Executive Summary

In Canada, approximately 27% of people with HIV do not know they have HIV.¹ In 2006, this equated to approximately 15,800 people.² This means that a large number of people are not aware that they should be receiving support and treatment. Up to 40% of people find out they are HIV positive less than a year before being diagnosed with AIDS. Cutting the number of new infections per year in half would save the Canadian health care system and society approximately $1.5 billion over five years.³ These figures also mean that many people are not aware that they should be taking measures to avoid further spread of HIV. Research has shown that approximately 50% of new HIV infections are transmitted by individuals who themselves are newly infected.⁴ There is an urgent need to increase the number of people who are aware of their HIV status. The challenge is to get people tested.

As part of its ongoing work to support implementation of Nova Scotia’s Strategy on HIV/AIDS, the Nova Scotia Advisory Commission on AIDS contracted Pyra Management Consulting Services Inc. to complete this report on the future of HIV testing in Nova Scotia. The report presents findings of a literature review and key stakeholder interviews, including an outline of alternatives and recommendations for increasing HIV testing in Nova Scotia.

Today, nominal and non-nominal HIV testing are available across Nova Scotia. Anonymous testing has, to date, been available only in Halifax and Sydney with outreach to surrounding areas. Anonymous testing services have also very recently been announced for Truro (although the service is not yet implemented). Ninety percent of stakeholders interviewed feel it is very important that all three testing options be available in Nova Scotia. However, they believe that testing is not evenly distributed throughout the province and point out it is not equitably available to those who do not have a family physician. Many stakeholders interviewed feel that the guidelines for HIV testing in Nova Scotia, which include informed consent, confidentiality,
and pre and post test counseling, are not being met and that health provider education and alternatives to the current test providers are required to improve the situation.

Both the literature and key stakeholders identified populations that are currently not accessing HIV testing services, including, but not limited to people who use injection drugs, people living in rural or small communities, youth, Aboriginals, and women. Barriers to accessing testing identified by both the literature and key stakeholders include real or perceived lack of confidentiality and privacy, stigma and discrimination, lack of awareness of their risk for HIV, cultural norms of hostility toward HIV, fear of adverse consequences and personal isolation, cost, lack of transportation, and for youth, lack of testing available in youth-friendly settings. The single largest barrier to making people aware of their HIV status may be the continued reliance on a single model of HIV counseling and testing, which has remained unchanged since the mid 1980s. As a result, a number of alternative approaches to and models of testing have been proposed. These include rapid point of care testing, routine testing, and various combinations of a number of existing tests, such as streamlined counseling, and opt-out rather than opt-in models. Stakeholders also suggested increasing awareness through social marketing and public education campaigns, increasing the number of rural test sites, creating a network of drop in centres, increasing outreach services, and making testing part of regular screening services.

A number of clear messages have emerged from the literature and from the interviews with Nova Scotia stakeholders:

- HIV testing is an important public health issue that needs ongoing attention. The importance of this issue has been recognized in other jurisdictions within Canada and the United States, as evidenced by the resources that have recently been allocated to increasing the number of people who seek testing.
- HIV issues in general, and HIV testing in particular, has a very low profile in Nova Scotia. The key informants contacted to participate in interviews for this report were selected as representative of the people who would be most knowledgeable about HIV testing in Nova
Scotia. Many interviewees stated that they had little knowledge of HIV testing and two key informants declined to participate in the interview citing lack of knowledge. The experience of conducting the interviews is a serious reminder about how low on the priority list HIV has become on the public health agenda in Nova Scotia.

- The Standards for Blood Borne Pathogens Prevention Services in Nova Scotia have not been implemented consistently across Nova Scotia. Despite a significant investment of resources and expertise to create the Standards based on best practices, attention and resources have not been dedicated to the implementation and monitoring of the Standards. Some of the key informants interviewed for this report were not even familiar with the Standards.

- Although the current model of offering three types of testing in Nova Scotia (nominal, non-nominal, and anonymous) is valued among stakeholders, it is clear the current implementation of this model is not effective in making HIV testing equitably accessible to all Nova Scotians, particularly those who may be most at risk for HIV.

- There is support for doing things differently. One of the first steps in making a significant change is ensuring that there is readiness for change. Based on the key informant interviews, it appears that there may be willingness to try a new approach to HIV testing in Nova Scotia.

- While there have been recent efforts in other jurisdictions to increase the number of people tested, there is not a strong body of evidence pointing to one approach over another. This suggests, as does the advice of the key informants, that several different strategies may need to be tried in order to increase testing. Nova Scotia has an opportunity to try and evaluate new approaches, and contribute to the body of knowledge about effective strategies.

- Key informants were clear that one approach will not work with all communities, and that communities must be engaged in finding solutions that work for them.

Action steps to increase HIV testing in Nova Scotia include:

- Commit resources to address HIV testing on the part of the Departments of Health and Health Promotion and Protection as well as District Health Authorities;
• Provide provincial leadership for HIV testing and initiatives around blood borne pathogens by allocating responsibility for overseeing implementation of the Standards for Blood Borne Pathogens Prevention Services to a dedicated person within Public Health Services that is given sufficient time to manage the issue;

• Implement and fund the Standards for Blood Borne Pathogens Prevention supported by human resources dedicated to this task in each District Health Authority, making increased HIV testing the first priority;

• Implement a community development approach to increase HIV testing by engaging geographic communities and communities of people with common characteristics, such as out of school youth or people who use injection drugs, in identifying solutions that will work for them;

• Provide point of care rapid testing as a testing option in addition to nominal, non-nominal and anonymous testing; these four options should be available to Blood Borne Pathogens Coordinators and the communities they work with to select the option most appropriate for their needs;

• Implement a social marketing campaign, appropriately targeted to different audiences, that encourages people to seek HIV testing and provides them with information about where to get an HIV test; and

• Implement a pilot test of routine screening in several primary care practices throughout the province. Through the pilot test, assess the impact of routine screening on numbers of people tested, number of positive tests, time impact for the physician and the experience of the client.
# Table of Contents

Executive Summary ......................................................................................................................... i
1.0 Introduction and Background ................................................................................................... 1
2.0 Methodology ............................................................................................................................ 3
   2.1 Literature Review .................................................................................................................. 3
   2.2 Key Informants ..................................................................................................................... 3
   2.3 Data Analysis and Storage ................................................................................................ 5
   2.4 Scope and Limitations ......................................................................................................... 5
3.0 Definitions ............................................................................................................................... 7
4.0 Issues in HIV Testing ................................................................................................................. 9
   4.1 Consent ................................................................................................................................. 9
   4.2 Counseling ............................................................................................................................ 11
   4.3 Confidentiality ...................................................................................................................... 12
   4.4 Stigma .................................................................................................................................. 14
   4.5 Mandatory Testing ............................................................................................................. 15
   4.6 Routine Testing .................................................................................................................... 17
5.0 Approaches to HIV Testing .................................................................................................... 18
   5.1 Approaches to HIV Testing ................................................................................................ 18
   5.2 Distribution of HIV Testing Services in Nova Scotia ......................................................... 18
   5.3 Stakeholder Perceptions ...................................................................................................... 19
6.0 Barriers to HIV Testing ......................................................................................................... 23
   6.1 Populations Not Being Tested in Nova Scotia as Identified by Interviewees .................... 23
   6.2 Barriers to Testing Identified in the Literature ................................................................... 23
   6.3 Barriers to Testing Identified By Interviewees ................................................................... 25
   6.4 Low Profile of HIV Issues is a Significant Barrier to Testing ............................................ 26
7.0 Potential Opportunities for Increasing HIV Testing ............................................................... 28
   7.1 Opportunity: Increase the Profile of HIV Issues in Nova Scotia Among Public Health Decision Makers .............................................................................................................. 28
7.2 Opportunity: Social Marketing to Promote HIV Testing .......................................................... 30
7.3 Opportunity: Expand Anonymous Testing................................................................................. 34
7.4 Opportunity: Point of Care Rapid Testing ............................................................................... 36
7.5 Opportunity: Routine Testing .................................................................................................. 41
7.6 Opportunity: Strengthening Health Providers’ Capacity ....................................................... 44
7.7 Opportunity: Improving Uptake of the Standards for Blood Borne Pathogens................. 45
7.8 Other Potential Opportunities to Increase Testing................................................................. 46
8.0 Summary of the Findings ........................................................................................................ 48
9.0 Action Steps To Increasing HIV Testing in Nova Scotia ...................................................... 50
10.0 Conclusion ............................................................................................................................ 57
References ...................................................................................................................................... 58
Appendices ..................................................................................................................................... 64
Appendix 1 – Cost Estimates ........................................................................................................ 65
Appendix 2 – List of Key Informants .......................................................................................... 66
Appendix 3 – Interview Guides ................................................................................................... 67
Appendix 4 – Background Documents ....................................................................................... 80
Appendix 5 – Guidelines for Pre and Post Test Counseling ...................................................... 90
1.0 Introduction and Background

In Canada, approximately 27% of people with HIV do not know they have HIV.\(^1\) In 2006, this equated to approximately 15,800 people.\(^2\) In the United States the figures range from 200,000 to 300,000, or from 25% to 50% of people living with HIV being unaware they have HIV.\(^5\)-\(^10\)

Many people with HIV do not receive their diagnosis until late in the disease; up to 40% of people find out they are HIV positive less than a year before being diagnosed with AIDS.\(^5,\ 11\)

These figures are disappointing at a time when we know that knowing one’s HIV status motivates many to adopt safer behaviours, that effective treatment exists, and with early diagnosis, treatment can reduce morbidity and prolong life.\(^10\)-\(^13\) This means that a large number of people aren’t aware that not only should they be taking measures to avoid further spread of the disease, they also should be receiving support and treatment themselves. From a health system perspective, in Canada, cutting the number of new infections per year in half would save the Canadian health care system and society approximately $1.5 billion over five years.\(^3\)

Additionally, it is estimated that approximately half of new HIV transmissions are by people who themselves were newly infected.\(^4\) For all of these reasons, there is an urgent need to increase the number of people who are aware of their HIV status, but the challenge is to increase the number of people who are tested.

Between 1983 and 2006, there have been almost 700 HIV positive tests reported in the provinces of Nova Scotia and Prince Edward Island. Although this number does not take into account deaths, persons undiagnosed, and migration in or out of province, it does illustrate that HIV is an issue faced by many Nova Scotians. Proxy indicators for HIV infection, particularly recent high rates of the sexually transmitted infection chlamydia, indicate that Nova Scotians are engaging in practices that place them at high risk for the sexual transmission of HIV.\(^14\) In order to guide Nova Scotia’s response to HIV/AIDS, in 2003 community and government stakeholders released *Nova Scotia’s Strategy on HIV/AIDS*. 
Nova Scotia’s Strategy on HIV/AIDS identifies the need to develop and deliver a collaborative awareness campaign to provide the public with information on HIV/AIDS. Led by the Nova Scotia Advisory Commission on AIDS, steps have been taken to address this recommendation. A two phase project, which began in 2007, targeted prenatal HIV testing. Phase One of this project sought to gather information from Nova Scotian women who were currently pregnant, had recently been pregnant, or were planning to conceive in the near future. Focus groups were held with this population group to determine their perceptions of prenatal HIV testing. These perceptions would then be used to inform Phase Two, a social marketing campaign to increase uptake of prenatal HIV testing. This project began based on evidence that prenatal HIV counseling and screening in Nova Scotia is sub-optimal and does not meet current guidelines. The results of the Phase One work showed that pregnant women in Nova Scotia were generally accepting of prenatal HIV testing yet had a low awareness of HIV/AIDS. The results also demonstrated that many healthcare practitioners are not complying with standards for HIV testing (informed consent, counseling, and confidentiality). As a result, the Nova Scotia Advisory Commission on AIDS tabled the Phase Two social marketing campaign in order to conduct a broader exploration of strategies to increase HIV testing in Nova Scotia.

The Nova Scotia Advisory Commission on AIDS contracted Pyra Management Consulting Services Inc. to explore and recommend options for increasing the provision, quality and awareness of HIV testing services in Nova Scotia. Specifically, this report presents:

- a literature review of existing models of HIV testing in Canada and other jurisdictions;
- key Nova Scotia stakeholder interviews held to identify knowledge and perceptions about the current state of HIV testing, issues in HIV testing and suggestions for the future of HIV testing in Nova Scotia;
- based on the analysis of the interviews and the literature review, options to increase the provision, quality and awareness of HIV testing services in Nova Scotia; and
- recommended future actions to increase HIV testing throughout the province.
2.0 Methodology

Data for this project was collected using two methods: a search of the formal and grey literature, and key informant interviews. This section outlines how the review of the literature was conducted, how the key informants were selected, how interviews were conducted and how the data was analyzed. It also reviews the scope and limitations of the project.

2.1 Literature Review

The literature review included both formal peer-reviewed literature and grey literature available via the Internet. The search of formal literature was conducted using electronic databases including PubMed, CINAHL, Cochrane and the federated literature search engine Prowler. The search of grey literature was primarily conducted using the search engine Google, including Google Scholar and various specific search engine tools available on government web pages. Keywords used in the search strategies, either alone or in combination included: HIV testing, Canada, models of HIV testing, current trends in HIV testing, anonymous testing, point of care testing, rapid testing, mandatory HIV testing, and voluntary HIV testing. An additional search was conducted for material specific to testing in hospital emergency departments using the search terms HIV testing, emergency units and emergency departments. The Acting Research Officer at the Advisory Commission on AIDS also provided Internet links of some examples of approaches to HIV testing that were not uncovered in the literature search. Searches were mainly restricted to material published between 2000 and 2008.

2.2 Key Informants

A non-representative purposive sample was used for the selection of key informants. In collaboration with representatives from the Nova Scotia Advisory Commission on AIDS, 24 potential key informants from Nova Scotia were identified as central, northern, eastern, western, or provincial stakeholders. All potential interview candidates were contacted by e-mail to request participation in an interview. Positive responses were followed up with an e-mail or
phone call requesting that an appointment be made for a telephone interview, and background information related to the project and interview was provided (see Appendix Four). Two potential key informants declined to participate in interviews citing lack of knowledge about Nova Scotia HIV testing services. Two others suggested alternative people they felt would be better able to provide accurate or meaningful information in response to the interview questions. The suggested replacement interviewees were also interviewed (see Appendix Two). To guide the interviews, specific interview questions for regional and provincial key informants were developed with input from the Nova Scotia Advisory Commission on AIDS. The contractor developed a draft interview guide to cover the scope of information requested by the Advisory Commission on AIDS. The Acting Research Officer and Chair of the Commission provided input on the first draft of the interview guides, which was incorporated into the final version. These interview guides can be found in Appendix Three.

During May 2008, 22 interviewees were interviewed in 20 semi-structured telephone interviews. Two interviews were conducted with two informants concurrently. Table I outlines the distribution of key informants in terms of the jurisdiction they are from within Nova Scotia. Prior to the interview, interviewees were sent a background document that included definitions of four types of HIV tests, the HIV testing guidelines, an explanation regarding consent to participate in the interview and the interview questions. These background documents can be found in Appendix Four. Prior to beginning the interview questions, each interviewee provided verbal informed consent regarding their participation in the interview and permission to include their names in the Appendix. Informants were made aware that their information would be shared with the Nova Scotia Advisory Commission on AIDS and that it may be shared with other jurisdictions or placed on the provincial government’s website at a later date. Interviews ranged from 20 to 60 minutes in length. Data from the interviews were captured in the form of notes taken by the interviewer.
Table I: Distribution of Interviewees

<table>
<thead>
<tr>
<th>Region</th>
<th>Number of Interviews</th>
<th>Number of Interviewees</th>
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<td>11</td>
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<tr>
<td>Central</td>
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</tr>
<tr>
<td>Eastern</td>
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<td>2</td>
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<tr>
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<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>22</td>
</tr>
</tbody>
</table>

2.3 Data Analysis and Storage

The literature review and telephone interview results were analyzed to identify current models and availability of HIV testing, the need for HIV testing, standards and guidelines for HIV testing, public awareness, and HIV as a public health issue. Quotes from the interviews are provided throughout the report to illustrate the perspectives of key informants. To protect the anonymity of the interviewees, these quotes are not attributed to specific individuals. They appear in the report as indented italicized paragraphs. All raw data associated with this project has been stored in a locked filing system to ensure the confidentiality of individual key informants’ responses.

2.4 Scope and Limitations

The scope of the literature review included models of HIV testing and issues associated with HIV testing. The scope of the key informant interviews included key informants from Nova Scotia.

It is important to note several limitations which impacted the findings of this review. Responses provided by the key stakeholder interviewees are largely perception based. Many of the questions asked for their opinions or perceptions, for instance regarding whether or not the
guidelines for HIV testing in Nova Scotia are consistently applied, or whether or not the
standards for blood borne pathogens are useful. While their perceptions may be informed, they
are perceptions only. Many of the interviewees are not HIV test providers and are not involved
directly or indirectly in the provision of testing services. In some cases, their knowledge of the
status of HIV testing in Nova Scotia may be limited. All of the interviewed key stakeholders are
from Nova Scotia, resulting in a lack of information about other jurisdictions across Canada.

When commissioning this report, the Nova Scotia Advisory Commission on AIDS requested that
a review of the literature on models of HIV testing used elsewhere in order to inform a process
for increasing HIV testing in Nova Scotia. Specific details about implementation of HIV testing
models were not in abundance in the formal and informal literature available via the internet.
Much of the formal literature regarding HIV testing is American and as such may not be
generalizable to the Canadian and/or Nova Scotia population. It is possible that an
environmental scan involving interviews with content experts from other jurisdictions may have
enhanced the review of existing HIV testing programs and methods. Finally, a literature review
is a snapshot in time, and the body of literature continues to evolve, especially in the HIV/AIDS
field.
3.0 Definitions

Four main types of HIV testing are considered in this report. They are nominal, non-nominal, anonymous and point of care rapid testing. All types of testing are to be accompanied by pre- and post-test counseling, informed consent, and confidentiality.

**Nominal or name-based testing** means the person ordering the HIV test knows the identity of the person being tested. If the test result is positive, the person who ordered the test is required to notify public health officials with the person’s name, and is responsible for notifying the person’s sexual partners and drug use contacts. Nominal testing is typically accessed through family physicians or other clinics.

**Non-nominal testing** means the person ordering the test may know the identity of the person being tested, however the HIV test is ordered using a code or the initials of the person being tested. If the test result is positive, a public health official will contact the person who ordered the test and determine whether sexual partners have been notified of the possibility of exposure to a sexually transmitted infection and should go to their own health care provider for counseling and testing. If satisfied that the partners have been contacted, the official will not ask for the name of the person being tested. Non-nominal testing is typically accessed through a person’s family physician or other clinic.

**Anonymous testing** is where the person ordering the HIV test does not know the identity of the person being tested; the HIV test is carried out using a code. If the HIV test is positive the person being tested is responsible to contact his or her sexual partners and/or drug use contacts. Test results are not recorded on the health care record of the person being tested. Between three and four percent of HIV tests in Nova Scotia are conducted anonymously.
**Point of care rapid testing** refers to the “practice undertaken by health care professionals of providing:

- pre and post-test HIV counseling that is modified to suit point of care settings; and
- HIV testing using rapid tests in the point of care setting.”

Point of care rapid testing can be used in:

1. Medical settings such as an emergency room.
2. As an outreach strategy for HIV testing services.

There is often confusion between the terms *point of care testing* and *rapid testing*, with the terms sometimes incorrectly used interchangeably. Point of care testing refers to the setting in which HIV testing is conducted. It has been defined as testing in the presence of a health professional rather than a testing procedure that is carried out without involvement of a health professional, such as home testing. Rapid HIV tests are those that can be conducted and analyzed on-site, rather than having blood drawn and sent to a centralized laboratory for analysis. A fluid sample is taken and a test result of final negative results or preliminary positive results are typically available within an hour of the testing, meaning that the results can be provided to the person being tested within a single visit. Preliminary positive and indeterminate test results require a confirmatory blood test. This is different from the three forms of testing described above, which all require that the blood sample drawn during the first visit is sent to a central laboratory for analysis, and the results are not available until two or three weeks later. This requires the individual being tested to return for a second appointment with their health care provider to receive test results and post-test counseling.

For clarity, the term **point of care rapid testing (POCR)** is used to describe the fourth approach to HIV testing discussed in this report. Theoretically, POCR can be nominal, non-nominal, or anonymous.
4.0 Issues in HIV Testing

This section of the report explores current thinking in the literature and among stakeholders around key issues in HIV testing that are highly relevant to discussions about future approaches to HIV testing for Nova Scotia, including consent, counseling, confidentiality, stigma, mandatory testing, and routine testing. Background about these issues provides important context for future deliberations about approaches to HIV testing.

4.1 Consent

Consent, along with confidentiality and counseling, is one of three fundamental components of HIV testing. Physicians in Canada are legally and ethically required to obtain voluntary, specific, and informed consent from people being tested for HIV, as outlined in the Canadian Medical Association Guidelines for HIV Testing. Despite this requirement there is both research and anecdotal evidence that HIV testing without specific informed consent is widespread.18

Within the literature, there is a strong recognition of the need to increase the number of people who are aware of their HIV status. However, there appears to be two schools of thought related to the role or place of informed consent within this movement. Those who would like to see HIV testing become more of a routine medical test tend to criticize the requirement for informed consent. Informed consent and counseling, together, have been referred to as “extra steps” that have prevented HIV testing from becoming a routine part of medical care, resulting in missed opportunities to diagnose, treat and stop its spread. In this case, verbal informed consent and enhanced post test counseling are recommended.19

One American study that looked at missed opportunities for HIV testing in medical settings determined that the requirement for informed consent prior to testing is a barrier to expanding HIV testing due to the time it requires of providers. This ten year retrospective chart review of
patients seen at an HIV clinic also noted that for broader HIV testing to occur, additional resources would be needed if explicit written informed consent continues to be required.\textsuperscript{11}

On the other hand, there are those who uphold the importance of informed consent within the context of increased HIV testing. POCR testing, one could argue, is a strategy to decrease missed opportunities for HIV testing and should therefore not be subject to strict informed consent rules. Regardless, in Canada POCR testing still requires the informed consent of the person being tested. While the Public Health Agency of Canada’s Guidelines for Health-Care Professionals using Rapid HIV Test Kits recognizes informed consent as a challenge to rapid testing in the point of care setting, it also recognizes that it is a key aspect of the legal, ethical and human rights framework within which HIV testing occurs.\textsuperscript{1} An American review of policies regarding consent considered the arguments for and against testing critically ill (and other incompetent) patients without consent. It concludes that non-consented HIV testing should only take place when the physician determines that the tests are likely to alter diagnostic or therapeutic management, the patient in unable to consent to or refuse testing, and effective treatment is available for the patient.\textsuperscript{13} In 2004, the United Nations Joint Programme on HIV/AIDS/World Health Organization (UNAIDS/WHO) issued a policy statement with a number of recommendations related to increasing testing services, including shifting to provider-initiated testing and the use of new technologies. Informed consent (along with confidentiality and counseling) however, remained one of the three key elements for all voluntary HIV testing.\textsuperscript{20}

All jurisdictions in Canada provide HIV testing as part of routine prenatal screening. However, some use an opt-in model, where the woman must agree to have the testing, and others use an opt-out model, where the test will be done unless the woman refuses.\textsuperscript{21} Nova Scotia is currently operating within an “opt-in” model. In all cases, however, testing is voluntary and requires informed consent.\textsuperscript{20}
4.2 Counseling

One of the three guidelines for HIV testing, counseling, has been a part of conventional HIV testing since its inception in the mid 1980’s. In 2000, there was widespread agreement that quality pre and post test counseling were essential components of HIV testing. Canadian Medical Association policy requires that physicians provide pre and post test counseling, and very specific components for both pre and post test counseling are outlined. Counseling plays a critical role in the HIV testing process since there are serious personal, social, and legal implications to receiving a positive test result. Counseling supports a person from each of these perspectives. Pre test counseling on its own has a preventive function, and post test counseling provides not only a link to care and services, but also reduces the personal risk of transmission.

Despite the requirement for counseling, at times its provision does not meet HIV testing guidelines. One Canadian study of 40 women with HIV showed that many received no counseling at all. A qualitative evaluation of the CMA Guidelines found that more than one-third of primary care physicians did not have a copy of the Guidelines that outline the requirement for counseling, and 17% reported that they provided counseling only for patients who tested positive for HIV. The requirement to return to a health care provider to receive a test result and post test counseling is also known to be a deterrent to testing for youth and it was also commonly cited by many interviewees as an issue.

Over time, with the advent of new testing technologies and the sense of urgency to increase the number of people who know their HIV status so they can access treatment and take action to avoid spreading the virus, need for and adequacy of counseling has come into question. As a result, other models of counseling have been considered. The Centres for Disease Control and Prevention compared enhanced counseling (four interactive sessions) with brief counseling (two interactive sessions) and a didactic information-giving model. Results showed the brief counseling was more effective at increasing condom use and preventing STIs. Rapid testing, which involves counseling at the time of the HIV test only, has been shown in a meta-analysis of
alternative HIV counseling and testing methods to result in a substantial decrease in high-risk behaviour for HIV infected persons as compared to those who are not aware of their status. Post test counseling only has also been suggested in the literature but it has not yet been evaluated.

One study that looked at the best practice experiences of test providers, found that HIV counseling was highly individualized based on the individual’s risk, knowledge, social and cultural characteristics, presenting a number of challenges to providers. Canadian work has also shown that HIV test recipients expect their individual characteristics and circumstances to be recognized and responded to in the testing and counseling process rather than receiving a standardized process and information.

One randomized, controlled trial looked at the efficacy of prevention counseling with rapid testing (with one counseling session), as compared to standard HIV testing (with pre and post test counseling). The study found rapid testing to have definite advantages. However, in terms of the counseling component, it acknowledged that with standard testing, clients spend more time with the counselor. While this waiting period may be stressful for some, for others, the effect of having longer to reflect on their risk behaviour is a positive thing.

### 4.3 Confidentiality

The issue of confidentiality is especially important because of the stigma and discrimination experienced by people with HIV or AIDS. Some would say the stigma and discrimination faced by those with HIV today, is as serious as it was in earlier years. People at risk for or living with HIV need to be able to trust the health care system to treat them with respect, dignity and confidentiality. When this is not the case, people do not get tested or treated and the consequences on the individual and community at large are serious.

There is a long-recognized duty of confidentiality between health care professionals and their patient. This duty is recognized both by statute and professional codes of conduct. However,
there are instances within which this confidence may be breached. This is typically in the case where protection of a third party is necessary.\textsuperscript{18} The Canadian Medical Association (CMA) is explicit in stressing the need to respect the confidentiality of patients with HIV infection. There are very specific circumstances under which the name of the HIV positive person can be disclosed but the CMA still “urges those involved to maintain confidentiality to the greatest extent possible and to take all reasonable steps to inform the patient their information is being disclosed.”\textsuperscript{23} The CMA believes that disclosure of an individual’s HIV status to a current sexual partner may be warranted when a person with HIV is unwilling to inform the person at risk.\textsuperscript{23} The issue of confidentiality as it relates to HIV ultimately pits two highly valued principles against each other; confidentiality of the patient-provider relationship and the good of the public’s health.\textsuperscript{18}

The initial impetus behind anonymous testing was to ensure that people could learn their HIV status without risking the confidentiality of the test result.\textsuperscript{20} One American study, which interviewed 24 test providers to determine their best practices in testing and counseling, identified “ensuring confidentiality” as one of the best practices related to relationship building and counseling in general. It also found that providers in both anonymous and other HIV test settings, were clearly aware of the impact of having an outsider find out a person’s HIV status.\textsuperscript{22}

Confidentiality or the perception of a lack of confidentiality was cited numerous times by key stakeholder interviewees as a barrier to people accessing HIV testing. Confidentiality is seen as especially problematic in rural or small communities, including Aboriginal communities. Given Nova Scotia’s rural nature, this is a large problem. Even Halifax, one interviewee noted, is a relatively small community. Interviewees noted that people aren’t necessarily afraid that their primary health care provider will not keep their information confidential. They are often concerned about a medical receptionist, secretary, other office staff, lab worker or other people in the waiting room. In small communities, not only does everyone know each other, many people are related to each other.
4.4 Stigma

Many people who are infected with HIV already face other forms of discrimination, such as homophobia, gender inequality, negative attitudes toward sex workers and people who use injection drugs, racism, fear of contagion, and rigid ideas about sexuality. In these cases, being HIV positive compounds the issue of stigma. In the case of those who are not already stigmatized based on any of the above noted factors, fear of stigmatization exists because others often associate a positive HIV status with a negative behaviour. These scenarios show how closely related the concepts of confidentiality and stigma are. Confidentiality is particularly important as it relates to HIV because of the stigma and discrimination experienced by people with HIV or AIDS. In both cases, lack of confidentiality plays a key role in minimizing, or at least not exacerbating, the issue of stigma. Stigma has been shown to drive those perceived as vulnerable underground, and as such they may not access testing and treatment services.

The concept of “AIDS exceptionalism” is used to describe the phenomenon whereby AIDS and AIDS policies are treated differently than other diseases. This comes out of the concern for “the protection of people from stigma and discrimination in a time when public fear of AIDS was high and there was no HIV antibody test or effective treatment for AIDS.” Today however AIDS exceptionalism is being challenged based on the desire to increase the number of people who know their HIV status. In fact, there are those who suggest that AIDS exceptionalism actually promotes the stigma associated with HIV and may contribute to a reluctance to seek testing. It is suggested that routine HIV testing would help to address this. Some hope that more widespread screening for HIV will decrease its associated stigma and suggest that the routine testing of pregnant women and others has shown this to be the case. Others continue to believe that the current way in which testing and counseling are delivered is necessary to protect the individual.

Interviewees were asked their opinions on whether or not the way in which HIV testing is currently provided throughout Nova Scotia helps or hinders the issue of stigma. Opinions were
mixed. Six interviewees feel that the way testing is currently provided hinders the issue of stigma and another six either didn’t know or weren’t sure if it helps or hinders the issue of stigma. Three feel that stigma is an entirely separate issue from the way in which HIV testing is currently provided.

“It’s not the way the testing is being done that is causing the stigma. Access is the issue. The way it is advertised contributes to stigma. Don’t call it ‘AIDS testing day’, call it a ‘health information day’ or ‘sexual health day’, and include mental health and other services. If there isn’t enough access, there is stigma. If people knew they could do it without giving their name, it would decrease stigma.”

“We need to normalize it, but how do we do this? Legislatively we have set it apart from other blood borne pathogens. This contributes to the stigma.”

“It contributes to stigma because it is not being consistently offered and there hasn’t been a social marketing campaign. The three options should be equally available and supported. Anonymous testing shouldn’t be perceived as being sneaky.”

4.5 Mandatory Testing

Mandatory testing refers to HIV testing that is forced upon an individual, and in some cases also involves forced disclosure of test results. In the early days when the extent of the HIV/AIDS epidemic was just being recognized and when understanding was low and fear ran high, it is understandable that there were calls for mandatory testing. There were many unknowns: the disease, its prevention, and treatment. Calls for mandatory testing were a common political response to the situation because such calls gave the appearance of governments taking strong action to protect the public from a new and very harmful threat.
Even today, in an age when we know that many people who have HIV are not aware of their status and we want those people to learn their status so that they can take preventive measures to avoid spreading the virus, mandatory testing may still appeal to some. However, there are strong legal, ethical and financial grounds on which mandatory testing is not supported. There are no benefits achieved through mandatory testing that can not be achieved through voluntary testing with informed consent. Furthermore, mandatory testing may be a barrier to testing and seeking care and could adversely affect voluntary, informed HIV testing and counseling. As a result, opt-out models of testing, which have been shown to increase testing and the number of people learning their status, are preferred. Mandatory reporting, on the other hand, was not found to negatively impact the HIV testing rate in a study conducted in Alberta in 2003. This study used information from the Provincial Laboratory for Public Health between 1993 and 2000 and also found that an opt-out (as compared to mandatory) model for prenatal HIV testing resulted in a dramatic increase in the number of females being tested.

The World Health Organization has stated that “programmes that do not respect the rights and dignity of individuals are not effective.” Others have argued for mandatory testing on the basis of protecting public health. However, mandatory testing is not in the public interest because:

- the stigma and discrimination associated with HIV could cause people to avoid testing and obtaining needed services;
- it damages the credibility of health services;
- it will never identify all HIV positive people;
- it creates a false sense of security for those who would not be required to be tested and further could use this as an excuse to not take precautions, and
- it is expensive and diverts valuable funds from prevention activities.

The Canadian Medical Association endorses informed mandatory testing for HIV infection in cases involving the donation of blood, body fluids or organs. UNAIDS/WHO support a similar
position and further do not support mandatory testing on public health grounds based on the fact that voluntary testing is more likely to result in behaviour change than mandatory testing.\textsuperscript{20}

In Nova Scotia, the current regulations on Mandatory Testing and Disclosure allow for a defined list of people to request mandatory testing for HIV, hepatitis B and hepatitis C of another individual only when they have been exposed to bodily fluids. The request must be supported by a form completed by a physician. Examples of those who may request it include peace officers, correctional service workers, emergency first aid providers and health care workers, clerks of the court, registered paramedics, and police officers.\textsuperscript{31}

\textbf{4.6 Routine Testing}

Routine HIV testing refers to the practice of utilizing an opt-out testing approach with patients in all healthcare settings as part of routine clinical care. The debate over the merits and drawbacks of routine testing have come to the forefront in recent years following the decision of the United States Centres for Disease Control and Prevention (CDC) in 2006 to recommend routine HIV testing for adults, adolescents, and pregnant women. Due to the opt-out nature of the tests, patients are informed that they will be tested and then have the option to decline. Critics worry that it will discourage some individuals from seeking care, and that it will compromise the standards of obtaining informed consent and providing pre- and post-test counseling when conducting HIV testing.\textsuperscript{32} Routine HIV testing is currently not practiced in Canada. However, with the shift towards routine testing in the United States this practice has become a current issue for HIV testing in Canada.
5.0 Current Status of HIV Testing in Nova Scotia

5.1 Approaches to HIV Testing

Many approaches to HIV testing exist, including nominal, non-nominal, anonymous, and point of care rapid tests. The majority of HIV tests conducted are blood tests, however there are tests available in some jurisdictions using oral fluid or urine. Different approaches to testing are available in a variety of settings such as physicians’ offices, community health centres, sexual health centres, and sexually transmitted infection (STI) clinics throughout various jurisdictions in Canada. In Canada, physicians perform the majority of HIV tests.27

5.2 Distribution of HIV Testing Services in Nova Scotia

Today, nominal and non-nominal HIV testing are available in all provinces and territories in Canada,15 including Nova Scotia. The majority of these types are undertaken by family physicians. Anonymous testing is currently available in eight provinces in Canada.15 In Nova Scotia, anonymous testing has, to date, been available only in Halifax through the Halifax Sexual Health Centre and in Sydney through the AIDS Coalition of Cape Breton. The AIDS Coalition of Cape Breton does outreach to universities, Antigonish, Port Hawkesbury, and other communities upon request. The Halifax Sexual Health Centre has in the past done local outreach, and recently announced that anonymous testing services will be provided in Truro through an arrangement with the Northern AIDS Coalition, however, this service has not yet been implemented.

Another example of testing services in Canada is Manitoba, where only non-nominal testing was available until January of 2007, when nominal and anonymous testing were introduced.33 Since its introduction in January 2007, uptake of nominal testing has steadily grown, now representing more than 70% of HIV testing in Manitoba.33 There are currently two anonymous test sites in Manitoba and uptake has been fairly low.33 Whereas in Alberta, efforts are currently focusing on
nominal testing, rather than anonymous testing, by emphasizing to the public that nominal testing is a truly confidential service.33

5.3 Stakeholder Perceptions

5.3a Types and Location of Testing
Interviewees were asked if the current way in which testing was provided throughout Nova Scotia allows for access to the current three types of testing; nominal, non-nominal and anonymous. Some interviewees were not sure if access to all three types of testing exists. In the central region, one interviewee knew that anonymous testing was available but was unsure how nominal and non-nominal testing takes place. Overall, interviewees acknowledged that nominal and non-nominal testing are widely available, but that anonymous testing is not. They feel that testing is not evenly distributed and is not equitably available to those who do not have a family physician or face other barriers such as transportation.

5.3b Importance of Testing Options
Eighteen interviewees felt that it is valuable to employ a system of HIV testing that utilizes nominal, non-nominal and anonymous testing services. Many feel that it is important to provide options and choice to those who want or need to be tested because, as one interviewee put it, “one size does not fit all.” Offering a choice of tests is felt to increase the number of people tested. It offers anonymity to those who want it or allows a patient to share their information with their family physician if they are comfortable doing so. Choice, as viewed by interviewees, puts some degree of control in the patient’s hands.

5.3c Test Providers
Eighty percent of interviewees said they were uncertain or did not know who the main providers of HIV testing are in Nova Scotia. However, many of them provided their perception. Among three quarter of the interviewees, the perception is that family physicians are the main providers
of HIV testing in Nova Scotia. One interviewee pointed out that we know this to be true given that approximately 97% of HIV testing in Nova Scotia is nominal or non-nominal testing – tests which are ordered by family physicians. Almost half of the interviewees identified nurses (registered nurses, public health nurses, community health nurses or nurse practitioners) as providing most of the HIV testing in Nova Scotia. Two interviewees identified licensed practical nurses as providers of HIV testing.

5.3d Perceived Importance of HIV Testing to Providers

Almost half of the interviewees perceive that providers of HIV testing feel that HIV testing is not important. An additional five respondents either did not know or did not want to speculate on the importance that providers place on HIV testing. Three interviewees felt that providers of HIV testing feel that it is important and three others felt that the importance that providers place on HIV testing is mixed. It should be noted that these responses do not reflect the actual value or importance that providers of HIV testing place on the test. These responses are perceptions only and are limited to the interviewees’ knowledge of other providers’ practices. Some interviewees pointed out this limitation.

5.3e HIV Testing Guidelines: Perceived Extent of Their Application

Interviewees were asked whether or not the current way in which testing is provided in Nova Scotia allows for the consistent application of the guidelines of informed consent, confidentiality and pre and post test counseling. Over half of the interviewees feel that the way testing is currently provided in Nova Scotia does not allow for the consistent application of the guidelines for HIV testing. However, responses vary for each guideline. Generally, most interviewees feel that informed consent is most consistently obtained, that confidentiality is at times not being consistently applied, and that pre and post test counseling is the most problematic of the guidelines in terms of being consistently applied. Some key informants believe that some health professionals are not fully aware of what informed consent is, and, in the case of family
physicians, are often under time constraints to obtain fully informed consent. An additional one quarter of interviewees was either not sure or did not know if the guidelines are being consistently applied.

A number of barriers to the consistent application of the three testing guidelines were identified by interviewees. These barriers were largely related to the skills and capacity of health care providers, and included their lack of understanding of the guidelines (knowledge of or familiarity with the guidelines, their importance, ramifications of test results), lack of tools, resources and supports available to health care providers, lack of education regarding pre and post test counseling for at-risk patients, level of comfort and lack of experience with HIV testing. Other barriers to the consistent application of the guidelines identified by interviewees included lack of access to a regular family physician, and physicians’ lack of time available to consistently apply the guidelines. One interviewee suggested that alternative billing codes and/or payment methods may be necessary to support physicians in providing quality pre and post test counseling.

The literature supports many of the identified barriers to the application of the HIV testing guidelines. It acknowledges the lack of time on the part of physicians in primary care settings, especially with respect to counseling and the lack of resources required to obtain informed consent, a potentially resource-intensive process.\(^{11,12}\) The literature recognizes that physicians have not traditionally received training in counseling techniques and that additional training in this area would benefit HIV testing services.\(^{27}\)

Nineteen out of the twenty interviewees agreed that it is valuable to have an HIV testing system in place that requires informed consent, confidentiality and pre and post test counseling. They feel that the guidelines help to ensure consistency, uphold an individual’s human rights, are important from a legal and ethical point of view, are best practices, and give individuals some control, power and/or comfort over the process of HIV testing. It was pointed out, however, that the public needs to be made aware of the guidelines so that they know their rights and know what to expect and demand of HIV testing. One interviewee felt that these guidelines apply to all
medical testing, for example cholesterol testing, and that by specifying them for HIV testing, it perpetuates the stigma associated with HIV.
6.0 Barriers to HIV Testing

Many people who are HIV positive are unaware of their status and therefore could be unknowingly spreading the virus and missing opportunities for early treatment. For those who know they are at risk and want to be tested, there are also a number of barriers to accessing HIV testing. The literature further identifies certain populations who are at high risk and for whom efforts are or should be targeted to increase testing. These include Aboriginal people, those from HIV-endemic countries, people who use injection drugs, men who have sex with men, women, youth, and prison inmates.21

6.1 Populations Not Being Tested in Nova Scotia as Identified by Interviewees

Interviewees were asked if there are any particular populations who may be at risk of contracting HIV who are not accessing HIV testing services in Nova Scotia. A number of populations were identified, including people who use injection drugs, youth (including street involved youth, young women, and rural youth), people living in rural areas or small communities (including rural youth), Aboriginal people (living on reserve), female partners of men who have sex with men, men who have sex with men, African Canadians, immigrants, sex trade workers, people who have unprotected sex, people who are criminally involved, and those who are marginalized socio-economically and behaviourally including those affected by mental health issues, homelessness and addictions.

6.2 Barriers to Testing Identified in the Literature

The literature cites many barriers to HIV testing. These include:

- fear of adverse consequences;
- lack of expectation of benefit;
- lack of perception of HIV risk;
- cultural norm is not to test or is hostile to testing;
- test is not available;
- lack of privacy in counseling;
- lack of guarantees of confidentiality;
- cost;
- inconvenience – e.g. same day testing is not available;
- personal isolation; and
- lack of provision for testing couples or social support.\(^{24}\)

At the International Public Health Dialogue on HIV Testing and Counselling, a Public Health Agency of Canada research paper identified barriers to testing, many of which were the same as those cited above. This paper identified barriers as social or structural in nature and they included poverty, racial and gender inequality, the “sexual code of silence” in some societies, HIV related stigma and discrimination, misperceptions regarding one’s risk factors, social disruption caused by war and civil disorder, and lack of leadership or political will.\(^{20}\) Culture and language have been found to be barriers to HIV testing for pregnant women, where a greater proportion of immigrant women decline HIV testing.\(^{34}\)

Youth also face a number of barriers to HIV testing, some of which are similar to those already noted and others that are different. These include:

- Lack of availability of alternative new technologies such as rapid testing, requiring two separate visits to be tested and to receive test results. About 40% of youth do not return for test results.
- Lack of health care provider understanding of adolescent-specific consent and confidentiality. Youth often don’t feel that test results are confidential or will remain confidential.
• Health care providers are underutilized as promoters of HIV testing. Repeated encouragement by clinicians has been shown to increase HIV testing among youth.
• Lack of access to testing and care in youth friendly settings or settings where youth can easily be reached such as school-based clinics.
• The requirement for parental consent to HIV testing in some jurisdictions.25

It should be noted as well that young people knew less about certain aspects of HIV in 2003 than youth did in 1989.3 This lack of awareness is another barrier to testing. Youth who don’t know they are at risk, don’t know to seek testing.

It has been suggested in the literature that the single largest barrier to testing is the continued reliance on a single model of HIV counseling and testing, which has essentially remained unchanged since the mid 1980s and has prevented HIV testing from becoming a routine medical test.19

6.3 Barriers to Testing Identified By Interviewees

Interviewees were asked what they felt were the most significant barriers to accessing HIV testing in Nova Scotia. Their responses mirrored many of the barriers that were identified in the literature. Access to testing, which involves a number of components, was most often identified as a barrier. This involves a lack of testing sites, lack of knowledge about the location of existing sites, lack of knowledge of the testing options, and the inability to get to testing sites. People who do not have a regular physician or other health care provider are also faced with a lack of access to HIV testing. People’s lack of knowledge and understanding of the risk factors, and the knowledge that they, themselves, are at risk was the second most frequently identified barrier to accessing HIV testing. Stigma and fear of discrimination were the third most frequently identified barriers by key informants. Other barriers to accessing HIV testing identified by interviewees included confidentiality, personal attitudes (complacency), criminalization, and lack of normalization of HIV testing.
In the opinions of the interviewees, barriers for the perceived populations not being tested are similar to the barriers mentioned above. However, the frequency with which each was identified is different. The most commonly identified barrier to testing for populations perceived to be not being tested is stigma and discrimination. Lack of education and awareness that they are at risk and perceived lack of confidentiality are the second and third most commonly identified barriers by interviewees, respectively. Lack of access to a health care provider and health care services in general, complacency about testing, and lack of transportation to testing locations are also barriers to populations who are not being tested for HIV. Four interviewees specifically identified confidentiality and trust as the major barrier to accessing testing for the Aboriginal population. Confidentiality within small communities was also identified as a major barrier for the African Nova Scotian population.

6.4 Low Profile of HIV Issues is a Significant Barrier to Testing

6.4a Literature

In earlier years, especially the 1980s, HIV and AIDS were highly visible concerns within the context of public health issues at that time. As tests and treatments have become available, there are now concerns that people have become complacent about HIV and have abandoned, for instance, safer sex practices. Because treatments now exist, HIV is often considered a chronic disease. Today’s youth were not even born during the initial HIV/AIDS crisis of the 1980s, so an entire generation does not appreciate the potential personal and public health crises that could result from HIV and AIDS. The literature also identifies that the commitment to addressing HIV and AIDS in Canada has faded over time as other priorities have emerged. Interviewees were asked how we can make sure that HIV testing is recognized as a significant public health issue in Nova Scotia, given that there are limited resources within the health care system and that there are competing priorities for these limited resources, and how HIV should be positioned to ensure it gets adequate funding for testing services. Many interviewees found these difficult questions to answer.
6.4b Interviewees

Consistent themes emerged from the interviews in terms of the challenges that HIV faces in relation to being recognized as a significant public health issue. Some of these themes reflected those that emerged from the literature. A number of interviewees commented that because modern treatments for HIV and AIDS are effective, HIV and AIDS are now seen as chronic diseases, like diabetes and cancer, as compared to the death sentence that they once were. This means that they compete with other diseases for both public profile and funding.

“We have 67,000 infected people in Canada. We never need to justify resources for cancer or diabetes. There is no stigma or discrimination associated with those diseases.”

Several interviewees also commented that there is now “complacency” toward HIV and that it needs to be seen as something that affects the community, not just the individual because it influences everyone.

“It doesn’t have the ‘sexiness’ it had before. We talk about it now like it’s a chronic disease.”

“It’s not the top story like it was in the 80’s, but it gets a little momentum now and again.”

“It is seen as a chronic disease with different outcomes now. It is under resourced because we don’t see it as the big deal that it was.”

This low profile of HIV in general is a significant barrier to HIV testing in Nova Scotia. If public health decision-makers are not aware of the importance of the issue, little or no effort will be expended to address the issue. If the public is not aware of the importance of HIV, people who are at risk will not realize it, and will not seek testing.
7.0 Potential Opportunities for Increasing HIV Testing

Among middle and high income countries it is common that HIV testing policies and standards support voluntary counseling and testing. Often, testing is targeted to high risk populations and is made available to people in high risk settings such as medical settings. However, many countries are reviewing their policies and approaches to testing in order to increase the number of people aware of their HIV status. In some countries, initiatives to increase HIV testing are the primary strategy in the effort to fight HIV. This section explores some of the options to increase testing that have been suggested by interviewees and in the literature.

Interviewees were asked for their opinions about the best ways to increase HIV testing among people who may be at risk in Nova Scotia. The most commonly identified strategy to increase HIV testing was to increase awareness of HIV among the public and health care providers. Outreach testing and making HIV testing part of regular screening (for example pap screening, immunizations or diabetes screening for Aboriginal people) or linking it to other services were the next most frequently identified suggestions for increasing testing. Other suggestions included providing POCR testing, asking populations most at risk what would work for them, social marketing, incentives (pay) to be tested, increasing the number of test sites in rural areas, creating networks of drop in centres, and providing evening hours at clinics. Interviewees appear to see a role for Public Health in increasing HIV testing by working with physicians to promote anonymous testing and by providing education about HIV prevention. Most of these suggestions are explored in greater detail throughout the remainder of this section.

7.1 Opportunity: Increase the Profile of HIV Issues in Nova Scotia Among Public Health Decision Makers

The current low profile of HIV issues among public health decision makers is an important barrier to overcome in order to ensure adequate resources are allocated to efforts to increase HIV testing. Interviewees named this as an important step in increasing HIV testing. Interviewees
suggested positioning HIV as a significant public health issue by sharing evidence such as statistics of prevalence and incidence and cost information with the public and government decision makers. It was noted that if the public and decision makers knew the individual cost (health challenges, barriers and inconveniences to having a normal active lifestyle, impact on relationships, family, and others) and the cost of treating HIV in the health care system (hospital stays, medications, lab services, etc.), they would be more willing to invest in the prevention of HIV.

“Politicians need to be on board with this. They need to understand the impact on the health care system. This could get out of hand really quickly. It has elsewhere.”

“If you want to double the problem, turn your back on it. That’s the perfect quote for HIV. If we want to continue to ignore this public health issue, it will become so overwhelming we won’t be able to deal with the consequences.”

“It should be considered as important an issue as smoking. You always see smoking campaigns.”

It was also suggested that linking HIV to other diseases that already have higher profiles could be beneficial. A few interviewees pointed out that HIV and AIDS are diseases of the immune system, so people who have HIV and AIDS often end up getting other diseases and illnesses (such as cancer and diabetes) that have a higher profile than HIV and AIDS. It was suggested that statistics regarding how many people that die with these diseases and also have HIV should be made available. Linking HIV to these other types of diseases and deaths was proposed as a strategy to increase its profile and potentially garner additional funding.

“Keep talking about it, like breast cancer. Pink is everywhere. If only people would pay this kind of attention to it. We don’t get half the awareness.”
7.2 Opportunity: Social Marketing to Promote HIV Testing

Social marketing is "the application of marketing technologies developed in the commercial sector to the solution of social problems where the bottom line is behaviour change. It involves the analysis, planning, execution and evaluation of programs designed to influence the voluntary behaviour of target audiences to improve their personal welfare and that of society." Social marketing is the adaptation of commercial marketing techniques to social goals. It can be applied to health, education, the environment, the economy and issues such as violence, racism and human rights. Health promotion social marketing combines the ideologies and strategies of commercial marketing and behaviour change theory. Social marketing is an integrated part of the health promotion strategies of federal and provincial governments and has been used to deliver messages about smoking cessation, fetal alcohol syndrome, sudden infant death syndrome, Aboriginal diabetes and HIV/AIDS.

Social marketing in the health field is designed to help individuals make decisions related to maintaining and improving their health and well-being and that of their families and communities. It combines the best elements of the traditional approaches to social change in an integrated planning and action framework, and utilizes advances in communication technology and marketing skills. It uses marketing techniques to generate discussion and promote information, attitudes, values and behaviours. Most importantly, it helps to create a climate conducive to social and behavioural change. Social marketing related to HIV and AIDS has been used and evaluated in a number of countries, the best of which have resulted in increased HIV testing. Social marketing is also seen by UNAIDS to be an effective, cost efficient tool in limiting the spread of HIV/AIDS.

Social marketing does however have its challenges, including the fact that it needs to be coordinated with the availability of accessible services including testing, counseling, prevention and linkage to care and treatment, and that it needs to be sustained for a period of time to be effective. If successful, a social marketing campaign will increase demand for testing meaning...
that providers of HIV testing need to be adequately resourced to meet the demand. In the case of youth, more media and computer related modalities to prepare them for testing are suggested due to youth’s familiarity with these tools.25

**Stakeholders Perceptions About Social Marketing**

Sixteen interviewees indicated that a social marketing or public education campaign would be beneficial in increasing the uptake of HIV testing services in Nova Scotia. Two main “themes” for social marketing and public education emerged from the interviews. Some interviewees suggested concurrent campaigns with two foci. One on general education and awareness to remind people of the risks of HIV, that HIV exists in Nova Scotia, and how they can access testing, the aim of which would be to normalize HIV testing. The other focus would be targeted to specific at-risk populations, the aim of which would be to encourage and increase testing.

“The target population has changed. It used to be gay men, but it goes beyond this now. We need social marketing and public education that reflects other segments of the population.”

It was noted by a few interviewees that there is no point to investing in social marketing and/or public education if equitable and adequate testing services are not available throughout the province. It was suggested by one interviewee that typical social marketing has the greatest impact on low risk people, and doesn’t reach high risk groups so it may not be of much help in increasing the uptake of HIV testing. Several noted that social marketing and/or public education could help reduce the stigma associated with HIV and HIV testing. One interviewee did not support the notion of a social marketing or public education campaign stating that a typical social marketing campaign would not be beneficial and that awareness-raising needs to specifically target at-risk populations.

Eighteen interviewees indicated that it would be a useful investment of resources to proceed with a social marketing campaign. However, it is not clear if their responses referred to social
marketing, public education, or both. It was also not clear that all interviewees have the same understanding or interpretation of what social marketing and public education are. One interviewee pointed out that social marketing and public education are not the same thing and that a social marketing campaign would only be useful if it included more than public education alone. Another asked what was meant by public education but indicated that social marketing would be more effective.

“...It would certainly stimulate discussion. Nova Scotia is such a conservative province. Can you just imagine what would happen if Rodney MacDonald started talking about HIV testing? There might be a negative reaction, but it would be a reaction.”

Example Social Marketing Campaigns

“The Bronx Knows” is an example of a social marketing campaign undertaken by the New York City Department of Health and Hygiene. The campaign is aimed at every citizen that lives in the Bronx between the ages of 18 and 64, and encourages every person to get an HIV test. All social marketing materials provide information about why people should be tested and where to get an HIV test. In preparation for the campaign, the Department of Health and Hygiene worked collaboratively with doctors, community health clinics, hospitals, community organizations and correctional facilities to identify multiple testing sites, organized by neighborhoods within the Bronx. Social marketing materials include print and web-based materials. People are encouraged to find a testing site convenient to them by using the online directory, calling 311 for assistance in locating a site, or text messaging their zip code to have the nearest testing site texted to their phone. An evaluation of this initiative has not yet been published.39

The Balm In Gilead Inc. is a not-for-profit, non-governmental organization whose mission is to improve the health status of African American people by building the capacity of faith communities to address life-threatening diseases, particularly HIV/AIDS. One of the initiatives of the organization is “Our Church Lights the Way,” a social marketing campaign developed in partnership with the Centers for Disease Control. The purpose of the campaign is to encourage
African Americans to seek HIV testing and know their HIV status. The campaign consists of public service announcements and a resource kit for faith-based organizations to promote testing within their congregations on an ongoing basis and through specific events. Their goal for 2008 is to have 10,000 people tested for HIV during events hosted by faith organizations.\(^{40}\)

Another example of a social marketing campaign is the National HIV Testing Mobilization Campaign in the United States, a big component of which is National HIV Testing Day that happens every June 27. On that day events such as health fairs, community and media outreach, special testing-related events and extended hours are held to bring attention to and increase awareness about HIV and provide opportunities for testing. The annual event is produced by the CDC and the National Association of People with AIDS (NAPWA-US). During National HIV Testing Day, NAPWA-US works with communities to reduce AIDS social stigma through public messages and culturally appropriate education materials.\(^{41}\) When the CDC studied the impact of National HIV Testing Day on the number of HIV tests conducted, they found that from 1995 to 1998, the number of tests conducted during the week of National HIV Testing Day was higher than the preceding week. In addition, each year, the number of positive HIV tests was higher the week of National HIV Testing Day than the week before testing day.\(^{42}\)

In addition to National HIV Testing Day, the National HIV Testing Mobilization Campaign promotes local, community level discussions about HIV-related stigma and risk factors and works to increase the number of people tested. Print materials about HIV and HIV testing targeted to different audiences are made available to organizations free of charge, as are public service announcements. According to the Campaign website:

“The Campaign brings ‘get tested for HIV’ messages to new audiences. These include civic groups, faith communities, businesses, organizations, and individuals that typically do not talk about health issues, especially HIV prevention. The Campaign is mobilizing old and new partners to get the word out to their members and constituents. The
Campaign is sending speakers and materials to events and activities across the United States, including trade shows, conventions, conferences, and festivals. By speaking out and distributing information at these events, the Campaign is spreading the word that all sexually active Americans need to be tested for HIV. **43**

**7.3 Opportunity: Expand Anonymous Testing**

Nova Scotia currently offers anonymous testing in two locations that also provide outreach services, with Truro to be added as an outreach location in the near future. One opportunity for increasing testing is to expand the availability of anonymous testing thought the province.

There are a number of benefits associated with anonymous testing. It encourages people, particularly those at greatest risk, to be tested because fears of breaches of confidentiality are addressed. People who undergo anonymous testing are also afforded all the benefits associated with “best practice” pre and post test counseling. Research that took place over seven states found that people who accessed anonymous testing accessed testing and medical care services earlier than those who used confidential testing programs.**10** Many of the concerns associated with anonymous testing, including that it prevents the collection of important epidemiological data, compromises partner notification and is expensive, have been refuted.**18** Some suggest that anonymous testing is redundant because as soon as an HIV positive person seeks treatment, their anonymity is lost. However, stigma and discrimination related to HIV are still pervasive in Canada and for this reason there is a place for anonymous testing.**18**

**Stakeholder Perceptions About Anonymous Testing**

Most key stakeholder interviewees feel that it is very important to have anonymous testing available across all regions of Nova Scotia. Interviewees from the central and eastern regions of the province, where anonymous testing is available, all see the availability of anonymous testing as very important or extremely important to their area. In the northern region, where anonymous
testing services have very recently been announced as forthcoming, interviewees also see it as important. In the western region, where anonymous testing is not currently availability, its availability is seen as very important. Almost all of the interviewees who provided a provincial perspective agreed that the availability of anonymous testing in all regions of the province is very important. Anonymous testing is seen as providing protection from stigma and the lack of confidentiality, real or perceived, in rural and small communities. Interviewees feel that protection from stigma will translate into an increase in the number of people being tested, knowing their HIV status, and being able to take appropriate action to not spread the virus.

All interviewees view anonymous outreach services as very important or extremely important, largely because of either the rural nature of their region or because outreach provides access for those at-risk individuals who would otherwise not access testing. Anonymous outreach testing services are seen as important to interviewees in the western region. However, providing anonymous outreach testing services over a predominantly rural geographic area was identified as a possible barrier to feasibility in this area. Those interviewees who provided a provincial perspective on HIV testing all indicated that anonymous outreach testing is very important. Anonymous outreach services are not currently available in most parts of Nova Scotia.

“We forget that anonymous testing allows us access to those who are at risk. This is an opportunity to have a conversation about risk, assess their HIV status and move them quickly into treatment and care sooner rather than later, if they are positive.”

**Example of a Recent Expansion of Anonymous Testing**

Because many people do not get tested due to the stigma associated with HIV, the Ontario government has expanded its anonymous testing service to 50 sites across the province. Rapid tests are available at these sites as well. The expanded service is supported by a campaign called *Say Yes To Knowing*, the aim of which is to raise awareness among select target populations. These are gay and bi-sexual men, African Caribbean Ontarians, Aboriginals and people who use injection drugs. The campaign involves using posters (for example in restaurants, bars and
testing sites), local media and a 30 second Cineplex advertisement. Campaign strategies are currently being developed for women in the latter three groups and women who undertake risky behaviors with all four target groups. Funding for the campaign, which is one of the three strategies of Ontario’s AIDS Strategy, was provided by the Ministry of Health and Long Term Care, however specifics regarding the cost of the campaign were not available at the time of preparing this report.44

7.4 Opportunity: Point of Care Rapid Testing

Background

The literature cites a number of advantages or benefits associated with POCR testing. This approach provides test results quickly so that results are known to the person being tested during the same visit in which they were tested. This eliminates the need for the person to return at a later date to receive test results, decreases anxiety related to waiting for test results, and results in an increase in overall patient satisfaction.1, 10, 18, 45, 46 UNAIDS/WHO encourage the use of POCR tests for these reasons and so that post-test counseling can be provided immediately.20

The Canadian HIV/AIDS Legal Network also points out that POCR testing can improve access to HIV screening, and that rapid screening kits are easier and safer to administer than conventional HIV tests. POCR testing increases the number of people who receive test results and increases access to hard-to-reach populations including people who use injection drugs and people visiting STI clinics.18, 45-47 POCR testing is useful in a variety of settings (rural and remote settings, medical and non-medical settings) and allows for timely access to HIV preventive treatment for women in labour and health care workers after needle-stick injuries.46, 47

POCR testing also has the potential to decrease costs in part because there is no need for follow up visits for negative tests, which saves costs in terms of client transportation, the time of clients, health professionals and clinic administration.46, 48

The 2000 Canadian Strategy on HIV/AIDS identifies many of the above noted advantages of POCR testing. It also notes that people’s autonomy is enhanced by providing a choice between
conventional and rapid testing, and increasing the acceptance of HIV testing as additional advantages of rapid testing. The Strategy, however, qualifies these advantages. It notes that anxiety is often reduced only for those who receive a negative test result because reactive (positive) results must be followed up with a confirmatory blood test. Anxiety during the waiting period of a follow up test in rural and remote areas where test results could take longer and less support for the person during this waiting period may be available, could be significant.18

Patients failing to return for a follow-up required confirmatory HIV test remains a challenge for POCR testing.18, 46 There are a number of other disadvantages associated with POCR testing as well. These are largely related to quality assurance, counseling and consent. POCR testing requires that the specimen is collected by the same person who performs the test. This person must be adequately trained and resourced to ensure proper administration of the test.1 There are concerns that the counseling associated with POCR testing is not adequate.18 POCR counseling must be modified from standard or conventional counseling due to the immediate availability of the test results.1 Health care providers may be hesitant about their ability to properly support the person who receives a preliminary reactive result at the time of the test, and concerned about delivering a preliminary reactive result when a significant number of false-positives will occur if the test is taken during sero-conversion.18, 46 They may also find it difficult, along with the regular counseling, to inform people with a reactive result that upon confirmation of a positive result there are legal implications associated with their status; the law requires them to inform all partners of their status regardless of whether or not transmission occurs.1

There may also be challenges related to providing adequate counseling in certain settings, such as the primary care setting where patient visits are often brief and lack of time may impact on the quality of counseling delivered. In this situation, alternative supports or methods of counseling may be required.46 POCR testing also presents concerns around consent. “Informed consent is a process of communication that enables a person to make a reasonable and informed decision. Consent is always contextual. To be truly informed, consent requires full awareness of all
relevant information – and to be true counseling, the process requires substantively more than mere delivery of information, as important as this may be.”1 This definition of informed consent and its nuances explains why there is general concern around informed consent for not only anyone undertaking POCR testing, but also women in labour who may not have the opportunity to be fully and properly informed.18

**Stakeholder Perceptions About POCR Testing**

Approximately two thirds of interviewees feel that POCR testing should be available in Nova Scotia. However, many of these provided qualified or cautious support. Many of these cautions related to concerns and limitations that were identified in the literature. Some who support the notion of POCR testing are concerned about the accuracy of the test and would be more confident in it if they could see more evidence to support it. The literature, however, has shown that the sensitivity and specificity of rapid tests are similar to those of standard HIV tests.48 Others feel it should be available, but would need to be reassured that the three HIV testing guidelines (informed consent, confidentiality and pre and post test counseling) are applicable to POCR as they are to standard testing. Interviewees indicated that POCR testing would meet an unmet need for testing among transient populations including Aboriginal people, youth, people who are homeless or who are experiencing drug or alcohol addictions or mental illness, people who inject drugs, those who are too anxious to wait for test results, and those who face transportation issues. It was also pointed out by more than one interviewee that, for anyone, the decision to be tested is a big one and that POCR testing is an important way to avoid delay in receiving test results and increase the probability that those people will proceed with testing.

"*Once a person builds up enough courage to ask for the test, you don’t want them to have to wait or go elsewhere, which is a deterrent.*"

Five interviewees were not sure whether or not POCR testing should be available in Nova Scotia. The reasons they cited were similar to the cautions noted above and because they had concerns that the test would be similar to an at-home pregnancy test, which does not benefit from pre or
post test counseling. There were also concerns that if POCR testing is undertaken too soon (during the sero-conversion period), this may result in inaccurate results in the short term and lead to a person not being tested after the period of sero-conversion, when there is a much better chance of accuracy. Two interviewees did not support the introduction of POCR testing in Nova Scotia; one based on lack of knowledge about the accuracy of POCR testing, the other based on feelings that POCR could contribute to a false sense of security when and if a person is tested within the HIV latency or sero-conversion period.

Cost Effectiveness
Several studies on United States populations have shown that POCR testing is more cost-effective than standard HIV testing. One study compared the economic costs associated with standard HIV testing, a one-step POCR test and a two-step POCR test, where one-step rapid testing involved multiple rapid tests on the same day so that clients could receive either positive or negative test results on that day. The two-step rapid testing also involved multiple rapid tests on the same day. If the rapid test was negative, the client was given that result. However, if multiple rapid tests pointed to a reactive or positive result, the client had to return two weeks later for the final results after a confirmatory blood test. This study found that the one-step POCR test was generally the least expensive of the three types of tests and the two-step rapid test was the most expensive.

Examples of POCR Testing
POCR testing is not consistently available across Canada. It is currently being introduced in a phased approach in Manitoba. Phase one began in March 2008 in a community health clinic in Winnipeg. This clinic has long been considered the province’s primary site for HIV tests, and as such, has solid expertise in the field of HIV testing. Phase two will see the implementation of POCR testing in the province’s main tertiary care centre by the fall of 2008. The goal of this phase of implementation is to provide testing to pregnant women who have either not been tested yet or were tested earlier in their pregnancy but whose status may have changed. Phase three, targeted for the spring of 2009, will involve implementation in the emergency department of the
tertiary facility for situations where an HIV diagnosis could affect treatment. These three POCR settings are recognized by the Centres for Disease Control Morbidity and Mortality Weekly Report as relevant settings for POCR testing.33

In Ontario, POCR testing was very recently introduced in 50 anonymous testing sites, which include 22 public health units, 16 community health centres, 4 midwifery practices, 3 sexual health centres and 5 other locations (hospitals and agencies). POCR testing was also introduced in an additional 10 organizations (for a total of 60 POCR test sites) across the province where gaps in HIV testing services exist. The rationale behind developing and implementing a provincial POCR test program is based on a number of factors, including the stress associated with the long wait period for standard test results, it increases access to HIV testing, it is efficient in terms of not requiring a second visit for the person being tested, which in turn saves resources from the service delivery perspective, and that people in Ontario want POCR testing. While family physicians do conduct approximately 80% of HIV testing in Ontario, they do not use POCR testing because of the time and cost of test kits (which they can not pass on to the patient) associated with POCR testing.44

In New York City, the Gozala initiative is providing POCR testing throughout the city. Combined with a strong publicity campaign that encourages New Yorkers to get an HIV test, the Gozala initiative has three mobile units staffed with health professionals that provide POCR testing at events throughout the city such as health fairs and block parties as well as providing street outreach. The initiative also conducts HIV testing events in partnership with other organizations, such as churches and community organizations.49

In 2007, bioLytical Laboratories, the developer of an HIV rapid test approved for use in Canada, partnered with other organizations to provide a mobile testing service in Montreal and Toronto. The success of the initiative is unknown.50
7.5 Opportunity: Routine Testing

Routine testing has been suggested as a means to increase the number of people aware of their HIV status and able to respond with further prevention and/or treatment. In 2006, the United States Centers for Disease Control and Prevention (CDC) updated their recommendations around HIV testing for adults, adolescents and pregnant women. The guidelines now include diagnostic HIV testing (performing HIV tests for persons with signs or symptoms consistent with HIV) and opt-out HIV screening (performing screening after notifying the patient that the test will be performed and the patient may elect to decline or defer the test) as a part of routine clinical care in all healthcare settings. The new guidelines maintain the patient’s option to decline HIV testing and recommend annual screening for those at high risk. The voluntary and consent aspects of testing, routine nature of testing for persons attending STI clinics, and access to care, counseling, and support for HIV positive people remain unchanged from previous CDC recommendations. The CDC and others who support the notion of making HIV testing a routine screening argue that HIV infection meets all of the generally accepted criteria that other conditions meet to justify routine screening. The ability of the person to opt-out maintains the voluntary nature of the testing and the other components of the testing (consent, confidentiality and counseling, whether streamlined or not) are maintained as well. One study that looked at five years of data from the National Health Interview Surveys has shown that nearly half of HIV tests take place as part of medical check ups or prenatal care. This suggests that policy initiatives to integrate testing into routine medical care have had some success. However, there are ethical and feasibility concerns regarding routine testing, including the possibility of false positives, the implications of testing without pre test counseling, concerns that it might discourage high risk people from seeking care, and that it could eventually become mandatory. Routine testing has however been found to be more cost-effective than regular or conventional HIV testing and counseling, even in areas of low prevalence.

There is little literature available about Canadian policy perspectives on routine testing, however, the Canadian Medical Association has explicitly stated that it does not support routine testing.
The Canadian HIV/AIDS Legal Network also cautions against routine testing in the absence of evidence about the potential harms of testing without informed consent or counseling.52

**Routine Testing in Specific Settings: Emergency Departments**

Emergency departments (EDs) are a common source of medical services for low-income populations, people with limited access to health care, and others who are also at high risk for HIV infection.53, 54 EDs are therefore perhaps an obvious setting in which to identify persons with HIV. Despite 2001 CDC guidelines that recommended routine opt-in HIV testing for EDs in areas with a prevalence rate greater than 1 in 1000 discharges, many EDs in the United States failed to implement the guidelines consistently.53-55

Some of the barriers to implementing HIV testing in EDs that have been identified in the literature include lack of resources, time pressures, a lack of formal structure to facilitate HIV testing, and lack of motivation in areas of lower prevalence; also, in areas of lower prevalence, the cost per case of identifying positive cases is higher than in areas where prevalence is higher.11, 55 Similar to a general community setting, having to return to the ED for the HIV test result is a barrier to testing.11 Some of the benefits of performing routine HIV testing in the ED setting include that it helps to identify persons at risk of infection, provides opportunities for health care providers to assess risk behaviour, discuss the benefits of testing, provide prevention counseling, and refer for treatment and care where required.54 However, the benefits of HIV testing in the ED may not be fully realized if patients who test positive are not provided with follow-up care.55

The CDC published the preliminary results of the integration of rapid HIV testing into three EDs that took place between January 2005 and March of 2006. Two of the EDs used HIV counselors to increase HIV testing in their EDs and the other added the responsibility of HIV screening to existing ED triage nurses. This study found that the counselor based approach enabled in-depth assessment of risk and discussion of prevention (higher acceptance), but limited the number of patients who could be tested. The existing staff approach enabled more testing but resulted in
lower acceptance. Overall, 1% (97) of the ED patients considered in the study were found to be HIV positive and 88% (85) of these newly diagnosed patients were linked with HIV care and treatment, thus the researchers concluded that EDs should consider integrating rapid HIV testing into their routine medical services. 

In an effort to increase HIV testing and identify as many as possible of the approximately 40,000 Americans who are HIV positive but do not know their HIV status, the CDC further revised its guidelines for HIV testing in September of 2006. Specifically, the guidelines now recommend that EDs perform routine opt-out screening for HIV for all ED patients. Routine opt-out HIV screening in EDs has since been found to be feasible and subsequent studies have identified a number of opportunities for EDs to improve their rates of offering, accepting, conducting testing, and linking HIV patients to care when moving to implementation. Any sustainable organizational change requires administrative support at the highest levels, written and broadly known procedures for implementation, staff training and continuous quality improvement procedures. Implementation of HIV testing in EDs, also requires funding to sustain implementation.

**Routine Testing in Specific Settings: Prenatal Care**

Women of reproductive age in Canada and around the world are making up an increasing proportion of new HIV positive cases and pregnancy brings with it additional considerations as it relates to HIV testing. Prior to the early 1990s, little was known about HIV and pregnancy. In 1994, when it was discovered that mother to infant transmission could be significantly reduced with the use of certain medications, the debate about testing pregnant women began.

Prenatal HIV testing policies and practices vary among Canadian provinces and territories and other international jurisdictions. In 2006, British Columbia and Ontario provided routine opt-in testing, meaning that women must agree to an offer of testing. The United Kingdom, Sweden, and the provinces of Newfoundland and Alberta use opt-out models for routine prenatal HIV testing, which is essentially routine testing with the right to decline. The US CDC have also set
routine opt-out testing as the standard within the United States. In Australia, only pregnant women with identified risk factors are offered HIV testing.²⁰, ⁵⁸

In Nova Scotia, the current guidelines for HIV testing of pregnant women recommend an opt-in approach where patients are counseled and consent to the testing.⁵⁹, ⁶⁰ However, these guidelines are not applied consistently across the province, and when they are applied they have been found to be inadequate.⁶⁰ As a result, the Nova Scotia Advisory Commission on AIDS and a number of partners, including the Reproductive Care Program of Nova Scotia, conducted research to develop a social marketing campaign aimed at increasing prenatal screening for HIV throughout Nova Scotia. The results of the focus group testing used to inform the social marketing campaign demonstrated high levels of acceptance of prenatal HIV testing among Nova Scotian women, but low levels of HIV/AIDS awareness. Additionally, research showed low compliance with HIV testing guidelines by healthcare professionals.⁶¹ As a result, implementation of these recommendations has been deferred until the findings and recommendations of this report are complete, at which time, they will be reconsidered within the context of improving overall HIV testing across Nova Scotia.

7.6 Opportunity: Strengthening Health Providers’ Capacity

Half of the key stakeholder interviewees feel that health care professionals are, in some way, not meeting the current guidelines for informed consent, confidentiality and pre and post test counseling. Some interviewees feel that providers are meeting some of the guidelines and not others. In these cases many feel that informed consent is being provided but that confidentiality and especially counseling are not. Confidentiality is seen as an issue in small communities and lack of consistency in the application or delivery of counseling is also a concern. Other interviewees do not know whether or not providers are meeting the guidelines.

The most commonly cited suggestion for improving health professionals’ compliance with the guidelines was education, training and/or awareness, either through their formal medical
education or refresher and continuing education. Three interviewees indicated that compliance could be increased by having providers other than physicians conduct the testing and counseling. Tools, such as wallet cards that have prompts for the guidelines, were also suggested as a way to improve compliance. One interviewee suggested that along with increased education, providers may need to be remunerated differently to assist them in meeting the guidelines.

7.7 Opportunity: Improving Uptake of the Standards for Blood Borne Pathogens

The Standards for Blood Borne Pathogens Prevention Services in Nova Scotia were developed through a collaborative working group process with a range of stakeholders from the community, health care professionals, District Health Authorities, and others. They have been in place since May of 2004. The goals of the Standards are to:

1. prevent or reduce the harms associated with risk behaviours leading to blood borne pathogen infection;
2. increase access to programs and services that will reduce the harms associated with blood borne pathogens for all Nova Scotians, especially those at risk; and
3. reduce the vulnerability to blood borne pathogen infections among Nova Scotians by addressing the determinants of health.

The Standards for Blood Borne Pathogens Prevention Services in Nova Scotia are now a shared responsibility of the Department of Health and the Department of Health Promotion and Protection.

Stakeholder Perceptions About the Standards

Interviewees were asked if they believe the Standards for Blood Borne Pathogens Prevention Services are helpful in supporting HIV testing in Nova Scotia. Six out of the 20 interviewees indicated that the Standards are helpful. Many believe they provide a good framework for the
application of the Standards. An equal number of interviewees indicated that they don’t know if
the Standards are helpful because they are not familiar with them.

“I don’t know anything about them. That’s strange.”

Four interviewees said the Standards are both helpful and not helpful in supporting HIV testing:
helpful if people know about them, not helpful if they do not know about them. The remaining
four interviewees do not feel the Standards are helpful in supporting HIV testing in Nova Scotia,
most often citing that people do not know about the Standards or that they are simply not being
adopted. Many of the interviewees indicated that the Standards need to be implemented.

“The development involved people with expertise, but the resources to mobilize the
Standards have never been allocated. They are a phenomenal tool, but they need to go
the next step. If we put it off much longer, we’ll need new Standards.”

7.8 Other Potential Opportunities to Increase Testing

Other proposed interventions for increasing HIV testing identified in the literature include
offering testing with social support to couples and ensuring privacy of testing and confidentiality
of results.24 A number of jurisdictions have implemented different approaches to increasing
testing, however, evaluation results do not appear to have been published yet.

One approach to increasing HIV testing that is being used in other jurisdictions is to integrate
HIV testing into other health services such as sexual and reproductive health (SRH) services,
lesbian gay bisexual and transgender (LGBT) health services, and ethnically/culturally specific
health services. The literature cites many benefits and challenges to integrating HIV testing
within other health services. Some of the benefits include that integration creates opportunities
to reach a wide variety of people, and makes it easier for some individuals to seek out testing. In
addition, given their shared aims, the cost of establishing testing services within another service
are often reduced. Some of the challenges associated with integrating HIV testing within other health services include the need for additional financial and human resources to support adequately skilled staff and the real or perceived reduction in privacy associated with integration.62

Many of the strategies for increasing HIV testing described in this report are proposed without specifying if they are applicable to adults, youth, or both. However, there is literature that identifies specific strategies for increasing testing among adolescents. Video-tapes in waiting rooms, street outreach, small group intervention for pre-test counseling and social marketing are all reported to be effective in increasing HIV testing among adolescents. Community-level social marketing needs to be aimed specifically at youth and sustained for a period of time to be effective.25 The language, settings, facilitators and guidelines for testing must be tailored to adolescents’ developmental characteristics to be successful in increasing HIV testing among youth.25
8.0 Summary of the Findings

A number of clear messages have emerged from the literature and from the interviews with Nova Scotia stakeholders:

- HIV testing is an important public health issue that needs ongoing attention. The importance of this issue has been recognized in other jurisdictions within Canada and the United States, as evidenced by the resources that have recently been allocated to increasing the number of people who seek testing.

- HIV issues in general, and HIV testing in particular, has a very low profile in Nova Scotia. The key informants contacted to participate in interviews for this report were selected as representative of the people who would be most knowledgeable about HIV testing in Nova Scotia. Many interviewees stated that they had little knowledge of HIV testing and two key informants declined to participate in the interview citing lack of knowledge. The experience of conducting the interviews is a serious reminder about how low on the priority list HIV has become on the public health agenda in Nova Scotia.

- The Standards for Blood Borne Pathogens Prevention Services in Nova Scotia have not been implemented consistently across Nova Scotia. Despite a significant investment of resources and expertise to create the Standards based on best practices, attention and resources have not been dedicated to the implementation and monitoring of the Standards. Some of the key informants interviewed for this report were not even familiar with the Standards.

- Although the current model of offering three types of testing in Nova Scotia (nominal, non-nominal, and anonymous) is valued among stakeholders, it is clear the current implementation of this model is not effective in making HIV testing equitably accessible to all Nova Scotians, particularly those who may be most at risk for HIV.

- There is support for doing things differently. One of the first steps in making a significant change is ensuring that there is readiness for change. Based on the key informant interviews, it appears that there may be willingness to try a new approach to HIV testing in Nova Scotia.
• While there have been recent efforts in other jurisdictions to increase the number of people tested, there is not a strong body of evidence pointing to one approach over another. This suggests, as does the advice of the key informants, that several different strategies may need to be tried in order to increase testing. Nova Scotia has an opportunity to try and evaluate new approaches, and contribute to the body of knowledge about effective strategies.

• Key informants were clear that one approach will not work with all communities, and that communities must be engaged in finding solutions that work for them.
9.0 Action Steps To Increasing HIV Testing in Nova Scotia

This section presents a recommended approach for increasing HIV testing in Nova Scotia, as well as addressing the broader issue of preventing blood borne pathogen infection. Although the information is presented in a series of action steps for ease of reading, some of the activities may need to happen concurrently. Cost estimates to implement the action steps outlined below are contained in Appendix One.

**Step 1: Recommite to HIV Testing as a Public Health Priority**

In 2004, public policy makers in Nova Scotia recognized the importance of improving and standardizing public health services related to blood borne pathogens, including HIV. Public health and addictions services practitioners as well as community based organizations invested a significant amount of time and resources into the development of the Standards for Blood Borne Pathogens Prevention Services in Nova Scotia. The Standards recognize the critical importance of testing for HIV and other blood borne pathogens by dedicating an entire section of the standard to this topic. The first standard in the Counseling, Testing and Referral Section is:

> “District Health Authorities provide or facilitate access to counseling, testing and referral services for blood borne pathogens including:
>  
>  - Nominal hepatitis B and hepatitis C testing
>  
>  - Nominal, non-nominal and anonymous HIV testing.”

Since the Standards were published 4 years ago, there has been little effort at either a provincial or District Health Authority level to implement this Standard, or indeed, most of the Standards. This is not surprising given the low profile of HIV issues in the province.

**Action**

The first step in increasing HIV testing in Nova Scotia needs to be a renewed commitment on the part of the Department of Health, the Department of Health Promotion and Protection, and the
District Health Authorities to a phased in but complete implementation of the Standards for Blood Borne Pathogens Prevention Services. The Standard listed above about access to counseling, testing and referral should be a priority for implementation. A commitment of financial and human resources is required to implement the remaining actions steps below.

**Step 2: Ensure Provincial Leadership**

Again drawing upon the past success of health promotion efforts to reduce tobacco, an important key to successful implementation of the Standards for Blood Borne Pathogens Prevention Services will be strong provincial leadership that can support Coordinators in the Districts and work to provide the appropriate resources for the expansion of HIV testing options. Clear accountability for implementation of the Standards for Blood Borne Pathogens Prevention Services must be assigned to a dedicated person within Public Health that is given sufficient time within the context of their workload to provide adequate attention to the Blood Borne Pathogens file. This individual should be accountable for provincial initiatives, such as the social marketing campaign, supporting the development of a community of practice for the Blood Borne Pathogens Coordinators that enables provincial sharing of information and professional development for the Coordinators, developing and pilot testing new approaches to addressing the prevention of blood borne pathogens and ensuring that issues related to blood borne pathogens remain high profile among public health decision-makers.

**Action**

Provide provincial leadership for HIV testing and initiatives around blood borne pathogens by allocating responsibility for overseeing implementation of the Standards for Blood Borne Pathogens Prevention Services to a dedicated person within Public Health Services that is given sufficient time to manage the issue.
Step 3: Allocate Resources for Community Development to Support Testing for Blood Borne Pathogens

No health promotion initiative will succeed if it is not provided with adequate resources. Nova Scotia’s success in reducing smoking rates over the past seven years is clear evidence of the power of a health promotion initiative that is supported with resources. Promotion of HIV testing and implementation of the Standards for Blood Borne Pathogens Prevention Services are no different – resources have not been allocated to this work and not surprisingly, very little has happened. There are important lessons learned from the work in tobacco reduction that apply to HIV testing, even though the issues are very different.

One of the keys to success of the Tobacco Strategy has been the allocation of dedicated human resources in each District to tobacco prevention and reduction. Staff in each of the Districts have worked closely with their communities to implement tobacco reduction strategies that are meaningful to each unique community. Community development “is arguably the most important single approach available to health promotion practitioners, one that fully embodies the central health promotion principles of empowerment, participation and a sense of control by ordinary people.” The stigma associated with HIV and the fact that many of the people at greatest risk for infection are significantly marginalized combine to make HIV testing an issue that calls for a community development approach.

Action

Allocate at least one Full Time Employee (FTE) to each District Health Authority with the responsibility for coordinating implementation of the Standards for Blood Borne Pathogens Prevention Services across the District, beginning with the implementation of the Standard about access to counseling, testing and referral. The way in which this Standard is implemented across Districts will vary as each Coordinator implements approaches to testing that meet the needs of various communities within the District (the term communities is used broadly here to refer both to geographic communities and also to groups of people with some common characteristics, such as out of school youth, gay men or people who use injection drugs).
For some of the Standards for Blood Borne Pathogens Prevention Services, Coordinators will coordinate implementation; for other standards, the Coordinator may be directly involved in service delivery, such as may be the case for the testing Standard. For this reason, it would be appropriate for the Coordinator to be a professional that is qualified to administer HIV tests and provide the associated pre and post test counseling, as well as having experience in working with communities to find community-defined solutions.

Blood Borne Pathogens Coordinators will work with the many communities in their District to raise the profile of HIV and other blood borne pathogens, promote the importance of testing, and implement with community partners different options for testing that meet the needs of the communities they work with. For example, in their District, Coordinators may work with:

- youth health centres;
- faith groups;
- people living with HIV/AIDS;
- AIDS service organizations;
- Public health;
- the lesbian, gay, bisexual and transgender community;
- corrections community;
- non-profit social service organizations;
- mental health services;
- addictions services;
- community health centres;
- primary care professionals;
- Aboriginal communities and organizations;
- African Nova Scotia communities and organizations;
- STD/STI clinics;
- Sexual health centres;
- services for new immigrants;
• existing screening programs (like Well Women clinics); or
• emergency departments of the facilities within their District.

Each Coordinator will need to work with many partners to identify strategies that will work to increase testing in the District. Coordinators may also provide testing services themselves at existing locations identified as appropriate by community partners.

Step 4: Provide Four Options for HIV Testing
As Blood Borne Pathogens Coordinators work with communities to increase the number of people being tested, they must have different testing options available to them to meet the needs of different communities, including nominal, non-nominal, anonymous and POCR testing (which can be used anonymously).

Action
Ensure that POCR testing is available in Nova Scotia through the Blood Borne Pathogens Coordinators and other health professionals who provide HIV testing on a regular basis. Ensure that health professionals who use POCR testing are trained in the accompanying best practice pre and post-test counseling protocols.

Step 5: Implement a Social Marketing Campaign
Awareness about HIV and testing is low in Nova Scotia. A key part of getting more people tested is increasing awareness about the importance of testing. As described earlier in this report, there are numerous examples of social marketing campaigns that have been implemented elsewhere that can be used as inspiration for a campaign that is relevant to Nova Scotia. A well researched and developed social marketing campaign will provide a necessary support to the community development work that is undertaken by the Blood Borne Pathogens Coordinators. It is important that the Coordinators begin their role of establishing more options for testing throughout the province before the social marketing campaign is launched, so that people who
are motivated to be tested by the campaign will easily be able to find a place to be tested in the way they choose to be tested.
Action
Implement a social marketing campaign, appropriately targeted to different audiences, that encourages people to seek HIV testing and provides them with information about where to get an HIV test.

Step 6: Implement a Pilot Project to Evaluate Routine Screening in Primary Care Settings
Making HIV screening a regular screening test in primary care practices (with an opt-out option) is an important step to normalizing HIV testing. However, before this approach is implemented, primary care providers generally need to have greater comfort with HIV testing and counseling, as well as tools and supports that enable them to provide adequate counseling. Although some of the interviewees indicated they support routine screening, others did not. This suggests that there may not be readiness yet to change to a model of routine screening in Nova Scotia. Because of the potential benefits of routine screening described in the literature and the uncertainty of the implications of routine screening generally and in the Nova Scotia context, more information is needed.

Action
Implement a pilot test of routine screening in several primary care practices throughout the province. Include in the pilot test no more supports for physicians than would be provided if routine screening was to be made policy province wide (for example, do not provide training for physicians on HIV test counseling if during a province-wide implementation all physicians would not be offered the same training). Involve in the pilot test evaluation an ethicist who can help to assess some of the potential ethical issues that are of concern around routine testing. Through the pilot test, assess the impact of routine screening on numbers of people tested, number of positive tests, time impact for the physician and the experience of the client.
10.0 Conclusion

The need to increase HIV testing in Nova Scotia has been acknowledged for quite some time now, such as in the Nova Scotia’s Strategy on HIV/AIDS and in the Standards for Blood Borne Pathogens Prevention Services. Yet, little has happened to address this issue. This document once again underscores the importance of HIV testing and provides a series of suggested actions to move Nova Scotia in a direction that will see more people tested for HIV and potentially more people who have HIV learning about their HIV positive status early so they can access treatment.

The status quo around HIV testing in Nova Scotia is clearly not providing accessible testing options to all Nova Scotians. As with any health promotion initiative, the way forward begins with a commitment to invest in a change. If Nova Scotia is serious about increasing HIV testing, that commitment of resources and intention to improve will need to be the first step.
References


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(37) UNAIDS. Social marketing: an effective tool in the global response to HIV/AIDS. Author; 1998.


(44) Conversation with Ken English, Policy Analyst, AIDS Bureau, Provincial Programs Branch, Health System and Accountability Performance Division, Ministry of Health and Long-Term Care for Ontario. 31-7-2008. Ref Type: Personal Communication


(62) IPPF South Asia Regional Office, UNFPA. Integrating HIV voluntary counselling and testing services into reproductive health settings: stepwise guidelines for programme planners, managers and service providers. 2004.


Appendices
Appendix 1 – Cost Estimates

The following are estimates for the implementation of the action steps outlined in this report. Note that the cost of actual HIV tests, whether standard laboratory or rapid, are not reflected in this estimate.

START-UP COSTS

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<th>Estimate</th>
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<td>Social marketing campaign</td>
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<td>Includes development, design, pilot test and first year implementation cost</td>
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ONGOING ANNUAL COSTS

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<th>Item</th>
<th>Estimate</th>
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</thead>
<tbody>
<tr>
<td>Blood Borne Pathogens Coordinators</td>
<td>$674,100.00</td>
</tr>
<tr>
<td>Assumes for each DHA: 1FTE with base salary of $55,000 +18% benefits, plus community development budget $10,000</td>
<td></td>
</tr>
<tr>
<td>Continuing Education for Blood Borne Education Coordinators</td>
<td>$10,000.00</td>
</tr>
<tr>
<td>Provinicial Blood Borne Pathogens Coordinator</td>
<td>$95,000.00</td>
</tr>
<tr>
<td>Assumes 1FTE (recommended job classification level PR17) with base salary of $63,000 +18% benefits, plus program budget for year 1 (to support development of community of practice of DHA coordinators for example) of $20,000</td>
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</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>$779,100.00</strong></td>
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## Appendix 2 – List of Key Informants

<table>
<thead>
<tr>
<th>Name</th>
<th>Title/Position</th>
<th>Organization/Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diane Bailey</td>
<td>Program Director</td>
<td>Main Line Needle Exchange</td>
</tr>
<tr>
<td>Tammy Barbour</td>
<td>Program Coordinator</td>
<td>AIDS Coalition of NS</td>
</tr>
<tr>
<td>Carolyn Davison</td>
<td>Director, Addiction Services</td>
<td>Department of Health</td>
</tr>
<tr>
<td>Heather Ezurike</td>
<td>Community Health Nurse</td>
<td>Community Health &amp; Wellness Centre, North Preston</td>
</tr>
<tr>
<td>Monique Fong</td>
<td>Executive Director</td>
<td>Healing Our Nations</td>
</tr>
<tr>
<td>Richard Gould</td>
<td>Medical Officer of Health</td>
<td>Valley Regional Health Authority</td>
</tr>
<tr>
<td>Elaine Holmes</td>
<td>Director, Communicable Disease Prevention &amp; Control</td>
<td>Nova Scotia Department of Health</td>
</tr>
<tr>
<td>Nancy MacDonald</td>
<td>HIV Testing Nurse</td>
<td>Halifax Sexual Health Centre</td>
</tr>
<tr>
<td>Tracey MacDonald</td>
<td>HIV/AIDS Field Surveillance Officer</td>
<td>Public Health Agency of Canada</td>
</tr>
<tr>
<td>Maria MacIntosh</td>
<td>Executive Director</td>
<td>AIDS Coalition of NS</td>
</tr>
<tr>
<td>Cindy MacIsaac</td>
<td>Program Director</td>
<td>Direction 180</td>
</tr>
<tr>
<td>Frances MacLeod</td>
<td>Coordinator</td>
<td>Sharp Advice Needle Exchange</td>
</tr>
<tr>
<td>Juanita MacPhee</td>
<td>Nurse Manager</td>
<td>Communicable Disease Prevention &amp; Control, Capital Health</td>
</tr>
<tr>
<td>Al McNutt</td>
<td>Chair, Northern AIDS Connection Society</td>
<td></td>
</tr>
<tr>
<td>Dee Mombourquette</td>
<td>Coordinator, Communicable Disease Prevention and Control</td>
<td>Nova Scotia Department of Health Promotion and Protection</td>
</tr>
<tr>
<td>Cheryl Morris</td>
<td>Coordinator, BBP &amp; STIs</td>
<td>First Nations &amp; Inuit Health, Health Canada</td>
</tr>
<tr>
<td>Mary Musgrave</td>
<td>Nurse Manager</td>
<td>Public Health Services, Districts 7 and 8</td>
</tr>
<tr>
<td>Christine Porter</td>
<td>Executive Director</td>
<td>AIDS Coalition of Cape Breton</td>
</tr>
<tr>
<td>Robert Strang</td>
<td>Chief Public Health Officer</td>
<td>Nova Scotia Department of Health Promotion and Protection</td>
</tr>
<tr>
<td>Dianne Vaughan</td>
<td>Manager</td>
<td>Public Health Services, District 4, 5 and 6</td>
</tr>
<tr>
<td>Gaynor Watson Creed</td>
<td>Medical Officer of Health</td>
<td>Capital Health</td>
</tr>
<tr>
<td>Rod Wilson</td>
<td>Family Physician</td>
<td>Halifax, Nova Scotia</td>
</tr>
</tbody>
</table>
Appendix 3 – Interview Guides

Nova Scotia Advisory Commission on AIDS
Business Planning for HIV Testing

Interview Guide for Regional Key Stakeholders/Informants

PURPOSE

The purpose of the interview is to receive key informant knowledge and perspective about:

- The current status (availability, need, attitudes and behaviours of health care professionals) of HIV testing in Nova Scotia
- Existing and proposed models of HIV testing
- Compliance with standards for HIV testing

PROCESS

These interviews are being conducted as part of an information gathering process regarding the provision, quality, and awareness of HIV testing services in Nova Scotia where warranted. The interviews are being conducted by Pyra Management Consulting Services Inc.

INTERVIEW DETAILS

Name of Interviewer: _______________________________________________________

Name of Interviewee(s): ____________________________________________________

Title of Interviewee(s): ____________________________________________________

Region: __________________________________________________________________

Organization: __________________________________________________________________

Date of Interview: ____________________________

Digital Recorder File Name: __________________________________________________
INTERVIEWER INSTRUCTIONS

This document will be used by the interviewer to guide the interview discussion. The interviewer will begin the interview using the scripts and questions outlined below. Items below printed in italics are scripts for the interviewer.

Introduction
Thank you very much for taking the time to speak with me today. My name is Susan Anderson. I work with Pyra Management Consulting Services Inc. As you know, we have been contracted by the Nova Scotia Advisory Commission on AIDS to conduct interviews with a number of key stakeholders to help us gather information that will inform the development of a strategy to increase the provision, quality, and awareness of HIV testing services in Nova Scotia. Hopefully you have had a chance to review the interview questions, definitions of the three main types of HIV testing, and the information about the guidelines for HIV testing in Nova Scotia that we sent to you before the interview.

Consent
Before we proceed, I would like to remind you of how this information will be used and acquire your consent to participate in this interview. Participation in the interview is voluntary. Please let me know if you do not want to answer any particular questions I ask you. Your answers will not be associated with your name in any reports that are written. The responses that you provide will only be reported in aggregate, and although individual responses may be used as quotations, you will not be identified. The final report will be used by the Advisory Commission on AIDS to support future development of HIV testing policy and programs. The final report may be shared with other organizations, and/or posted on a government of Nova Scotia website.

Do you consent to participate in the interviews?
___Yes    ___No – thank the interviewee and terminate the interview if the response is no.

Do you consent to having your name included in the list of interviewees in the appendix of the report?
___Yes    ___No – assure the interviewee that they will not be identified in the report and write “DO NOT PUBLISH NAME” at the top of the page on the front of this interview guide.

INTERVIEW

The interview consists of approximately 20 questions in the areas of current availability and need for HIV testing, models of testing, standards, public awareness, and HIV as a public health issue. First, I’d like to talk with you about the current state of HIV testing in your area. Before I begin the interview questions, do you have any questions about the different types of testing that were described on the background information sheet that we sent to you?

SECTION A: HIV Testing in Your Region

1. Northern/Western Regions:
1.1. We know that anonymous HIV testing is not available in your region. In your opinion, is there a need for anonymous testing services in your area? (If no, go to question 1.2)

1.1.1. If yes, how important is it that there be anonymous testing in your region?

1.1.2. Do you think that anonymous outreach testing services would be beneficial to your region?

1.2. If no, why not?

1. Central/Eastern Regions:

1.1. We know that anonymous HIV testing is available in your region. In your opinion, how important are the anonymous testing services in your area?

1.2. We also know that outreach testing is provided in your region. In your opinion, how important are outreach testing services in your region?

2. Northern/Western Region: Aside from anonymous testing, which is not available in your area, in your opinion, does the current way in which HIV testing is provided in your area allow for people to have access to the other main types of testing such as nominal and non-nominal testing?

2. Central/Eastern Region: In your opinion, does the current way in which HIV testing is provided in your area allow for people to have access to the main types of testing (nominal, non-nominal, anonymous)?

3. In your opinion, is it valuable to employ a system that utilizes the three main types of testing? Why
or why not?

4. One of the types of testing described on the background information that was provided to you prior to this interview is point of care testing. Do you believe that point-of-care testing should be available in your region?

4.1. If yes, would point of care testing address any unmet need for testing in your area? Please describe.

4.2. If no, why not?

5. In your opinion, does the current way in which HIV testing is provided in your area provide for consistent application of the HIV testing guidelines of informed consent, confidentiality, and pre/post-test counseling?

- informed consent
- confidentiality
- pre/post-test counseling

5.1. If not, what are the barriers to consistent application of informed consent, confidentiality and pre/post-test counseling?

6. In your opinion, is it valuable to employ a system of HIV testing that follows the guidelines of informed consent, confidentiality and counseling? Why or why not?
7. According to the Public Health Agency of Canada, it is estimated that 27% of people with HIV in Canada do not know that they have HIV.

7.1. Overall, what do you feel are the most significant barriers to accessing HIV testing in your area?

7.2. Do you know if there are any particular populations who may be at risk of contracting HIV who are not accessing HIV testing services in your region?

7.3. What do you feel are the most significant barriers to accessing HIV testing for this/these groups?

7.4. In your opinion, what are the best ways to increase HIV testing among people who may be at risk for HIV?

8. In your opinion, does the way in which HIV testing is currently provided in Nova Scotia help or hinder the issue of stigma in relation to HIV?

9. In your opinion, what would be the best model or approach to HIV testing in Nova Scotia?

SECTION B: Healthcare Professionals and HIV Testing

Health care professionals are currently the main gatekeepers to HIV testing for the Nova Scotia Public so I’d like to ask you about their role in HIV testing.

10. Do you have a sense of the degree of importance that health care professionals in your area place on HIV testing?

11. What type of healthcare professional is providing most of the HIV testing in your region? (e.g. physicians, nurses)

The next set of questions is about Nova Scotia’s guidelines for HIV Testing. These were provided on the background information sheet that was sent to you prior to this interview. They are informed consent, confidentiality, and pre-/post-test counseling.

12. Do you believe that health care professionals are able to provide HIV testing that meets the current guidelines in terms of:

12.1. Informed consent
12.2. Confidentiality
12.3. Pre and post-test counseling.

13. What do you think needs to happen to support health professionals in fully complying with these three guidelines?

SECTION C: Standards

HIV testing is an important component of Nova Scotia’s Standards for Blood Borne Pathogens Prevention Services. I would now like to ask you a question about these standards.

14. Do you feel that Nova Scotia’s Standards for the Prevention of Blood Borne Pathogens are helpful in supporting HIV testing in Nova Scotia?

14.1. If yes, how do they help support HIV testing in Nova Scotia?

14.2. If not? In what way do the standards not support HIV testing in Nova Scotia?

SECTION D: Public Awareness

Now, I would like to ask you for your thoughts about HIV testing and public awareness.

15. How beneficial do you think a social marketing or public education campaign would be in increasing
the uptake of HIV testing services in Nova Scotia?

16. Do you feel this would this be a useful investment of resources?

SECTION E: HIV as a Public Health Issue

Finally, I would like to ask you for your thoughts about HIV as an important public health issue.

17. Given that there are limited resources within the health care system and that there are a number of competing priorities for those resources, in your opinion how can we make sure that HIV testing is recognized as a significant public health issue?

18. How can we position HIV testing in relation to other public health issues to make sure that necessary funding is allocated to support HIV testing across the province?

That is the end of my interview questions. Do you have any other comments that you would like to add?
If you should think of anything that you would like to add in the coming days, please contact me at 633-2929 or susan@pmcs.ca.

Thank you very much for your time today.
Interview Guide for Provincial Key Stakeholders/Informants

PURPOSE
The purpose of the interview is to receive key informant knowledge and perspective about:

- The current status (availability, need, attitudes and behaviours of health care professionals) of HIV testing in Nova Scotia
- Existing and proposed models of HIV testing
- Compliance with standards for HIV testing

PROCESS
These interviews are being conducted as part of an information gathering process regarding the provision, quality, and awareness of HIV testing services in Nova Scotia where warranted. The interviews are being conducted by Pyra Management Consulting Services Inc.

INTERVIEW DETAILS

Name of Interviewer: ____________________________________________

Name of Interviewee(s): __________________________________________

Title of Interviewee(s): __________________________________________

Region: ________________________________________________________

Organization: __________________________________________________

Date of Interview: _______________________________________________

Digital Recorder File Name: _______________________________________
INTERVIEWER INSTRUCTIONS
This document will be used by the interviewer to guide the interview discussion. The interviewer will begin the interview using the scripts and questions outlined below. Items below printed in italics are scripts for the interviewer.

Introduction
Thank you very much for taking the time to speak with me today. My name is Susan Anderson. I work with Pyra Management Consulting Services Inc. As you know, we have been contracted by the Nova Scotia Advisory Commission on AIDS to conduct interviews with a number of key stakeholders to help us gather information that will inform the development of a strategy to increase the provision, quality, and awareness of HIV testing services in Nova Scotia. Hopefully you have had a chance to review the interview questions, definitions of the three main types of HIV testing, and the information about the guidelines for HIV testing in Nova Scotia that we sent to you before the interview.

Consent
Before we proceed, I would like to remind you of how this information will be used and acquire your consent to participate in this interview. Participation in the interview is voluntary. Please let me know if you do not want to answer any particular questions I ask you. Your answers will not be associated with your name in any reports that are written. The responses that you provide will only be reported in aggregate, and although individual responses may be used as quotations, you will not be identified. The final report will be used by the Advisory Commission on AIDS to support future development of HIV testing policy and programs. The final report may be shared with other organizations, and/or posted on a government of Nova Scotia website.

Do you consent to participate in the interviews?
___Yes  ___No – thank the interviewee and terminate the interview if the response is no.

Do you consent to having your name included in the list of interviewees in the appendix of the report?
___Yes  ___No – assure the interviewee that they will not be identified in the report and write “DO NOT PUBLISH NAME” at the top of the page on the front of this interview guide.

INTERVIEW

The interview consists of approximately 20 questions in the areas of current availability and need for HIV testing, models of testing, standards, public awareness, and HIV as a health issue. First, I’d like to talk with you about the current state of HIV testing in your area. Before I begin the interview questions, do you have any questions about the different types of testing that were described on the background information sheet that we sent to you?

SECTION A: HIV Testing in Nova Scotia

1. In your opinion, does the current way in which HIV testing is provided throughout Nova Scotia allow for people to have access to the main types of HIV testing (such as nominal, non-nominal, and anonymous testing)?
2. We know that anonymous HIV testing is available in some regions of Nova Scotia and not in others. In your opinion, is there a need for anonymous testing services in all regions of the province?

2.1. How important is it that there be anonymous testing in all regions of the province?

3. We know that outreach testing services are available in some areas of Nova Scotia and not in others. In your opinion, how important are outreach testing services?

4. In your opinion, is it valuable to employ a system of HIV testing that utilizes the three types of testing? Why or why not?

5. One of the types of testing described on the background information sheet that was provided to you prior to this interview is point of care testing. Do you believe that point-of-care testing should be available in Nova Scotia?

5.1. If yes, would point of care testing address any unmet need for testing in Nova Scotia? Please describe.

5.2. If no, why not?

6. In your opinion, does the current way in which HIV testing is provided throughout Nova Scotia provide for the consistent application of the HIV testing guidelines of informed consent, confidentiality, and pre/post-test counseling?

- informed consent
- confidentiality
- pre/post-test counseling

6.1. If not, what are the barriers to consistent application of informed consent, confidentiality and pre/post-test counseling?

7. In your opinion, is it valuable to employ a system of HIV testing whose guidelines include informed
consent, confidentiality and counseling? Why or why not?

8. According to the Public Health Agency of Canada, it is estimated that 27% of people with HIV in Canada do not know that they have HIV.

8.1. Overall, what do you feel are the most significant barriers to accessing HIV testing in Nova Scotia?

8.2. Do you know if there are any particular populations who may be at risk of contracting HIV who are not accessing HIV testing services in Nova Scotia?

8.3. If so, what do feel are the most significant barriers to accessing HIV testing for this/these groups?

8.4. In your opinion, what are the best ways to increase HIV testing among people who may be at risk for HIV?

9. In your opinion, does the way in which HIV testing is currently provided throughout Nova Scotia help or hinder the issue of stigma in relation to HIV?

10. In your opinion, what would be the best model or approach to HIV testing in Nova Scotia?

SECTION B: Healthcare Professionals and HIV Testing

Health care professionals are currently the main gatekeepers to HIV testing for the Nova Scotia Public so I’d like to ask you about their role in HIV testing.

11. Do you have a sense of the degree of importance that health care professionals in Nova Scotia place on HIV testing?

12. What type of healthcare professional is providing most of the HIV testing in Nova Scotia? (e.g. physicians, nurses)

The next set of questions is about health care professionals and Nova Scotia’s guidelines for HIV Testing. These were provided on the background information sheet that was sent to you prior to this interview. They are informed consent, confidentiality, and pre-/post-test counseling.

13. Do you believe that health care professionals are able to provide HIV testing that meets the current guidelines in terms of:

13.1. Informed consent
13.2. Confidentiality
13.3. Pre and post-test counseling.

14. What do you think needs to happen to support health professionals in fully complying with these three guidelines?

SECTION C: Standards

HIV testing is an important component of Nova Scotia’s Standards for Blood Borne Pathogens Prevention Services. Now I would like to ask you a question about these standards.

15. Do you feel that Nova Scotia’s Standards for the Prevention of Blood Borne Pathogens are helpful in supporting HIV testing in Nova Scotia?

15.1. If yes, how do they help support HIV testing in Nova Scotia?
15.2. If not? In what way do the standards not support HIV testing in Nova Scotia?
SECTION D: Public Awareness

Now, I would like to ask you for your thoughts about HIV testing and public awareness.

16. How beneficial do you think a social marketing or public education campaign would be in increasing the uptake of HIV testing services in Nova Scotia?

17. Do you feel this would be a useful investment of resources?

SECTION E: HIV as a Public Health Issue

Finally, I would like to ask you for your thoughts about HIV as an important public health issue.

18. Given that there are limited resources within the health care system and that there a number of competing priorities for those resources, in your opinion, how can we make sure that HIV testing is recognized as a significant public health issue in Nova Scotia?

19. How can we position HIV testing in relation to other public health issues to make sure that necessary funding is allocated to support HIV testing across the province?

That is the end of my interview questions.
Do you have any other comments that you would like to add?
If you should think of anything that you would like to add in the coming days, please contact me at 633-2929 or susan@pmcs.ca

Thank you very much for your time today.
Appendix 4 – Background Documents

Background Information and Interview Questions for HIV Testing Interviewees
April 2008

Thank you very much for agreeing to participate in an interview to help us develop a plan to improve HIV testing services. As background information for the interview, below you will find definitions of various forms of HIV testing, information regarding Nova Scotia’s guidelines for HIV testing, the consent process, and the interview questions.

Main Types of HIV Testing

1. **Anonymous testing** is where the person ordering the HIV test does not know the identity of the person being tested; the HIV test is carried out using a code. If the HIV test is positive the person being tested is responsible to contact his/her sexual partners and drug use contacts. Test results are not recorded on the health care record of the person being tested.

2. **Non-nominal testing** is where the HIV test is ordered using a code or initials of the person being tested. If the test result is positive, a public health official will contact the person who ordered the test and determine whether sexual partners have been notified of the possibility of exposure to a sexually transmitted infection and should go to their own health care provider for counseling and testing. If satisfied that the partners have been contacted, the official will not ask for the name of the person being tested.

3. **Nominal or name-based testing** is where the person ordering the HIV test knows the identity of the person being tested. If the test result is positive, the person who ordered the test is required to notify public health officials of the person’s name, and is responsible for notifying the sexual partners and drug use contacts.

4. **Point of care testing** refers to the practice undertaken by health care professionals of providing a) pre and post-test counseling at the site of patient care, and b) using rapid HIV tests at the site of patient care. Rapid HIV tests provide results quickly so that results are provided to the person being tested during the same visit in which they were tested. When using non-rapid HIV test, blood is drawn in one visit and sent to a laboratory for testing so that the person being tested needs to return for a second visit to receive their test results.
Guidelines for HIV Testing in Nova Scotia

There are three main elements to the guidelines for HIV testing in Nova Scotia, including:

- **Informed Consent** to HIV testing is when an individual gives permission for a health professional to test for HIV and that consent is specific, informed, and voluntary. Informed consent to testing has two parts: 1. understanding the type of test, possible results, and potential implications of the test or the results; 2. agreement to proceed with the test.

- **Confidentiality** refers to keeping any medical information, including inquiries and test results, in ways that respect the privacy of the individual. It means that health professionals cannot give any health related information about an individual to another person unless the individual has agreed.

- **Pre- and Post-Test Counseling** refers to discussion with a qualified professional before and after HIV testing regarding advantages and disadvantages of being tested or not being tested, risk behaviours, test results, prevention of HIV, and referral to services if necessary. The pre-test counseling also helps to ensure that informed consent has been given.

Consent to Participate in the Interview

When we call you for the interview, before we ask any interview questions, you will be asked to consent to your participation.

Participation in the interview is voluntary and if you do not want to answer a particular question, you will not be required to. Your answers will not be associated with your name in any reports that are written. The responses that you provide will only be reported in combination with other responses, and although individual responses may be used as quotations, you will not be identified. The final report will be used by the Advisory Commission on AIDS to support future development of HIV testing policy and programs. The final report may be shared with other organizations, and/or posted on a government of Nova Scotia website.

Interview Questions

3. **Northern/Western Regions:**
   3.1. We know that anonymous HIV testing is not available in your region. In your opinion, is there a
need for anonymous testing services in your area? (If no, go to question 1.2)
3.1.1. If yes, how important is it that there be anonymous testing in your region?
3.1.2. Do you think that anonymous outreach testing services would be beneficial to your region?

3.2. If no, why not?

2. Central/Eastern Regions:
2.1. We know that anonymous HIV testing is available in your region. In your opinion, how important are the anonymous testing services in your area?

2.2. We also know that outreach testing is provided in your region. In your opinion, how important are outreach testing services in your region?

4. Northern/Western Region: Aside from anonymous testing, which is not available in your area, in your opinion, does the current way in which HIV testing is provided in your area allow for people to have access to the other main types of testing such as nominal and non-nominal testing?

7. Central/Eastern Region: In your opinion, does the current way in which HIV testing is provided in your area allow for people to have access to the main types of testing (nominal, non-nominal, anonymous)?

8. In your opinion, is it valuable to employ a system that utilizes the three main types of testing? Why or why not?

9. One of the types of testing described on the background information that was provided to you prior to this interview is point of care testing. Do you believe that point-of-care testing should be available in your region?

9.1. If yes, would point of care testing address any unmet need for testing in your area? Please describe.
9.2. If no, why not?

10. In your opinion, does the current way in which HIV testing is provided in your area provide for consistent application of the HIV testing guidelines of informed consent, confidentiality, and pre/post-test counseling?

10.1. If not, what are the barriers to consistent application of informed consent, confidentiality and pre/post-test counseling?

11. In your opinion, is it valuable to employ a system of HIV testing that follows the guidelines of
informed consent, confidentiality and counseling? Why or why not?

8. According to the Public Health Agency of Canada, it is estimated that 27% of people with HIV in Canada do not know that they have HIV.  

9.1. Overall, what do you feel are the most significant barriers to accessing HIV testing in your area?  
9.2. Do you know if there are any particular populations who may be at risk of contracting HIV who are not accessing HIV testing services in your region?  
9.3. What do you feel are the most significant barriers to accessing HIV testing for this/these groups?  
9.4. In your opinion, what are the best ways to increase HIV testing among people who may be at risk for HIV?  

10. In your opinion, does the way in which HIV testing is currently provided in Nova Scotia help or hinder the issue of stigma in relation to HIV?  

11. In your opinion, what would be the best model or approach to HIV testing in Nova Scotia?  

SECTION B: Healthcare Professionals and HIV Testing  

13. Do you have a sense of the degree of importance that health care professionals in your area place on HIV testing?  

14. What type of healthcare professional is providing most of the HIV testing in your region? (e.g. physicians, nurses)  

15. Do you believe that health care professionals are able to provide HIV testing that meets the current guidelines in terms of:  
13.1. Informed consent  
13.2. Confidentiality  
13.3. Pre and post-test counseling.  

14. What do you think needs to happen to support health professionals in fully complying with these three guidelines?  

SECTION C: Standards

15. Do you feel that Nova Scotia’s Standards for the Prevention of Blood Borne Pathogens are helpful in supporting HIV testing in Nova Scotia?
   14.3. If yes, how do they help support HIV testing in Nova Scotia?
   14.4. If not? In what way do the standards not support HIV testing in Nova Scotia?

SECTION D: Public Awareness

17. How beneficial do you think a social marketing or public education campaign would be in increasing the uptake of HIV testing services in Nova Scotia?

18. Do you feel this would be a useful investment of resources?

SECTION E: HIV as a Public Health Issue

19. Given that there are limited resources within the health care system and that there a number of competing priorities for those resources, in your opinion how can we make sure that HIV testing is recognized as a significant public health issue?

20. How can we position HIV testing in relation to other public health issues to make sure that necessary funding is allocated to support HIV testing across the province?

Your interview will be conducted by Susan Anderson or Karen Pyra. If you would like any additional information about the interview process, please contact us at 633-2929 or via e-mail at susan@pmcs.ca.
Background Information and Interview Questions for HIV Testing Interviewees
April 2008

Thank you very much for agreeing to participate in an interview to help us develop a plan to improve HIV testing services. As background information for the interview, below you will find definitions of various forms of HIV testing, information regarding Nova Scotia’s guidelines for HIV testing, the consent process, and the interview questions.

Main Types of HIV Testing

1. **Anonymous testing** is where the person ordering the HIV test does not know the identity of the person being tested; the HIV test is carried out using a code. If the HIV test is positive the person being tested is responsible to contact his/her sexual partners and drug use contacts. Test results are not recorded on the health care record of the person being tested.

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3. **Nominal or name-based testing** is where the person ordering the HIV test knows the identity of the person being tested. If the test result is positive, the person who ordered the test is required to notify public health officials of the person’s name, and is responsible for notifying the sexual partners and drug use contacts.

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Guidelines for HIV Testing in Nova Scotia

There are three main elements to the guidelines for HIV testing in Nova Scotia, including:

- **Informed Consent** to HIV testing is when an individual gives permission for a health professional to test for HIV and that consent is specific, informed, and voluntary. Informed consent to testing has two parts: 1. understanding the type of test, possible results, and potential implications of the test or the results; 2. agreement to proceed with the test.

- **Confidentiality** refers to keeping any medical information, including inquiries and test results, in ways that respect the privacy of the individual. It means that health professionals cannot give any health related information about an individual to another person unless the individual has agreed.

- **Pre- and Post-Test Counseling** refers to discussion with a qualified professional before and after HIV testing regarding advantages and disadvantages of being tested or not being tested, risk behaviours, test results, prevention of HIV, and referral to services if necessary. The pre-test counseling also helps to ensure that informed consent has been given.

Consent to Participate in the Interview

When we call you for the interview, before we ask any interview questions, you will be asked to consent to your participation.

Participation in the interview is voluntary and if you do not want to answer a particular question, you will not be required to. Your answers will not be associated with your name in any reports that are written. The responses that you provide will only be reported in combination with other responses, and although individual responses may be used as quotations, you will not be identified. The final report will be used by the Advisory Commission on AIDS to support future development of HIV testing policy and programs. The final report may be shared with other organizations, and/or posted on a government of Nova Scotia website.
Interview Questions

SECTION A: HIV Testing in Nova Scotia

1. In your opinion, does the current way in which HIV testing is provided throughout Nova Scotia allow for people to have access to the main types of HIV testing (such as nominal, non-nominal, and anonymous testing)?

2. We know that anonymous HIV testing is available in some regions of Nova Scotia and not in others. In your opinion, is there a need for anonymous testing services in all regions of the province?
   2.1. How important is it that there be anonymous testing in all regions of the province?

3. We know that outreach testing services are available in some areas of Nova Scotia and not in others. In your opinion, how important are outreach testing services?

4. In your opinion, is it valuable to employ a system of HIV testing that utilizes the three types of testing? Why or why not?

6. One of the types of testing described on the background information sheet that was provided to you prior to this interview is point of care testing. Do you believe that point-of-care testing should be available in Nova Scotia?
   6.1. If yes, would point of care testing address any unmet need for testing in Nova Scotia? Please describe.
   6.2. If no, why not?

7. In your opinion, does the current way in which HIV testing is provided throughout Nova Scotia provide for the consistent application of the HIV testing guidelines of informed consent, confidentiality, and pre/post-test counseling?
   7.1. If not, what are the barriers to consistent application of informed consent, confidentiality and pre/post-test counseling?

8. In your opinion, is it valuable to employ a system whose guidelines include informed consent, confidentiality and counseling? Why or why not?

9. According to the Public Health Agency of Canada, it is estimated that 27% of people with HIV in
Canada do not know that they have HIV.4.

9.1. Overall, what do you feel are the most significant barriers to accessing HIV testing in Nova Scotia?
9.2. Do you know if there are any particular populations who may be at risk of contracting HIV who are not accessing HIV testing services in Nova Scotia?
9.3. If so, what do feel are the most significant barriers to accessing HIV testing for this/these groups?
9.4. In your opinion, what are the best ways to increase HIV testing among people who may be at risk for HIV?

10. In your opinion, does the way in which HIV testing is currently provided throughout Nova Scotia help or hinder the issue of stigma in relation to HIV?

11. In your opinion, what would be the best model or approach to HIV testing in Nova Scotia?

SECTION B: Healthcare Professionals and HIV Testing

12. Do you have a sense of the degree of importance that health care professionals in Nova Scotia place on HIV testing?

13. What type of healthcare professional is providing most of the HIV testing in Nova Scotia? (e.g. physicians, nurses)

14. Do you believe that health care professionals are able to provide HIV testing that meets the current guidelines in terms of:

   14.1. Informed consent
   14.2. Confidentiality
   14.3. Pre and post-test counseling.

15. What do you think needs to happen to support health professionals in fully complying with these three guidelines?

SECTION C: Standards

16. Do you feel that Nova Scotia’s Standards for the Prevention of Blood Borne Pathogens are helpful in supporting HIV testing in Nova Scotia?

16.1. If yes, how do they help support HIV testing in Nova Scotia?
16.2. If not? In what way do the standards not support HIV testing in Nova Scotia?

SECTION D: Public Awareness

17. How beneficial do you think a social marketing or public education campaign would be in increasing the uptake of HIV testing services in Nova Scotia?

18. Do you feel this would be a useful investment of resources?

SECTION E: HIV as a Public Health Issue

18. Given that there are limited resources within the health care system and that there a number of competing priorities for those resources, in your opinion, how can we make sure that HIV testing is recognized as a significant public health issue in Nova Scotia?

20. How can we position HIV testing in relation to other public health issues to make sure that necessary funding is allocated to support HIV testing across the province?

Your interview will be conducted by Susan Anderson or Karen Pyra. If you would like any additional information about the interview process, please contact us at 633-2929 or via e-mail at susan@pmcs.ca.
Appendix 5 – Guidelines for Pre and Post Test Counseling

Pre- and Post-Test Counseling

- Counseling should be age-appropriate and individualized to the person being tested.
- Testing should be done only after informed consent has been obtained.

Pre-Test Counseling

- Clarify:
  - The confidentiality of HIV testing, reporting, and record handling.
  - The testing options available (i.e. nominal, non-nominal, anonymous)
  - That the test is for antibodies to HIV, not a direct test for the HIV virus or for AIDS.
  - That the majority of persons produce detectable antibodies within 3 months.
  - That an initial positive screening test is automatically followed by a confirmatory test (same blood sample) to rule out a false-positive result. This may mean a delay in the availability of the test result.
  - That the results should not be provided to the patient until confirmatory test results are available.
  - That the test results should be provided in person.
  - That returning for results is preferred, as it provides an opportunity to provide proper post-test counseling.
  - That a negative test may mean the person is not infected, or that it is too soon to detect antibodies.
  - That a positive test means the person is infected with HIV and is infectious to others through unprotected sexual contact, blood, breast milk, or tissue/organ donation.
  - That an indeterminate confirmatory test result means that testing should be repeated in 3 months or additional testing performed (e.g. qualitative HIV polymerase chain reaction – PCR – serum p24 antigen; please consult your local laboratory regarding test availability).
  - That HIV is not casually transmitted through sweat, saliva, urine, feces, or tears (unless there is a visible blood in any of these).
  - That transmission risks are as follows:
    - Unprotected sexual contact: anal sex (high risk), vaginal sex (high risk), oral sex (low risk).
    - Direct blood-to-blood contact.
• Sharing needles or syringes (including IDU, tattooing, piercing with shared/unclean equipment).
• Transmission from mother to child during pregnancy, at birth, or via breast milk.
• Receiving blood or blood products in Canada before November 1985 (elsewhere risk will depending on testing of donated blood).

• Discuss:
  o Specific risk factors, sexual and otherwise.
  o Availability of therapy to decrease the risk of mother-to-child transmission if the person is pregnant (decreased by > 80%)
  o Whether future testing will be necessary.
  o Risk-reduction behaviours (see Primary Care and Sexually Transmitted Infections chapter):
    ▪ Practice sexual abstinence (will eliminate risk).
    ▪ Ensure consistent use of latex or polyurethane condoms.
    ▪ Avoid casual/anonymous/unprotected sex.
    ▪ Avoid sharing needles, syringes, or other IDU equipment.

• Explore:
  o Psychological implications of testing.
  o Coping mechanisms to deal with either result; availability of support systems (personal, community, medical).

• Explain:
  o The need to return for test results and schedule a post-test counseling visit.
  o Public health notification for follow-up if the test is positive and the patient fails to return for results.
  o Post-test counseling procedures.
  o Partner notification and reporting requirements for HIV infection (depends on jurisdiction and availability of anonymous testing).
  o With a positive result, the need for full clinical and laboratory assessments and for discussion regarding antiretroviral therapy and prophylaxis for opportunistic infections.

Post-Test Counseling

• If the test is **negative**:
  o Interpret as;
    ▪ No infection or “window period” with infection, but no detectable antibodies. Retesting may be required 3 months after last potential exposure to allow for detection of an antibody response. Retesting 6 months after last potential exposure may be required for those presenting with late clinical signs and symptoms of HIV infection or in persons with an impaired immune response.
    ▪ In the case of sexual assault (see Sexual Abuse in Peripubertal and Prepubertal Children and Sexual Assault in Postpubertal Adolescents and Adults chapters) and occupational exposure (see Occupational
baseline testing should be performed, followed by additional testing at 6 weeks, 12 weeks, and 6 months.

- Reinforce risk reduction:
  - Avoid high-risk behaviours.
  - Avoid needle/syringe sharing.
  - Use lubricated latex or polyurethane condoms with sexual activity.

- If test is positive:
  - Interpret as:
    - Infected with HIV, not diagnostic of AIDS.
    - Explain that a confirmatory test to rule out a false-positive test has been performed.
  - Consider a first priority:
    - Dealing with the issues important to the infected person.
    - Discussing coping and support systems.
    - Discussing and assisting in partner-notification process (by the infected person or the local public health unit).
    - Providing specific guidance about avoiding HIV transmission:
      - Protect others from sexual secretions, blood and other body fluids.
      - Avoid donating blood, organs, tissue, sperm, or breast milk.
      - Be aware of infectivity (reinforce mechanisms of transmission, including high- and low-risk behaviours).
  - Discuss disclosure issues:
    - Persons with HIV infection should be informed of the medico-legal requirement to disclose their HIV status to a potential sexual or drug-injecting partner. This is particularly important if they will be engaging in high-risk behaviour(s).
    - Persons with HIV infection should inform their family physician and consider informing other health care providers (e.g. dentist).
    - Disclosure in the workplace is usually not mandatory but should be individualized (e.g. where the person with HIV infection has direct patient-care responsibilities).
    - Disclosure to friends or family is not essential but might be considered if there is potential for a positive outcome (e.g. positive family support).
    - Discuss benefits of treatment and follow-up.
  - Deal with soon:
    - Further medical support, immune testing, HIV viral load testing, CD4 count and counseling are required.
    - Discuss use of laboratory testing to make therapeutic decisions.
  - Discuss medical care:
    - Screen for Hepatitis B virus (HBV) infection and immunity (see Hepatitis B virus infections chapter). Screen for Hepatitis A virus (HAV) immunity in injection drug users, MSM, individuals with chronic liver disease and hemophiliacs.
    - Screen for Hepatitis C virus (HCV) infection.
    - Screen for syphilis and other STIs.
    - Screen for tuberculosis.
- Refer where required (e.g. HIV specialist).
- Discuss health-enhancing lifestyle modifications, empowerment.
- Discuss issues of confidentiality in the health care system, community, at school or at work.
- Discuss avoidance of activities that increase risk of toxoplasmosis and enteric pathogens.

Reference: