health affects one's mental health, and visa versa. However, some participants in the Montréal session felt that health care providers only measure good health as physical. Participants noted that some health care providers say, "Why are you complaining? Your viral load⁹ is undetectable and your count is high," or "You're alive; you should be happy."

Participants across locations most often referred to being healthy as having energy, the ability to be active, and being independent. Other signs of good health noted by some participants were being able to work and being drug free. In Edmonton, service providers emphasized the importance of having a safe place to stay and sleep as important to the health of their clients.

Mental health

Community members living with HIV/AIDS across locations related the importance of having good mental health. They talked about the need to be positive, self-accepting, and stress-free; along with having control over their lives and maintaining a supportive environment. One person said, "If you think negatively that you are going to die, you will." Some participants cited psychological factors in that they worried about what would happen next, felt like a burden on society, and felt they were not being productive. Depression as a side effect of medication was also noted.

⁸ For more details on each location, a summary report is available.

⁹ Viral load testing measures the amount of HIV present in blood.

Physical health

In terms of physical health, participants across locations most commonly saw good health as having a good CD4 count¹⁰ and undetectable viral load. For some participants, good physical health was related to maintaining their weight and not having to take HIV medication.

ii. Strategies for staying in good health

The best resource for a person living with HIV/AIDS is another person living with HIV/AIDS.

—**Community member, Truro consultation**

Across locations, there were some common strategies for staying healthy along with strategies that were specifically mentioned in one location.

Overall, participants across locations talked about the need to eat properly and to exercise. Accepting and managing one's health were also identified as important strategies for staying healthy. Having dreams and goals was also identified as important. Some participants said that accepting their illness, being positive and focusing on spirituality were important to staying healthy. Doing volunteer work and having pets was also commonly mentioned as a way to keep in good health.

In all three locations, community members discussed the importance of their peers as a form of support. For example, in the Montréal consultation, one participant said that it boosts his morale to be with people who are going through the same kind of things. Similarly, in the Truro consultation, peers were identified as critical supports. In Edmonton, the street-involved group related how they shared food and saw themselves as a family. They indicated the importance of each other as a support.

In Montréal, participants identified the importance of a loving, welcoming, and accepting environment as a strategy to promote good health.

In the Truro consultation, community members emphasized the importance of professionals such as psychologists and nutritionists to provide guidance, help set goals, and help with

¹⁰ Refers to how strong a person's immune system is and how far HIV has advanced. Normal CD4 counts in adults range from 500 to 1,500 cells per cubic millimetre of blood. In general, the CD4 count goes down as HIV disease progresses ([Stephen Lewis Foundation](#), 2007).

difficult times when they do not want to share how they are feeling with those closest to them.

One participant said:

An external person to guide you through a difficult time is important sometimes; she provides debriefing and how I am really feeling [when] I don't want to share with my partners, daughter and son how I am really feeling [because] they will worry. I would rather share it with her.

In the Truro consultation, participants also mentioned the importance of being aware of the choices they make and the implications of their choices. They also stressed the importance of having information about one's disease and what to do about it.

In Edmonton, community members reported on the importance of friends, family, and a safe and only place where they could go such as HAART House.

iii. Barriers to good health

Gay stigma, HIV stigma, African Nova Scotian, or Aboriginal and gay; triple dose of drug user, gay and HIV positive; all directly affects health.

—Community member, Truro consultation

Participants identified common barriers to good health across locations. These barriers were:

- poverty as a key determinant of health
- discrimination and stereotyping
- side effects from medication

Social determinants of health

The balancing act that a lot of people have to do: "Am I going to pay for my drugs this month, or heat or food?" Daily choices are awfully hard for most of them.

—Service provider, Truro consultation

Poverty

One service provider said, "The main social determinant of health is poverty." Participants across locations identified poverty as a key issue for people living with HIV/AIDS. They identified hardships for people living with HIV/AIDS in terms of getting their basic needs met. Basic needs are having a place to live, having food, and having access to medication.

In the Truro consultations, participants indicated that the percentage of people living with HIV/AIDS in Nova Scotia living in poverty is extremely high. Both community members and service providers felt that lack of income underlies many of the barriers to health and health care for people living with HIV/AIDS. They also identified issues such as lack of transportation, nutrition, and isolation, especially in rural areas. People living with HIV/AIDS who do not have access to transportation are isolated. They cannot get a coffee, see a friend, or go to the movies.

In Truro, providers' comments indicated that the income support system is not entitlement-focused. As one person said, "The system is set up to deny rather than provide services." People living with HIV/AIDS may not feel they are entitled to this support because of self esteem issues and a feeling of guilt. They may be denied approval for a special diet by Social Services. One community member spoke about the experience of losing money for her special diet because, as she said, "Community Services said I weigh enough now." She said that she is now getting \$62 instead of \$101 per month. She said that this was not enough money and that "They are not even paying attention to the letters my doctor has written." She also said, "I am not trying to get rich off the system. I am just trying to survive." In other cases, people may not know they have to renew their social assistance annually because the information about annual renewal is "buried under the jargon."

In the Montréal consultation, participants reported that a lot of people who are HIV positive are unemployed and exist with low financial means. They said that often welfare workers think a person living with HIV/AIDS does not look sick and should be working. Paying for medication was cited as a financial hardship. Participants related examples of some people who got medication by being a "guinea pig" for pharmaceutical companies. As a result, they experience side effects from the medication.

Housing

In Edmonton, the street-involved community group indicated that it is difficult to find a safe place that they can go to. They said that coffee shop managers will not let them warm up there, and places like shelters spread diseases. Comments indicated that a shelter would not be a good place to go to with a weak immune system because a person living with HIV will get sick there. Participants indicated that it would be healthier and safer to sleep outside. Some service providers felt that housing and homelessness are the number one factor in staying healthy. Comments indicated that housing and homelessness are intertwined, with issues of addictions and weather affecting both physical and mental health.

Stigma, discrimination and stereotyping

In all the consultations, participants discussed the discrimination that people who are HIV positive face and the stigma of being HIV positive. They also discussed the impact of this discrimination on people's well-being, particularly their mental health. Some participants identified feelings of isolation arising from the social stigma and talked about this as a factor in their mental health. At times, they said that simply getting out and seeing people could be a challenge. In the Truro consultation, participants related that people who were active before their HIV diagnosis may not feel comfortable talking about it or going out. This issue was exemplified by one person who said, "Some days I just stay in bed."

According to participants, one aspect of this stigma is that people who are HIV positive are afraid that other people will find out about their illness. Participants in Truro related that this is especially true in a small province like Nova Scotia where "everyone is connected to everyone else."

People living with HIV may not tell their children or other family members about their illness because they fear they will be judged. Participants indicated that there are cases where families perpetuate this stigma by rejecting the family member who is HIV positive. As examples, participants described situations of being rejected by families and fired from jobs when family members or employers found out about their status. They also said that family members may be ignorant about the disease and think they may "catch it." In other cases, families may also be stigmatized and subject to harassment. In the Truro consultation, service providers indicated that this stigma is magnified in communities that are already marginalized such as gay, Black, Aboriginal and immigrant communities. They said that the stigma is further magnified if the person living with HIV/AIDS is a drug user.

Participants in all locations described the ignorance of health care providers and others about their disease. They said this shows up in how people living with HIV are treated.

Participants in the Edmonton consultation indicated that the stigma also works in another way. For example, people who are living with HIV but who do not look sick may face pressures to get a job even if they are not well. Participants recounted experiences with the welfare system where the doctor working for welfare said their condition was temporary and now that people can live with HIV, they should be working. Other similar experiences included employers who expect people to produce but do not understand the disease, or employees who are not comfortable revealing their HIV status.

In the Truro consultation, participants said that trust is a big issue for people living with HIV/AIDS. They indicated that their worker and doctor may be the only ones who know they are HIV positive. Providers said that the stigma also applies to seeking help from a psychiatrist for mental health issues. People living with HIV/AIDS may not seek this help because of fear of being labelled. One provider explained how “Some families are so afraid to ask for help because going through the door of an AIDS service organization labels them as gay or HIV positive.” Community members also indicated that people who are HIV positive may feel shame and guilt about their disease and, as a result, may not trust or feel comfortable approaching AIDS service organizations and other health service organizations for the information and help they need.

Side effects from medication and diseases related to their illness

Across locations, participants discussed the fact that side effects of medication are a barrier to health. Some of the side effects were reported as very serious, with some participants explaining that they had been seriously ill or had brushes with death as a result of infections related to the side effects of medications they were taking. Some of the side effects participants reported were anaemia, depression, tiredness, displacement of fat, nausea, diarrhoea, vivid dreams, and vertigo. Some participants related that the effects of some medications on their appearance affected their self esteem. Some participants were concerned about the long-term effects of drugs.

B. Learning and Getting Information about Health

99% of [our] clients are living in poverty. If they had a computer, they would sell it.

—Service Provider, Truro consultation

i. Most common ways of getting information about HIV/AIDS

In all locations, participants said people living with HIV/AIDS get their information mainly from others living with HIV/AIDS, doctors, other service providers, pamphlets, and the Internet. Other sources of information reported were books, lectures, support groups, and Elders. Comments indicated that some people who are living with HIV will rely on one person within an organization for all their information needs. This is a person they trust and have connected with.

Community members said that they wanted information related to their illness to find out how to manage their health, the side effects of medications, how the disease will affect them, and whether there will ever be a cure.

Participants who cited the Internet as a source of information discussed the pros and cons. Some participants cited some good websites where they get information about HIV and their medication such as AIDSmeds.com and Medscape. Participants said they access the Internet at AIDS service organizations, the library, and at home. They acknowledged concerns about information on the Web in terms of what is true and what is false. Providers in the Truro consultation did not see the Internet as a way for their clients to get information because of poverty and lack of access.

Some providers indicated the importance of verbal information or easy-to-read posters and pamphlets. Some providers indicated that teachable moments with clients are informal and related to dispelling myths “in the moment.”

ii. Barriers to accessing information about HIV/AIDS

People need to look at HIV as a health issue without stigma and attachments and judgments. When I would speak I would ask if AIDS had been discovered in an old folks home would we have the same kind of stigma?

—Community member, Edmonton

Across locations, the most common barriers identified by participants were:

- stigma and prejudice
- literacy and language
- communication with health care providers

Stigma and prejudice

Participants across locations identified stigma and prejudice as a major barrier to accessing information about HIV/AIDS. They indicated that people living with HIV/AIDS may not be comfortable revealing their status or providing information about themselves. They may not ask questions or access information because of the stigma and prejudice that surrounds HIV/AIDS. People who are HIV positive may not access information and resources from AIDS service organizations because they fear their status will be discovered. In Nova Scotia, providers indicated that their clients may not use teleconference support because they fear that their voices will be recognized.

Literacy and language

Literacy and/or language barriers to accessing health-related information were identified in all three locations. Literacy issues were identified as a barrier to reading print information, looking up a phone number, and completing forms. Literacy was also identified as a barrier in terms of knowing how to go about finding information, asking the right questions, and knowing when and when not to volunteer information. Lack of clear language on government Web sites was identified as a barrier to understanding related to literacy.

In Montréal, participants identified a lack of information on HIV/AIDS in French on websites and an overall lack of information on HIV/AIDS in English. In the Truro consultation, it was noted that some Aboriginal people living with HIV/AIDS are not fluent in English. In Aboriginal communities, confidentiality in the process of translation can be an issue. People who have limited English need a translator when talking to the doctor. However, the translator is not required to sign a confidentiality agreement and they are not trained as translators—they are just good in English. This can be a barrier in trust.

Communication with health care providers

Across locations, communication with health care providers was identified as challenging by participants. One issue is that people living with HIV/AIDS may feel too intimidated to ask the doctor questions. At the same time, health care providers may not take the time to provide information. In Montréal, participants indicated that health care professionals may be misinformed about HIV and how a person can become infected.

Miscellaneous barriers

Participants identified a number of miscellaneous barriers to accessing health information. In the Montréal session, these barriers included lack of information on HIV/AIDS in rural areas and on the side effects of medications. In Edmonton, participants spoke about how people were informed of their HIV status. They spoke about lack of sensitivity in how they were told and mentioned breaches of confidentiality.

C. Experiences with Health Services

Living with the disease is a very minor point. It's people's reactions that are the worst.

—Community member, Montréal consultation

i. What is working well

Overall, people living with HIV/AIDS said they were getting excellent service from AIDS service organizations, specific HIV specialists, and HIV and gay-friendly doctors. Some participants cited their family doctors and pharmacists positively as well.

In Montréal, community members indicated that they are getting excellent service at Montréal's HIV clinics and service organizations. They indicated that without these organizations, people would be alone. They also said that keeping these organizations funded and functioning was a high priority. They said it was important that these organizations stayed focused. This comment was interpreted as meaning it was important for organizations to stay focused on the needs of their clients and to stay “grounded.”

In Edmonton, some community members indicated that they had positive experiences and good relationships with HIV/AIDS specialist doctors, their family doctors, pharmacists, and community-based health care providers, especially with AIDS service organizations. One person gave an example of his experience with a specialist, saying, “The specialist will hold your hand and hug you. They bring your heart back. They are right beside you...they are not afraid.” In another example, a participant indicated that one of the nurses at an AIDS service organization makes sure they take their medications and cares about them. Another person said that his pharmacist was very helpful when he started going to just one pharmacist for both his HIV and other medication.

In the Truro consultation, providers indicated that some of the work with the infectious disease clinic in their region was positive. One provider said that signed releases of information from clients means she can have direct contact with a clinician and she can then discuss the information with the client. This way the client does not have to digest the information all at once and the provider can discuss the feedback with the client. The provider referred to herself as a “translator.” In other cases, providers and their clients call the clinic together from their offices to get answers to the client's questions. Providers also noted that there is a good pharmacist and nutritionist at one particular clinic. However, they also said that the provision of service in social work and spiritual care has not been as good, although it is improving.

Providers also said that there are a few “amazing” doctors who work with the clinic. In these cases, clients experience the benefits of “team support.” These doctors were cited as knowledgeable, non-judgmental, good listeners, and honest. Clients feel they are getting good health care from these doctors. The provider group also indicated that there is a list of HIV and gay-friendly doctors that clients can get information from. It was noted that this is a “real plus in a small rural town.”

In Edmonton and Truro, providers noted that agencies that work with people living with HIV/AIDS are working together to share information and provide referrals.

ii. Barriers

This section describes the most common barriers to health care services for people living with HIV/AIDS across the three locations.

These barriers were:

- stigma, prejudice and discrimination
- lack of health care services
- place

Stigma, prejudice and discrimination

Both community members and providers identified prejudice and discrimination along with ignorance about HIV/AIDS as key barriers to accessing mainstream health care services along with social services.

Participants reported that many of their experiences with doctors and hospitals were not positive. They noted that many health care professionals do not know enough about HIV and that there is a lot of ignorance about the disease. Providers also indicated that health care professionals do not have enough knowledge about HIV and that often their clients have negative experiences. There was a tendency for community members living with HIV/AIDS to feel disrespected and not taken care of in hospitals. One common experience of people living with HIV/AIDS as related in the consultations was to be asked many questions about their HIV status rather than the reason they are seeking health care. Another common experience was the overuse or under use of gloves on the part of health care workers. For example, some would not wear gloves when drawing blood from a person living with HIV/AIDS. In other cases, a participant noted that a health care professional wore three sets of gloves. As a result of their negative experiences, people living with HIV/AIDS may not reveal their status to health care providers.

Community members and providers across locations related a number of examples to illustrate the negative experiences of people living with HIV/AIDS. In Montréal, for example, one participant said that the doctor listens to his heart with gloves on. In another example, a Montréal participant related how a dentist stood two feet away from him to examine his mouth.

In Edmonton, some participants related that they do not feel respected or taken care of when they go to the hospital. They thought health care workers in hospitals tend to be afraid of them when they know their status. One person said that in his experience, general staff at the hospital think that everyone is a junkie. He said, “They have a decisive lack of respect for us as human beings.” One participant related that she had a HIV positive sticker put at the end of her bed when she was in the hospital. Another person said she was put in an isolated room when the hospital found out her status. In another example, one provider from the Edmonton consultation was asked if she wears a mask and gown at work.

Edmonton providers also identified prejudice and discrimination as key issues, particularly racism and transphobia. One example given was that transsexual people may be made fun of when they go for health care services. As a result, they feel humiliated and may not access services. Providers said there is also the additional stigma of sex work. In cases where someone is treated after they have been raped, they may be asked, “Isn’t that a work hazard?” or told to get a different job.

In the Truro consultation, community members described their experiences with health care and other social services negatively. One person said, “One doctor wouldn’t touch me and wouldn’t examine me.” She explained that the doctor only told her that she had eczema and gave her a prescription. Another person said that treatment by health care professionals and workers makes him feel “discriminated against” and “alienated, dirty and immoral.”

Home care workers were raised as an issue in both the provider and community member groups in Truro. Providers said that there is a fine line in the [Victorian Order of Nurses](#) (VON) contract that indicates they can decline working with an HIV positive person. Training given by the Northern AIDS Connection Society tries to counter this thinking in their statement “You don’t have a choice in who you serve.” However, one community member’s story relates a negative experience. This person had a home care worker after being sick from pneumonia. The worker lasted a week and seemed nervous because the patient was HIV positive. The worker did not seem to know how to care for a person living with HIV/AIDS. Even though the community member was supposed to have a home care worker for 6 weeks, he requested that one not come because it was too stressful.

Providers in the Truro consultation also said that when drug users go to the Emergency department at the local hospital, they are followed around in the hospital because hospital staff think they will steal. They also said that the health concerns of people living with HIV/AIDS are not taken as valid because the health care providers assume they are just there for drugs. Often drug users will not go to the hospital because of this attitude on the part of hospital staff even if, as one put it, “they have swollen hands and arms because they can’t find a vein and they are in pain.”

Lack of health care services

In both Montréal and the Truro consultations participants indicated that there were a limited number of health care professionals and places where people who are HIV positive can get treated. Participants in all locations agreed that there were long wait times to see specialists.

In Montréal, participants reported that it is difficult to find dentists, generalists, and surgeons who will treat people who are HIV positive.

In the Truro consultations, providers noted a similar lack of services. For example, there is a 5-month waiting list for the gay, HIV-friendly services in Truro. Providers also said that there is only one psychologist in all of Nova Scotia who specializes in working with persons with HIV; this person is based in Halifax, the provincial capital. Providers indicated that there are long waiting lists to see mental health clinicians for those with HIV and issues of addiction. They further indicated that these agencies operate in separate “silos” and have different philosophies. They questioned how equipped mental health clinicians were to deal with HIV positive people. In addition, they felt that sexuality issues were ill-handled by psychologists.

In Montréal, participants in the French language group thought that Anglophones living with HIV/AIDS in Montréal had better services. They said Anglo services were better organized because there is one service organization. There are many organizations that serve Francophones, but participants said they have to go from one place to another; there is a duplication of services. Going from one organization to another to get all of one’s needs met takes a lot of energy.

Montréal participants indicated that different ethnic groups also have their own community groups. They also said that although there are many services for gay men, there are few for other groups including serodiscordant¹¹ couples, and those recently diagnosed such as youth, women, and straight men. They thought that if there was just one organization, regardless of identity, there would be fewer problems. Some participants wondered if having all services in one

¹¹ “Serodiscordant” is a term used to describe a couple in which one partner is HIV positive and the other is HIV negative (AIDSmed.com, 2008).

building would create stigma. This was countered by the suggestion not to have a public sign on the building and the need to be discreet. They indicated that all those living with HIV in Montréal end up in the same clinics, institutes, and hospitals. Sometimes people need different doctors for different issues as, for example, the HIV doctor may not treat gynaecological issues.

Place

Participants across locations discussed place as a barrier to accessing health services. They noted that in rural areas, there are fewer services for people living with HIV/AIDS. They also indicated that there are fewer health care providers who are knowledgeable about HIV/AIDS and want to treat people living with HIV/AIDS. Confidentiality was also identified as an issue in rural areas in that it is more difficult to keep one's status confidential. Travel is also an issue in rural areas where people living with HIV/AIDS may have to travel long distances to get services.

Providers in the Edmonton session noted that where an HIV positive person lives affects their health and their ability to access health care services. For example, homelessness was seen as major deterrent in accessing health care because people have to spend a lot of energy to find a place to stay. Homelessness is also tied in with addictions and survival. Those who are HIV-positive and homeless have to cope with freezing cold, and have no place to store food. They also noted that living on a reserve affects health and access to services. People living with HIV who live on reserves may be reluctant to access services on site—where “everyone knows their business.”

One person from the Montréal consultation said that when he was in a small town, he got pneumonia; the provider came swathed in protective clothing with gloves, a huge jacket, and a mask. One person had to return to Quebec because interpretation was no longer available in British Columbia. Comments from participants in Montréal indicated that people were migrating to the city from rural areas so they could get the services they needed.

IV. Participants' Recommendations for Strategies to Address Identified Barriers

We are not lepers.

—Community member, Edmonton consultation

Participants' recommendations have been organized according to the three priorities of the HLKC, which are:

- health literacy (with a priority on access, equity, and achieving basic health literacy for all)
- developing and sustaining healthy communities of life-long and life-wide learning
- strengthening the capacity of communities, practitioners, and public agencies/systems to implement intertwined health and learning strategies in comprehensive, sustainable, effective ways

A. Health Literacy

Learning will not happen until basic needs are met: systemic issues of income and food.

—Service provider, Truro consultation

Participants in the consultations indicated there was learning that people living with HIV/AIDS need to do. This learning needs to focus on self advocacy within the “system,” managing one’s health, self acceptance, and activism. In Truro, participants indicated the need for younger people to take over the activism when the current leaders retire.

In Truro, community members indicated the need for people living with HIV/AIDS to be well informed about HIV/AIDS because often their doctors are not. They also said the best learning for people living with HIV/AIDS is their peers. This learning tends to occur through support groups where people can talk about what it is like for them. One person noted, “Support groups are a key component of our health and well being.” However, they noted that networks and support groups for people living with HIV/AIDS have dropped off because some of the participants have died.

B. Developing and Sustaining Healthy Communities

Participants in the consultations made recommendations in the following two areas related to information and education about HIV/AIDS:

- public awareness
- sensitivity training for health care professionals and other institutions

i. Public awareness

Participants from all locations recommended that there be more public awareness and education campaigns about HIV/AIDS. Participants felt it was important to target all of society, but especially schools, young people at risk, churches, and hospitals. Participants across locations expressed the importance of a message that does not stereotype people living with HIV/AIDS or that does not criminalize HIV.

For example, Montréal participants would like to see a high profile person who can champion the issue. They felt that such a champion would be a better spokesperson than someone living with HIV because they have the potential to change the perception people have of HIV/AIDS. They want to see accurate information provided about HIV/AIDS in the media. They felt that public messages need to show that the disease transcends factors such as culture, gender, sexual orientation, and religion to touch all levels of society.

Similarly, Edmonton participants want accurate awareness-raising among the public and a normalizing of HIV/AIDS.

In Truro, community members made it clear that, generally, HIV in Canada and Nova Scotia has fallen off the radar screen. They said that students know more about AIDS in Africa than they do about AIDS in Nova Scotia or Canada. They felt people are more compassionate about babies born in Africa with AIDS than they are for gay men or prisoners in local jails, who are seen as “deviant.” Service providers saw the need for awareness building with the general population concerning what it is like to live with HIV/AIDS. Presently, as they said, media attention is on the criminalization of HIV rather than what it means to live with it and how it connects to individuals.

Community members in Truro agreed that awareness-building has to happen within churches. Some of this education has begun by working with allies. Participants gave a positive example of

raising awareness with churches by inviting them to the [AIDS Walk for Life](#).¹² Churches and other groups are told they can give half of what they raise in the *Walk for Life* to children in Africa. Now churches and other groups are saying they value the work of local and provincial AIDS organizations and want them to keep all the money. Other churches are “following suit.”

ii. Sensitivity training for health care professionals and other institutions

Everyone should come together and listen on how we are being treated.

—Community member, Truro consultation

Participants in all locations called for sensitivity training for health care professionals and others.

In Truro, participants talked about the importance of educating health care professionals (doctors, nurses, social workers, and home care workers) about HIV/AIDS. Some community members indicated that they used to put treatment information in doctors’ inboxes at the hospital, but that information about AIDS was removed from the boxes and now they take materials directly to “gay friendly” doctors.

Participants also emphasized the need for sensitivity training about HIV/AIDS in medical schools, churches, and with the police. It was noted that the system of physicians’ fees is set up to treat illness, not to provide education to either the patient or the physician. In addition, health care professionals may not be comfortable talking about HIV/AIDS because they see it as linked to gay men, prostitutes, and drug users.

In Montréal, participants recommended a series of courses on HIV (101, 102, 103) for all those who work in the health care field. They also wanted to see more awareness-raising among public servants. Truro participants also made similar recommendations. They also felt that HIV/AIDS training for doctors on areas related to their profession should be given by a doctor in conjunction with a person living with HIV/AIDS. One provider indicated that in one workshop delivered to public health staff, some of the participants did not know that an entry point was needed to contract AIDS.

In Edmonton, participants recommended that health care providers learn non-judgmental communication skills for working with their clients who are struggling with a number of different issues. Participants felt that cultural and sensitivity training for health providers should

¹² Canada’s largest national community-based HIV/AIDS awareness and fundraising event. The event raised \$1.73 million in 2007 and attracted approximately 14,000 participants in 54 events across Canada. See <http://www.aidswalkforlife.ca/Incentive%20Fund%202007%20-%20Communique.pdf>

address issues of homophobia and transsexual issues. Community members want work on reducing prejudice. Providers suggested that transsexual issues are a new frontier and that many communities are struggling with them. Sensitivity training should also include Aboriginal culture training and awareness-raising around endemic countries and the fact that they are not to blame for HIV/AIDS. Providers felt that they had a responsibility to mentor other health care professionals through presentations, stories, and their experiences.

C. Strengthening the Capacity of Communities, Practitioners, and Public Agencies/Systems

i. Public agencies and systems

In Truro, providers agreed that Community Services' approach is very conservative and that there is a need for leadership from the provincial Minister of Health to change the system and make it much more accessible. They stressed the importance of a poverty reduction strategy.

Participants in Montréal indicated that insurance companies need to reconsider their assessment of people who are HIV positive. Currently, people are considered as invalids and thought of as not able to work. Their policies do not consider the fact that people have energetic periods but cannot work fulltime.

In Edmonton, providers recommended stable housing as a way to better their clients' health care experiences.

ii. Community involvement and outreach

In Montréal, some participants felt that community organizations serving people living with HIV need to re-identify the needs of this community because people are living longer and their needs have changed. They indicated that there is less urgency, less money to operate, and fewer volunteers. There was the sentiment that these organizations need to rethink their objectives and their goals. There was also the sense that not as many people are working as volunteers for the cause any more because there is less of a sense of urgency. Participants thought that organizations should train people living with HIV to be employed in these organizations because they would be more competent than others who do not know anything about the disease.

Providers in Edmonton would like to see more services with doctors and social workers brought to clients such as the use of health vans. In addition, health providers should go to the

community and ask them what their barriers are. Providers would like to see more sustainable peer-driven initiatives and health care brokers.

iii. Health care professionals with HIV expertise

In Montréal, participants recommended creating innovative opportunities to increase the expertise of HIV in the health care field to compensate for the loss of expertise on HIV because HIV doctors are aging. For example, a biochemistry graduate after a year study of social work could help people living with HIV. They suggested creating specialists in the community sector rather than going to a doctor or nurse.

Montréal participants also wanted to ensure that there are more general practitioners who can work with people living with HIV. They suggested fast-tracking accreditation for doctors from other countries. They also suggested creating a network of specialists in the community sector and ensuring that they are well-paid to address the turnover in the sector.

V. Adult Working Group Recommendations for Setting a Knowledge Agenda

The recommendations that follow are based on the results of the AWG's cross-national consultations. The recommendations are directed to the [Health and Learning Knowledge Centre](#) to terms of supporting: 1) a research agenda that addresses key areas from the consultations, and 2) knowledge dissemination and mobilization. As such, the recommendations have been organized according to these two categories.

A. Supporting Research:

The AWG recommends that HLKC support research by:

- providing funding for the areas listed below
- including the research topics listed as priorities for HLKC's Requests for Funding Proposals (RFPs)
- raising awareness that the research priorities are important
- providing opportunities for researchers to meet to collaborate on the types of questions the research provokes

The AWG recommends that the HLKC specifically support:

- community-based participatory research on the interventions that could contribute to improving the access of people living with HIV/AIDS to the health services and health information they need, particularly community-based approaches that are working;
- organized, coordinated, documentation of the systemic discrimination that adults living with HIV/AIDS face in accessing health services, with a possible focus on specific types of institutions or health services that are proving problematic for these clients. The purpose of the research would be to develop strategies to address these lived-systemic barriers;
- the evaluation of policy interventions designed to address poverty, housing, literacy, and other social determinants of health related to people living with HIV/AIDS.

B. Knowledge Mobilization

- Ensure that that this consultation report is disseminated to a wide range of stakeholders including policymakers, researchers, and practitioners who can act on the recommendations made by those adults who participated in the consultations.
- Ensure that a wide range of stakeholders have access to the findings of this consultation report through fact sheets, briefs, newsletters, etc.
- Support action on the findings of this consultation report with respect to the social determinants of health. The AWG completed a state of the field report on health and learning that both indicate there is a great deal of research on the determinants already and a need for action is now required.

VI. Summary Statement

There are some consistent outcomes across the three locations where consultations were held.

The consultations show the importance of physical and mental health for people living with HIV/AIDS, along with how they affect each other. The results indicate that the stigma of HIV/AIDS, along with the prejudice and discrimination that people living with HIV/AIDS face, affects their health and well-being in all aspects of their lives. The consultation results show that many people—including health care providers—are misinformed about the illness and how one contracts it.

Participants' recommendations indicate that it is critical to address the larger social determinants of health such as discrimination, poverty, policies that prevent people from working, lack of housing, and lack of access to equitable health services, including mental health services. These determinants of health all affect the health of people living with HIV/AIDS.

Adult Working Group Consultations on Health and Learning: Final Report on Adults Living with HIV/AIDS

Appendix A: Adult Working Group Members:

Name	Institution/ Affiliation	Location	Area of Work or Interest
Helen Balanoff	NWT Literacy		
Wendy DesBrisay	Movement for Canadian Literacy	Ottawa , ON	Canadian literacy
Sue Folinsbee (Support and coordination to AWG)	Tri En Communications	Toronto, ON	Adult literacy as a social practice; union and worker-centred- literacy; clear language and literacy integration
Doris Gillis	St. Francis Xavier University & University of Nottingham (PhD Candidate, CIHR Fellow)	Antigonish, NS & Nottingham, UK	Health literacy; maternal and child nutrition; food security; community development and participatory research.
Hélène Grégoire (Co-Chair)	Public Health Sciences Department, University of Toronto	Toronto, ON	Social determinants of health for immigrants & refugees; community development and capacity-building; parent engagement in education, school- community partnerships.
Budd Hall	University of Victoria	Victoria, BC	Participatory action research; social movement learning; and the links between learning and health

Adult Working Group Consultations on Health and Learning: Final Report on Adults Living with HIV/AIDS

Name	Institution/ Affiliation	Location	Area of Work or Interest
Lilian H. Hill	College of Education and Psychology, University of Southern Mississippi	Hattiesburg, MS	Patient education & health professions education; professional practice; environmental adult education
Shelley Hourston	BC Coalition of People with Disabilities /AIDS & Disability Action Program/ Wellness & Disability Initiative/ Health Literacy Network	Vancouver, BC	Health and wellness for people with disabilities
Wendy Kraglund-Gauthier (Support and coordination to AWG)	St. Francis Xavier University	Antigonish, NS	Adult learning and literacy, skills development and recognition, distance and on-line learning
Al Lauzon	School of Environmental Design and Rural Development, University of Guelph	Guelph, ON	Foundations of adult learning and education; community capacity development; & rural health
Mahassen Mahmoud	St. Christopher House	Toronto, ON	Immigrants and refugees
Bosire Monari Mwebi	School of Education, St. Francis Xavier University	Antigonish, NS	HIV/AIDS and health education; curriculum development
Susan Nielsen	Toronto Adult Student Association	Toronto, ON	Adult Learners/students representation and participation; ESL; Literacy and upgrading

Adult Working Group Consultations on Health and Learning: Final Report on Adults Living with HIV/AIDS

Name	Institution/ Affiliation	Location	Area of Work or Interest
Marina Niks	Institute of Health Promotion Research University of British Columbia Research in Practice in Adult Literacy (RiPAL-BC)	Vancouver, BC	Non traditional approaches to research; adult literacy; health literacy
Ningwakwe /E. Priscilla George	National Indigenous Literacy Association	Toronto, ON	Aboriginal health & literacy
Allan Quigley (Co-Chair)	St. Francis Xavier University	Antigonish, NS	Adult literacy and education; research & international linkages
Marg Rose	St. Francis Xavier University graduate student in Master's of Adult Ed (health literacy study) & Movement for Canadian Literacy member	Victoria, BC	Factors that hinder and enhance collaboration between community literacy practitioners and health educators
Rima Rudd	Harvard University	Boston, MA	Health disparities and literacy related barriers to health activities, programs, services, and care; & design and evaluation of public health community- based programs
Louise Sauvé	Téluq (Télé- université)	Montréal, PQ	Life-long learning
Linda Shohet	The Centre for Literacy of Quebec	Montréal, PQ	Adult literacy policy and practice; literacy and health; literacy and community arts

Adult Working Group Consultations on Health and Learning: Final Report on Adults Living with HIV/AIDS

Name	Institution/ Affiliation	Location	Area of Work or Interest
Cate Sills	NWT Literacy Council	Yellowknife, NT	Aboriginal literacy; community literacy; community capacity building; literacy policy.
Nadine Sookermany	Parkdale Project Read	Toronto, ON	Community literacy; social justice; violence against women; ESL
David Stott	Capital Families	Victoria, BC	Community development, food security, and homeless shelters
Kate Swales	Yukon College	Whitehorse, YK	Early childhood education & development; parent and community support
Kim Thomas	Canadian AIDS Society	Ottawa, ON	HIV/AIDS prevention and education; voluntary sector engagement; and social justice

Appendix B: Sample Consent Practices

**Community Consultation on Health and Learning
for Adults Who Are Living with HIV/AIDS
Sponsored by the Adult Working Group of the Health and Learning
Knowledge Centre, Canadian Council on Learning**

What are the community consultations about?

The Adult Working Group (AWG) of the Health and Learning Knowledge Centre (HLKC), Canadian Council on Learning is sponsoring the consultations. We follow all standard procedures with respect to research ethics and confidentiality. The purpose of the consultations is to find out adults who are living with HIV/AIDS experience health, learn about health information, and access health care services. We want to find out from you what the barriers are and what is working well. What changes would you like to see to make things better? Who needs to learn what to make the situation better?

What will I do at the consultation?

Community members and service providers will attend the consultation for a total of about 20-25 people. We will ask questions about health, getting information about health, and your ability to access health care services. Community members and providers will work in two separate groups. Everyone will come together at the end to share highlights of their discussion.

How much time will it take?

The consultation will take about 4 hours. Lunch will be provided.

What if I want to stop my participation?

Participation is voluntary. You can leave the meeting at any time.

Will anyone know what I said?

We will not use your name or anything that can identify you in the report on the consultations.

What are the possible outcomes if I participate in the consultation?

The long-term benefits are that there may be some improvements in accessing information about health and health care services for you, your families and other people who have had similar experiences to yours.

Where do I get questions answered?

You can contact XX at XX

Appendix C: Consultation Questions

Questions for Consultations for Adults Living with HIV/AIDS

Community members	Providers, Practitioners
<p>1. What does being healthy mean to you?</p> <ul style="list-style-type: none"> • <i>Can you describe what it is like to be healthy?</i> • <i>What does it mean to be in poor health?</i> • <i>Why does this happen?</i> • <i>Why / When are you not healthy</i> <p>2. What do you do to be healthy or to stay healthy?</p> <ul style="list-style-type: none"> • <i>What do you need to get or keep good health?</i> • <i>Where do you get it?</i> • <i>What makes it difficult?</i> • <i>How does where you live affect your health?</i> <p>3. How do you learn about personal health? How do you get the information you need to be healthy?</p> <ul style="list-style-type: none"> • <i>Where do you find this information?</i> • <i>How do you get it?</i> • <i>Do you talk to people or do you read information or do you use the Internet?</i> • <i>If you use the Internet, where do you get access to a computer?</i> • <i>What problems do you have using this and how do you overcome them?</i> • <i>What health information have you found so far?</i> • <i>Would you use a HELP Web site to find the health –related information you need?</i> • <i>What works well for you to get the information you need?</i> • <i>What kind of information or health</i> 	<p>1. From your experience, what does being healthy mean to your clients?</p> <p>2. What do they do to get or keep in good health?</p> <ul style="list-style-type: none"> • <i>What do they need to get or keep good health?</i> • <i>Where do they get it?</i> • <i>What makes it difficult?</i> • <i>How does where you live affect your clients' health?</i> <p>3. What are your clients' experiences with health and health services?</p> <ul style="list-style-type: none"> • <i>What makes it difficult to have the kind of health your clients and their families want?</i> • <i>What's it like when your clients have to go to the doctor, the hospital, or a community health centre.</i> • <i>What works well?</i> • <i>What was difficult?</i> • <i>How does where you live affect what kind of health services you get?</i> • <i>What are some of the different cultural assumptions?</i> • <i>What could these organizations do differently to make it easier for their clients?</i> • <i>What could your clients do?</i> • <i>What else would help them access health services better?</i>

Community members	Providers, Practitioners
<p><i>topics is most important for you to get?</i></p> <ul style="list-style-type: none"> • <i>What's hard?</i> • <i>What would make it easier to get the health information you need?</i> • <i>What suggestions do you have for the health field?</i> • <i>How does where you live affect what kind of information you get about health?</i> <p>4. What are your experiences with health and health services</p> <ul style="list-style-type: none"> • <i>What makes it difficult to have the kind of health you want for you and your family?</i> • <i>What's it like when you have to go to the doctor, the hospital, or a community health centre?</i> • <i>How does where you live affect what kind of health services you get?</i> • <i>What works well?</i> • <i>What was difficult?</i> • <i>What could these organizations do differently to make it easier for you?</i> • <i>What can you and others do?</i> • <i>What else would help you get health services easier?</i> 	<p>4. How do you get information for your clients so they can learn about health for themselves and their family? How do they get information they need to be healthy?</p> <ul style="list-style-type: none"> • <i>Where do you find this information?</i> • <i>Do you use the Internet to get health-related information?</i> • <i>What information have you found that is useful? Please give examples.</i> • <i>Would you use a HELP web site to find the health –related information you need?</i> • <i>What works well for your clients to get the information they need?</i> • <i>What's hard?</i> • <i>How does where you live affect what kind of information clients get about health?</i> • <i>What kind of information or health topics is the most important for your clients?</i> • <i>What would make it easier for you to get the health information they need?</i> • <i>What suggestions do you have for the health field to do to improve the situation?</i> • <i>What kind of informal or formal learning would help? Who needs to learn?</i> • <i>How could this learning happen?</i>
<p>5. What types of learning can help address these barriers?</p> <p>6. Who should do the learning?</p> <p>7. What else needs to be done?</p>	<p>5. What types of learning can help address these barriers?</p> <p>6. Who should do the learning?</p> <p>7. What else needs to be done?</p>

Appendix D: Participant Profiles

Community Member Participant Characteristics Edmonton Consultations	
• Education	
Grade 9 or less	4
Some or completed high school	3
Some college or university	2
College or university degree	4
• Language	
English as first language	12
Other first language	1
• Gender	
Male	9
Female	4

Table 1: Edmonton community member participant characteristics

Community Member Participant Characteristics Montreal Consultation	
• Education	
Less than high school	3
High school diploma	5
Some college or university	6
University degree	1
Graduate degree	1
• Language	
French as first language	10
English as first language	2
Bilingual (French and English)	2
Spanish as first language	2
• HIV status	
Positive	15
Did not disclose	1

Table 2: Montreal community member participant characteristics

Community Member Participant Characteristics Truro Consultation	
• Education	
Grade 9 or less	2
Some or completed high school	3
Some college or university	1
College or university degree	4
• Language	
English as first language	9
Other first language	
• Gender	
Male	8
Female	2

Table 3: Truro community member participant characteristics