HIV Counselling and Testing in Nova Scotia:
Implications for Policy and Practice

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A research report prepared for the Nova Scotia Advisory Commission on AIDS by members of the HIV Counselling and Testing Community Advisory Committee
HIV Testing and Counselling in Nova Scotia: Implications for Policy and Practice

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PROJECT BACKGROUND

This report outlines the findings from the research study, “HIV Testing and Counselling in Nova Scotia: Implications for Policy and Practice.” The primary purpose of this study was to examine HIV testing rates and behaviours in Nova Scotia, including who is and is not accessing HIV testing in the province and why or why not, with the aim of offering evidence-based recommendations for HIV counselling and testing approaches in Nova Scotia. Community consultations were held with the research team and members of various government, health, and community-based organizations in the Fall of 2008. The goal of these consultations was to determine the various gaps in information, as well as to help set up a Community Advisory Committee for this research. The Community Advisory Committee assisted with the development of the interview guides for the in-depth interviews, provided input regarding HIV counselling and testing policy, shared their expertise and helped with the development of this report. Members of various communities and organizations were invited to attend Community Advisory Committee meetings (held monthly) to provide input and feedback regarding all aspects of this study.

Understanding HIV testing behaviours is an important aspect in the prevention of the HIV epidemic in Nova Scotia, since HIV counselling and testing can facilitate timely access to care, treatment and support for those who are found to be HIV positive, and is also significant in efforts to prevent the further spread of infection. This study utilized both qualitative and quantitative data in order to better understand the provincial HIV testing rates and reasons for seeking or not seeking HIV testing, as well as the experiences of those tested for HIV. First, provincial policies and research related to HIV counselling and testing services were examined. Next, anonymized HIV testing data were gathered from Nova Scotia Department of Health Promotion & Protection, Capital Health Laboratory and the Halifax-based anonymous HIV testing site from April 2009 to April 2010. Finally, qualitative in-depth interviews were conducted with a diverse sample of both rural and urban individuals who had or had not been tested for HIV in Nova Scotia in the past 12 months (at the time of the interview). The findings from this study can be used to help inform provincial HIV counselling and testing policies and also programmatic responses to identified gaps in the current provision of HIV counselling and testing services, programs, and information strategies. The final aspect of this study involved knowledge translation of the findings of the data to our key partners and stakeholders.
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LIST OF ACRONYMS

AIDS – Acquired Immune Deficiency Syndrome
ASO – AIDS Service Organization
BBP – Blood Borne Pathogens
CBO – Community Based Organization
CDHA – Capital District Health Authority
CMA – Canadian Medical Association
DHA – District Health Authority
DOH – Department of Health
ER – Emergency Room
GNP+ – Global Network of People Living with HIV/AIDS
HIV – Human Immunodeficiency Virus
HPP – Nova Scotia Department of Health Promotion and Protection
HRM – Halifax Regional Municipality
HSHC – Halifax Sexual Health Centre
MMWR – Morbidity & Mortality Weekly Report
NSACA – Nova Scotia Advisory Commission on AIDS
PBPPCC – Department of Health Prevention of Blood Borne Pathogens Coordinating Committee
PHAC – Public Health Agency of Canada
PHASSC – Provincial HIV/AIDS Strategy Steering Committee
PMCS – Pyra Management Consulting Services
STI – Sexually Transmitted Infection
QEII – Queen Elizabeth II Hospital
UNAIDS – The Joint United Nations Programme on HIV/AIDS
WHO – World Health Organization

EXPOSURE TYPES

Het-Risk – Heterosexual contact with a person at risk (e.g. IDU, HIV+)
IDU – Injecting drug users
MSM – Men who have had sex with men
MSM/IDU – Men who have had sex with men and have injected drugs
NIR – No identified risk, where no exposure type was indicated
NIR-Het – Heterosexual contact is the only reported exposure type and nothing is known about the partner’s risk
EXEClTIVE SUMMARY

1 INTRODUCTION
Developing and implementing appropriate HIV prevention, care, treatment and support strategies in Nova Scotia presents significant challenges for health care professionals and policy analysts alike. Despite the availability of HIV testing options, barriers to accessing HIV counselling and testing services persist in Nova Scotia, including geographic isolation for rural communities, a lack of anonymous testing sites, fear of disclosure particularly in small communities, poverty, and continuing stigma associated with HIV (PHASSC, 2003; PMCS, 2008). There is limited evidence related to what constitutes effective HIV counselling and testing, as well as the reasons for seeking or not seeking HIV testing amongst diverse communities in Nova Scotia. Recognizing that HIV counselling and testing is a means of facilitating timely access to care, treatment and support for those who are found to be HIV positive and to help prevent the further spread of infection, understanding HIV testing behaviours is a critical facet in stemming the HIV epidemic in Nova Scotia. In light of the shifting focus and scope of international testing policies (CDC, 2006) and the updating of Canadian guidelines for HIV counselling (CATIE, 2009; PHAC, 2006), we regard this as a key opportunity to understand the impact of various counselling and testing strategies on the health of Nova Scotians. The key objectives of this study were: 1) to understand the HIV testing rates and behaviours among individuals in Nova Scotia; and 2) to develop an evidence-based understanding of the experiences of individuals that have and those who have not been tested for HIV in the past year, to develop Nova Scotia-specific policy and programming recommendations.

2 DATA COLLECTION
The data collection for this study included: a review of relevant HIV policy and programming documents, a descriptive epidemiological summary of HIV testing and newly diagnosed HIV case data in Nova Scotia, and in-depth interviews with a sample of individuals from across Nova Scotia who had either sought or had not sought HIV testing in the past year. The policy component included a review of policy and research documents from Nova Scotia in relation to the provincial response to HIV counselling and testing. Provincial laboratory testing and HIV incidence data were gathered by the Nova Scotia Department of Health Promotion and Protection (HPP) and the Capital District Health Authority (CDHA) to examine HIV testing uptake across the province and the epidemiology of newly diagnosed HIV cases; information about anonymous testing was provided as a non-representative sample from the Halifax Sexual Health Centre (HSHC). 50 in-depth interviews were conducted with a diverse sample from across Nova Scotia in order to examine their perceptions and experiences of HIV counselling and testing.
This research study was approved by the Capital Health Research Ethics Board. The surveillance data collected were anonymized and aggregated, making it impossible to link back to individuals tested. Interviews were conducted by the research coordinator and research assistant, both of whom received training and signed confidentiality agreements. Interview participants were informed of the purpose of the research, as well as their rights as a participant prior to signing consent forms. An honorarium ($15) was given to participants to partially offset their time. All interviews were audio-recorded, transcribed and cleaned of identifiable information. All data collected were maintained by the principal investigator and research coordinator, stored in a secure locked cabinet, to be kept for a period of five years after the completion of the project in accordance to Dalhousie University guidelines. Member checking of the transcripts was limited to members of the Community Advisory Committee and the research team, all of whom were required to sign a confidentiality agreement. Some limitations of this research included:

- The interview data included representation from sub-communities in Nova Scotia, but were unable to assess the specific needs and issues of these groups (ethno-racial, geographic, etc.);
- This study was exploratory, and therefore further investigation of particular issues would be required for greater descriptive and explanatory power;
- The interview sample was restricted to those individuals who contacted us and this results in a non-randomly selected study sample that is not generalizable to the sub-communities described in this study;
- HIV screening data represented approximately 71% of tests, but it is not known if tests conducted outside Capital District Health Authority (CDHA) follow similar age and sex distributions; and
- The reason for testing is not available for the majority of HIV tests conducted, so further exploration of testing at the time of other STI testing, or Pap smear testing for females may indicate settings contributing to higher and lower HIV testing uptake.

3 FINDINGS
The research findings include a review of relevant HIV counselling and testing policies and research in Nova Scotia, a summary of testing and incidence data, and an overview of the in-depth interview data.

3.1 Policy review
Nova Scotia’s policy related to HIV counselling and testing is reflected in a variety of key documents published in recent years. First, we reviewed the Nova Scotia Department of Health (DOH) and Department of Health Promotion and Protection (HPP) statements of mandate (2010-11), and documents on cultural competence and safety (2008). Then we looked at the provincial HIV/AIDS strategy (2003), the blood borne pathogens prevention services standards (2004), reports produced for the pre-natal screening project commissioned by NSACA (2007), and the report produced for NSACA on

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2 See Appendix C: Consent Form.
a strategic approach to increase HIV screening in Nova Scotia (2008). A review of these documents enabled us to assess the current policies and research findings and how they support HIV/AIDS as an important public health issue in this province. Several salient themes emerged:

- Provide quality, efficient, effective and culturally-competent health care to Nova Scotians;
- Strengthen the harm-reduction health care model (to decrease negative impact of risk behaviours);
- Increase awareness about HIV in Nova Scotia, as well as awareness about the HIV testing and counselling options that are currently available;
- Build on existing HIV counselling and testing services in Nova Scotia by expanding options for HIV testing (including anonymous and rapid point-of-care testing);
- Ensure quality and equitable access to services by developing and implementing various HIV testing strategies for diverse communities and their unique needs;
- Increase clear communication between physicians and patients via pre-and post-test counselling, including a discussion of the nature of the test, the testing process, and the potential risks and benefits of being tested for HIV;
- Ensure cross-disciplinary collaboration beyond the health sector in increasing visibility, access and uptake of HIV counselling and testing; and
- Work collaboratively with the Departments of Health and Health Promotion and Protection, Public Health, District Health Authorities, the Commission and Community-based organizations to enhance the implementation of the Blood Borne Pathogens Prevention Services Standards (2004).

3.2 Surveillance

HIV testing and incidence data were collected and analyzed with the assistance of HPP and CDHA. The available data summarized includes: number of HIV tests conducted across the province (in 2008), number of tests per year over time (1999-2008), number of tests by age, sex and test setting (2009), number of newly diagnosed HIV cases by age and sex (2005-2009) as well as a comparison of risk factors identified by those tested at anonymous testing sites and those newly diagnosed with HIV (2005-2009). The following trends were observed:

- The number of HIV screening tests conducted per year has increased over time (1999-2008);
- 1081 physicians sent specimens for HIV screens between April 2009 and April 2010;
- Similar numbers of males and females are being tested when prenatal tests are excluded (prenatal screening guidelines do not call for testing of partners);
- Age distribution of tests is similar for males and females;
- Age and sex distribution of anonymous tests is similar to that for non-anonymous HIV tests;
- Newly reported HIV cases are predominantly male;
- Newly reported HIV cases tend to have an older age distribution (highest number of reports in 40 to 44 year age group) compared to the HIV screening test distribution (highest number of tests in 25 to 29 year age group);
- The most commonly reported HIV exposure type for newly diagnosed HIV cases was men who have had sex with men (MSM), while the majority of people who go for anonymous HIV tests did not report any identified risk (NIR) for HIV infection; and
Anonymous testing services at the Halifax Sexual Health Centre are being accessed predominantly by Caucasian individuals aged 20-30, equally split between men and women.

3.3 In-depth interviews

A total of 50 in-depth interviews were conducted between July 2009 and May 2010. Specific efforts were made for the inclusion of individuals from diverse ages, ethnicities, and locations across the province. The goal of the interviews was to learn more about the experiences and perceptions of HIV counselling and testing in Nova Scotia of both individuals who had and those who had not been tested in the past year, as well as their reasons for testing, reasons for considering testing, or for not considering testing. The themes that emerged from the analysis of the interviews examine both the barriers and facilitators to accessing HIV testing in Nova Scotia.

3.3.1 Experiences and perceptions of those not tested for HIV in past year

Participants who had not been tested for HIV in the past year:

1. Had never been tested before and did not consider testing;
2. Had never been tested but considered testing;
3. Had been tested before (prior to past year) but did not consider being tested again; or
4. Had been tested before (prior to past year) and considered being tested again.

3.3.1.1 Reasons for not being tested for HIV in the past year

Those who were not tested for HIV in the past year cited the following reasons for not seeking testing:

1. Reported they were not involved in HIV risk activities or had the perception of low risk activities;
2. Did not think much about HIV or hear much about HIV testing in NS;
3. Were involved in a long-term monogamous relationship;
4. Felt fear of learning the HIV test result (fear of a positive test result);
5. Believed that symptoms would have shown up by now if they were HIV positive;
6. Believed that knowing their HIV status wouldn’t change their health outcomes;
7. Were only tested when they were pregnant (NS prenatal screening guidelines include HIV testing);
8. Perceived stigma attached to HIV testing;
9. Believed that Canada is an “HIV-free environment” due to lower rates of infection;
10. Feared the anxiety experienced while waiting for the test results;
11. Feared the prospect of telling partners the HIV test results;
12. Was advised against HIV testing by their doctor;
13. HIV test was not suggested by their doctor, nor included with other tests;
14. Did not know where to go for HIV testing; or
15. Had fear or difficulty with having blood drawn.

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3 See Appendix D for a breakdown of participant demographics.
3.3.1.2 Reasons for considering being tested for HIV in the past year

Of those who had not been tested for HIV, several considered being tested for the following reasons:

1. Were involved in HIV-related risk activities (such as sexual activity or drug use);
2. Believed that people should be tested because it is the “smart thing to do”;
3. Believed that it is better to know HIV status (even if it is positive) than to not know;
4. Believed that HIV testing is important in general or within their community;
5. It had been a while since the last time they were tested for HIV; or
6. Were tested for other STIs and considered HIV as similar or a part of that.

3.3.2 Barriers to accessing HIV testing

The following barriers to HIV testing emerged in conversation with the participants:

1. Low awareness of HIV and HIV testing in Nova Scotia;
2. Misinformation or lack of information about HIV & HIV testing;
3. Stigma and discrimination about HIV and HIV testing; and
4. Accessibility / acceptability of HIV testing options and testing sites.

3.3.3 Experiences and perceptions of being tested for HIV in the past year

Participants who had been tested for HIV in the past year described this process in terms of:

1. Initiating the test (pre-test counselling);
2. Waiting for the test results; and
3. Receiving the test results (post-test counselling).

3.3.3.1 Reasons for being tested for HIV in the past year

Those who had been tested for HIV in the past year provided the following reasons for being tested:

1. Involvement in HIV-related risk behaviours (such as sexual activity or drug use);
2. Believed in personal responsibility for sexual health;
3. Believed that despite being monogamous, there is still a risk;
4. Were tested as a part of a routine health regimen;
5. Were tested “just to be sure”;
6. Had previous experience with STIs;
7. Their doctor suggested an HIV test; or
8. Experienced unexplained symptoms.

3.3.4 Facilitators to accessing HIV testing

Some potential facilitators to accessing HIV counselling and testing services included the following:

1. Increased education about HIV and HIV testing;
2. Increased availability of multiple testing options; and
3. Increased availability of accessible and supportive services.
4 DISCUSSION

Some key discussion points include who is seeking testing and who is testing positive; information and education about HIV and HIV testing (patient, practitioner, and general public); provision of accessible HIV testing services for diverse communities; and testing options (such as anonymous HIV testing and rapid point-of-care HIV testing) in various locations and contexts across the province.

4.1 Who is seeking testing and who is testing positive?

The laboratory testing data show that the number of HIV screening tests has increased over time, and that a large number of physicians from across the province send specimens for HIV screens, showing that efforts to increase uptake have been effective to a degree; however, continued efforts and further study are needed to ensure equitable access to health care services (as identified in the DOH mandate, 2010). Approximately equal numbers of males and females were being tested when prenatal tests were excluded (prenatal screening guidelines do not call for testing of partners), and the age distribution of tests was also similar for males and females. Our quantitative data suggests that approximately half of the women tested were done so as part of prenatal screening (as per our surrogate marker), but when this group is removed, the number of men and women seeking HIV testing is almost the same.

Individuals testing positive in the province have been predominantly male, between the ages of 40 and 44, although those most commonly accessing testing are individuals aged 25-29. The most commonly reported HIV exposure type for newly diagnosed HIV cases was men who have sex with men (MSM). It is important to understand the characteristics of those testing positive for HIV, but also to be mindful of the fact that there are HIV positive persons not represented in the provincial statistics. This may be due to the fact that individuals have been tested outside of Nova Scotia and later move to the province, or may be HIV+ but not been tested at all. Provincial statistics measure HIV incidence (new diagnoses) rather than prevalence (Nova Scotians living with HIV), which means that the number of newly diagnosed HIV cases do not necessarily represent the full burden of HIV in Nova Scotia.

4.2 Accessible HIV testing for diverse communities

The research participants described multiple ways in which they felt most comfortable accessing HIV testing as well as sexual health services in general. While several participants noted that they had a good or close relationship with their doctor, other participants said that they would not feel comfortable accessing HIV testing through their family doctor. Additionally, not everyone in Nova Scotia has a family doctor, or is comfortable accessing the services that are currently available to them (such as hospitals
and clinics in small or rural communities). There is a need to provide accessible HIV testing (in terms of location and method of testing) in order to meet the needs of diverse communities. Integrating HIV testing with sexual health services could be explored as a means to increase access to these services. It is important to look at alternatives to the continued reliance on the traditional model of HIV testing and counselling for all people in the province (PMCS, 2008).

4.3 Anonymous and point-of-care rapid HIV testing options

There is a need to increase availability of multiple HIV testing options by expanding anonymous testing services and introducing an option for rapid point-of-care testing in Nova Scotia. Anonymous testing sites have the potential to address concerns of confidentiality, and provide increased testing options for various populations across the province. Anonymous HIV testing services are meant to be provided in a safe, supportive environment (PBBPCC, 2004). The anonymous counselling, testing and referral strategy encourages increased counselling in combination with testing in order to strengthen prevention and risk reduction efforts. Rapid point-of-care testing may also provide a good alternative for some communities throughout the province since it lessens the waiting period between the initial reactive or positive test result and the confirmatory test result, which may have the potential to increase the number of individuals who receive their test results. Based on the results from four CDC studies, it was found that the performance of rapid tests is similar to or sometimes even better than conventional tests (Delaney et al., 2006). Concerns about quality assurance and how to deal with positive tests must be considered; rapid testing should occur at the point of care (not in the home) and it must also maintain counselling as a priority (Canadian Legal AIDS Network, 2000).

4.4 Information and education about HIV and HIV Testing

**Patient knowledge.** A lack of general knowledge about HIV, and HIV counseling and testing procedures, was common amongst the participants. A number of participants also stated that they were not aware of pre- and post-test counseling guidelines, since they did not receive counselling or they had not been tested before. This shows a potential lack of knowledge about the full range of testing options available in Nova Scotia, potentially stemming from limited communication between doctors and patients and the limited marketing of HIV testing in Nova Scotia by public health and other sectors.

**Practitioner knowledge.** Guidelines for testing and counselling provided by the Canadian Medical Association (CMA, 1995) require that patients are asked about their reasons for testing, and informed about the potential risks and benefits of the test; of course, these guidelines are being updated and are
due to be released soon (CATIE, 2009; PHAC 2006). The experiences of pre-and post-test counseling
described by research participants suggest that many practitioners in Nova Scotia are not following the
recommended practice guidelines for counseling and/or obtaining informed consent.

**General public knowledge.** Many participants suggested that increased education would be helpful to
them specifically, and their community in general. Previous research also recommends that further
outreach activities are needed in order to increase visibility of HIV and HIV testing and counseling
services in diverse communities across the province; the need for these outreach activities, of course,
needs to be identified by the community itself (PMCS, 2008).

**5 RECOMMENDATIONS**

The following recommendations identify potential strategies to address the issues identified in the
findings and discussion. These recommendations will be given more direction and depth with the
release of PHAC’s updated counselling guidelines for HIV testing.

**5.1 Integrate and innovate**

Integration of provincial health care policies and innovation with care provision is essential to providing
effective and accessible HIV testing. This emphasizes HIV testing as part of the continuum of quality
health care for Nova Scotians:

- Integrate HIV prevention, care and treatment and support strategies with the Nova Scotia Department
  of Health and Health Promotion and Protection mandate (e.g. collaborative practice, provision of
  quality care, culturally safe and culturally-competent care provision, integrated into existing system);
- Link HIV prevention strategies with Public Health Renewal strategy, providing opportunities for local
  innovation projects (See report on Public Health Renewal – HPP, 2006, and Nova Scotia Public Health:
  A Journey Towards Renewal, 2010c);
- Include strategies from diverse communities to make HIV testing and counselling services accessible to
  all Nova Scotians (one strategy does not suit the needs of all people);
- Promote awareness by providing HIV counselling and information for HIV testing to patients seeking
  sexual health related services such as pap testing, prostate examinations, STI testing, testicular cancer
  screening; and
- Innovate strategies in order to adapt to the changing needs of diverse Nova Scotian communities (e.g.
  sexual health / HIV educators in the community, training for outreach workers, information sharing in
  ways that is useful to the community).

**5.2 Increase education about HIV/AIDS in general and HIV testing in particular**

The next recommendation is to increase education amongst practitioners, patients, and the general
public about HIV testing and counselling options, as well as HIV in general. This reflects policy
suggestions and previous research findings (Extreme Group, 2007; PHASSC, 2003; PMCS, 2008; Thinkwell
HIV Testing and Counselling in Nova Scotia: Implications for Policy and Practice

5.2.1 Practitioners (offering, requisitioning, doing HIV testing)

Practitioners offering, requisitioning or doing HIV testing should have access to and be able to provide information about the following:

- Testing options available (general process and location of each);
- Pre- and post-test counselling information for patients (including a discussion of risks and benefits of testing, and including informed consent requirements);
- Referral services – where to go for further HIV information besides a family doctor; and
- Cultural competence – train practitioners in line with cultural competence strategies.

5.2.2 Patients (considering or accessing testing)

Patients who are considering or accessing HIV testing should be informed about the following:

- What questions to ask practitioners, such as HIV risk factors, the risks and benefits of HIV testing, knowing what they are being tested for and when this is happening; and
- Testing options that are available, and where (see pamphlet – HPP, 2009b).

5.2.3 General public / specific groups

With the involvement of diverse community representatives, strategies should be developed to share the following information with populations across the province:

- Basic information about HIV for the general public (risk factors, when to be tested, types of tests available, reporting and partner notification, and available treatments for HIV);
- Social marketing to reduce stigma of HIV and HIV testing (amongst diverse communities); and
- Heterogeneous, population-specific messages (directed by diverse communities).

5.3 Standardize population-appropriate counselling

Pre-and post-test counselling has been identified as an important component of HIV testing in Nova Scotia (PBBPCC, 2004; PHASSC, 2003; PMCS, 2008); it needs to be standardized and simplified, so that it can be delivered in a clear, concise, patient-appropriate and cost-effective manner. Some suggestions:

- Provide a pamphlet about pre-and post-test counselling for practitioners (with clear, easy-to-understand information about what patients need to know about the test and outcomes);
- Practitioners must (at minimum) inform patients what they are being tested for, to avoid assumptions that they have been tested for HIV, when in fact they have not;
- General discussion about HIV risk factors when patients access general STI testing;
- Counselling messages (whether traditional or streamlined) should be standardized to include necessary information, yet appropriate to the needs of the population being served; and
• Pilot targeted group information sessions which could serve as either a public awareness session and/or preliminary pre-test counselling.

5.4 Increase testing options available in Nova Scotia

There has been a consistent push to increase access to various testing options, particularly anonymous testing, in order to address certain barriers to testing in Nova Scotia, such as confidentiality concerns (PBBPCC, 2004; PHASSC, 2003; PMCS, 2008). The following options could mitigate these barriers to HIV testing, within the broader continuum of health and health care:

• Increase number of anonymous testing sites (available at multiple locations across the province, particularly in small or rural communities, where confidentiality and anonymity are a concern);
• Introduce rapid point-of-care testing, addressing quality assurance issues to increase benefits and mitigate risks of testing (potential to decrease the waiting period and increase the number of those who receive their test results, but must consider how to handle positive test results);
• Design and pilot a comprehensive annual sexual health examination, which includes HIV testing for targeted groups of sexually active individuals; and
• Encourage physicians who have a high immigrant base to consider HIV (and sexual health in general) as a discussion item during patient visits in a manner that does not further potential stigma.

5.5 Conduct further HIV-related research

Directions for further HIV testing research to consider, in conjunction with the previous recommendations, include:

• Assess community-specific needs for increasing access and uptake of HIV testing (generated by an interest and involvement from within the community);
• Develop an effective HIV testing social marketing strategy with appropriate messages for diverse Nova Scotian communities (again, with interest and involvement from the community);
• Conduct a sero-prevalence study to develop HIV prevalence estimates for Nova Scotia;
• Examine HIV testing rates by geographic communities and ethno-racial populations;
• Understanding HIV risk of infection for different populations would require details of sexual networks and associated sexual behaviours to determine whether those being tested are representative of those at risk of HIV infection;
• The reason for testing is not available for the majority of HIV tests conducted. Further exploration of testing at the time of other STI testing, or pap smear testing for females, may indicate settings contributing to higher and lower HIV testing uptake; and
• Further investigate why more females than males are tested in the Emergency Room setting (potential links to research and policy around sexual assault).

6 CONCLUSION

“HIV Counselling and Testing in Nova Scotia: Implications for Policy and Practice” was carried out in order to better understand the HIV testing rates in Nova Scotia, as well as the perceptions and experiences of HIV testing and counselling of a sample of rural and urban adults. This research is meant to provide evidence that will increase uptake of testing by addressing the barriers to access experienced by various communities throughout the province, and improve experiences of testing by implementing
facilitators to access. The Department of Health, Department of Health Promotion and Protection, District Health Authorities, physicians, allied public health professionals, community-based organizations and members of populations most impacted by these issues are strongly encouraged to work collaboratively to address the recommendations in this report and find ways to increase accessibility to HIV testing in Nova Scotia. We must acknowledge and address both the individual and societal barriers to HIV testing in order to realize the provincial mandate of quality and equitable health services for all people in Nova Scotia. This research promotes action geared toward shifting policy and increasing access to HIV counselling and testing services to service the needs of the many diverse Nova Scotian populations.
1 INTRODUCTION

Throughout the world, HIV/AIDS kills more people than any other known infectious disease (WHO, 2010). It is estimated that approximately two million deaths occurred from AIDS in 2008, ranking it the sixth leading cause of mortality (WHO 2010; WHO, 2008). At the end of 2008, approximately thirty million people worldwide were living with HIV, and close to three million people became newly infected (WHO, 2010). HIV remains the leading cause of death among women of childbearing age (WHO, 2008).

Internationally, HIV counselling and testing policies and practices are at a crossroads. International debate about the importance of voluntary HIV testing and counselling procedures is ongoing (Canadian HIV/AIDS Legal Network, 2005; CDC, 2008; CDC 2006; Fisher et al., 2006; PHAC, 2006) and a major driver of this debate is the fact that many individuals are unaware of their infection or receive late diagnoses, both of which may result in forward transmission and poorer health outcomes (Chadborn et al., 2006; Marks et al, 2006). The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) support provider-initiated HIV testing, though they continue to promote increased client-initiated HIV counselling and testing (WHO, 2007). For opt-out testing to be in the best-interests of the patient, they suggest service providers must ensure sufficient information is given for patients to make informed decisions, maintaining confidentiality, performing post-test counselling and referring patients to the appropriate services. This policy reflects a widespread shift in HIV testing guidelines from pre-test counselling to a discussion and provision of information.

In the US, the Centers for Disease Control (CDC) have recommended that HIV testing should become a routine part of medical treatment in all health-care settings for those aged 13-64 (opt-out testing), and requirements for written consent and pre-test counselling should be removed (CDC, 2006). This policy suggests high-risk individuals should be tested for HIV at least annually, and perinatal screening should be offered routinely in order to scale-up HIV prevention. Additionally, the UK’s National Testing Guidelines for HIV suggest that all patients going to a Genitourinary Medical (GUM) Clinic should be offered HIV testing (Rogstad et al., 2006). Patients considered to be “high-risk” should be given increased time for more in-depth pre-test discussion.

The Public Health Agency of Canada (PHAC) is currently revising the Canadian Medical Association (CMA) counselling guidelines for HIV testing from the mid-90s and developing a new HIV counselling and testing policy framework for all Canadians (CATIE, 2009). These revisions, in conjunction with the ongoing international debate, acted as a major impetus for the current research study. We see this as a key opportunity in the development of counselling and testing strategies for Nova Scotians.
1.1 HIV/AIDS in Canada

HIV/AIDS remain a significant threat to the health and well-being of Canadians. While men who have sex with men (MSM) continue to make up the majority of cases, the number of new infections due to unsafe injection drug use (IDU) practices and heterosexual contact with an HIV infected partner has increased steadily since the late 1980s (Dodds et al., 2001). New HIV infections are also becoming more prevalent among groups that are often marginalized in our society such as: Aboriginal populations, persons from countries where HIV is endemic, people in correctional facilities, individuals with lower socio-economic status, and the homeless (CAH, 2009; CATIE, 2009; CPHA, 2005). In 2008 approximately 26% of all new infections occurred in women (of all ages), and both Aboriginal persons and persons from HIV-endemic countries continue to be over-represented in Canada’s HIV epidemic (PHAC, 2009a).

In 2008 there was an estimated 2300 to 4300 new HIV infections in Canada (PHAC, 2009a). It is believed approximately 27% of persons living with HIV are unaware of their infection. This means that an estimated 16 900 Canadians are likely HIV positive but have not been tested (PHAC, 2009a). It is apparent that even in countries like Canada where HIV testing is readily available, the number of people who access HIV testing remains relatively low. There are numerous factors that can serve as barriers to accessing testing (including issues of confidentiality and fear of stigma and discrimination) that continue to deter people from HIV screening (Canadian HIV/AIDS Legal Network, 2005). Without an effective continuum of HIV primary and secondary prevention, including a fuller understanding of HIV testing policies, those in need of care, treatment and support may be missed by health care efforts.

1.2 HIV counselling and testing in Nova Scotia

Nova Scotia, a small province with unique cultures and communities, provides health care professionals and policy analysts with many challenges for developing and implementing appropriate HIV prevention, care, treatment and support strategies, particularly in relation to HIV counselling and testing. Since 1985, approximately 700 persons have tested positive for HIV in Nova Scotia, though the actual number of HIV infections is probably higher since some HIV positive individuals may be unaware of their status or they may have been tested in another province (PHAC, 2009a). Nova Scotia offers three types of HIV testing: nominal testing (available since 1985); non-nominal testing (available since 1991); and anonymous testing (available since 1994). The anonymous HIV testing service was initiated in Halifax, the province’s capital, and in 2007 became available in Sydney, the second largest urban centre in Nova Scotia (with outreach to rural communities upon request). People can call or drop in to these locations
to make an appointment (6009 Quinpool Road in Halifax, or 150 Bentinck Street in Sydney). HIV testing offered in Nova Scotia is mandated to be opt-in testing (requiring the client’s consent to be tested).

Nominal testing – your name will be used on the form that is sent to the laboratory with your blood sample. Your name will also be used on the test result when the lab sends it back to your doctor. If the test result is positive, the lab and your doctor will report it to the Medical Officer of Health using your name. Nominal testing is available through your family doctor and at various health clinics.

Non-nominal testing – a number code created by your doctor will be used on the form that is sent to the laboratory with your blood sample. This code will be used on the test result when the lab sends it back to your doctor. If the test result is positive, the lab and your doctor will report it to the Medical Officer of Health using the code. Only you and your doctor will be able to link your name back to the code used. The test result may be recorded in your medical file by your doctor and reporting of the actual name is possible. Non-nominal testing is available through your family doctor and health clinics.

Anonymous testing – getting a test for HIV without giving your name. You must call an anonymous testing clinic for an appointment using a first name. At no time will you be asked for a full name, and your name will not be recorded or reported even if the result is positive. Anonymous testing is available only at anonymous testing clinics in Halifax, Sydney, and available outreach locations.


Opt-in testing – the HIV test is offered as a routine part of discussions with all patients in a given setting or meeting certain criteria (e.g. all pregnant women or all patients using STI health services). The client must specifically agree to the test, rather than merely not decline it.

Opt-out testing – the HIV test is performed after notifying the patient that the test will be performed and that they have the right to decline or defer testing. Consent to be tested is assumed unless the patient explicitly declines testing.


Despite the availability of nominal, non-nominal and anonymous testing options, barriers in accessing HIV counselling and testing persist in Nova Scotia. These include geographic isolation for rural and remote communities, not enough anonymous testing sites in the province, fear of disclosure particularly in small communities, poverty, and continuing stigma associated with HIV testing (PHASSC, 2003). There is still limited evidence to support what constitutes effective counselling, testing and reasons for seeking or not seeking HIV testing in various communities throughout Nova Scotia.
1.3 Study purpose

As we see the HIV testing climate continue to shift and change (CDC, 2006; PHAC, 2006), we regard this as a key opportunity to understand the implications of various testing and counselling strategies on the health of Nova Scotians. Recognizing that HIV counselling and testing is a means of facilitating timely access to care, treatment and support for those who are found to be HIV positive and to help prevent the further spread of infection, understanding HIV testing behaviours is a critical facet in the prevention of the spread of HIV in Nova Scotia. For example, it is widely understood that the health outcomes are far worse among those who are tested and diagnosed later in their infection. Therefore the objectives of this study were: 1) to understand the HIV testing rates and behaviours among individuals between the ages of (15 to 65) in Nova Scotia and 2) to develop a better understanding of the experiences of individuals that have been tested (with a positive or negative result); or those who have not been tested (and have or have not considered testing).

In addition to these broad research goals, particular attention was paid to social inclusion in an effort to give voice to the various issues faced by members of diverse geographic and ethno-racial communities across Nova Scotia. The provincial HIV/ AIDS strategy identifies a need for more research about all aspects of HIV/AIDS, particularly in Aboriginal and African-Nova Scotian populations (PHASSC, 2003). The information presented in this report reflects an attempt to address some of these gaps, keeping in line with the aim of developing and implementing a comprehensive prevention and harm-reduction strategy geared towards diverse populations within a variety of service settings (PHASSC, 2003). This is a pivotal time to consider how national HIV counselling and testing developments and strategies may influence the HIV testing experiences of people living in provinces such as Nova Scotia.
2 DATA COLLECTION

The data collection methods for this study were divided into three interconnected phases, each one building on the other. The core elements included a review of relevant HIV policy and programming documents, followed by the assessment of surveillance data related to the rate of HIV testing in Nova Scotia, and ending with in-depth interviews with a purposive sample of individuals from across Nova Scotia who had either sought HIV testing or had not sought HIV testing in the past year.

Community consultations were held in the Fall of 2008 to determine the various gaps in information, as well as to help set up a Community Advisory Committee for this research study. This committee assisted with the development of the interview guides and provided input on relevant policy issues and concerns from diverse perspectives. Members of various communities and organizations were invited to attend the Community Advisory Committee meetings (held monthly) to provide valuable input and suggest various issues of importance to this project. The final aspect of this project involved knowledge translation of the findings to our key partners and stakeholders.

2.1 Policy review

This study commenced with a review of Nova Scotia provincial HIV counselling and testing policies and programmatic responses. Key policy and research documents from Nova Scotia were gathered in order to undertake a critical review of these policies with the aim of ensuring they maximize an effective provincial response to HIV. An initial scoping exercise to search the research and policy literatures took place in collaboration with members of the Advisory Committee who provided input into document selection and analysis. Relevant documents meeting the search criteria for inclusion in the policy analysis were reviewed by the research team members. The final stage of the policy review phase involved the integration of themes from across the documents and a comparison to the themes emerging from the qualitative interviews, and then linking this information to the recommendations.

2.2 Surveillance

HIV surveillance data, including numbers of laboratory screening tests and epidemiologic information on positive cases, were gathered by Health Promotion and Protection (HPP) and the Capital District Health Authority (CDHA). The CDHA is the largest provider of health services in Nova Scotia and covers the Halifax Regional Municipality (HRM). The CDHA laboratory, along with five other laboratories across the province, conduct HIV screening tests. Estimates of the numbers of HIV screening tests conducted across the province for 2008 were provided by the Provincial Public Health Laboratory Network. Data collected
for all HIV screening tests performed at the CDHA laboratory between April 2009 and April 2010 were extracted from the Capital Health Laboratory Information System, representing nearly three quarters of all HIV tests conducted in Nova Scotia. These data were anonymized prior to analysis. Data fields analyzed included age group, sex, probable prenatal screen and test setting. Nova Scotia’s Department of Health Promotion and Protection (HPP) collects demographic and epidemiological information on all laboratory confirmed HIV positive cases and all anonymous screening tests. Data fields analyzed for newly diagnosed HIV cases and for anonymous tests include age group, sex, and exposure type. Demographic information for those who have accessed anonymous testing in Halifax (between 2006 and 2010) was provided by the Halifax Sexual Health Centre (HSHC) as a non-representative example of who is accessing this service. These data sets provide a snapshot of the HIV testing uptake rates for Nova Scotia and allow for a better understanding of the gaps in HIV testing.

2.3 In-depth interviews

50 in-depth interviews were conducted between July 2009 and May 2010 with individuals who had sought an HIV test in the 12 months prior to the interview (open to both those who have tested positive, as well as those who have tested negative), and those who had not sought testing. A major priority of this study was to include the voices of diverse populations in Nova Scotia, particularly those who have not traditionally sought HIV testing and counselling services. Although purposive sampling was employed to ensure representation from diverse populations in Nova Scotia, all participants needed to volunteer and be self-selecting. Recruitment fliers were distributed to various community-based, health and government organizations across the province, and with their referrals and cooperation, it was possible to locate and conduct interviews with diverse participants. The Community Advisory Committee provided input into sampling design for in-depth interviews and content of the interview guide.

Interviews were conducted by the research coordinator and a research assistant, both of whom received training and signed confidentiality agreements before conducting the interviews. The participants were informed of the purpose of the research, as well as their rights as a participant, prior to commencing the interviews. Information resources about HIV testing, care, treatment and support was offered to all participants, including information about counselling services. An honorarium ($15) was given to participants to partially offset their time, and they signed a receipt of payment form. All interviews were audio-recorded with permission of the participants and were transcribed verbatim, and then cleaned of identifiable information.

4 See appendices for copies of the recruitment posters and interview guides.
The interview data were analyzed and managed with the assistance of qualitative software program, Atlasti. Thematic analysis was undertaken to determine the key testing issues faced by the participants. This process included reading and re-reading the transcripts, creating codes from a systematic review of the data, and allowing for the emergence of themes. Atlasti assisted in identifying frequent and outstanding findings in the qualitative data, which were then categorized with attention to the common themes but also with respect to the diverse perceptions and experiences of the participants. Through the process of analysis, many themes emerged related to the perceived and experienced barriers and facilitators to accessing HIV counselling and testing services.

2.3.1 Sample of interview participants

Participants were asked to answer demographic questions in order to track the representation from diverse communities in this study. Specific efforts were made to include Aboriginal, African-Nova Scotian, immigrant and rural populations. Some of the questions asked enabled the participant to self-identify, meaning that the demographic information collected does not constitute discrete or exhaustive categories. For example, participants were asked what they considered to be their ethnicity. A comprehensive list of all the self-identified ethno-racial categories includes: Acadian, African, African-Canadian, Anglo-Saxon, Black, Canadian, Caribbean, East Indian, English, First Nations, French, German, Indian, Irish, Italian, Native, Native American, Nova Scotian, Métis, Mexican, Mi’kmaq, Scottish, and White. In order to protect the identity of participants, more generic groups of Aboriginal, African-Nova Scotian and Caucasian are linked to quotations for context (each of the participants with multiple ethnicities belonged to one of these groups). Age ranges will also be used in lieu of the participants’ actual ages to further protect their identities.

Participants who were members of an Immigrant population were not overtly asked to self-identify as an immigrant, although this information often emerged in the course of interviewing these participants. Again, participants were asked to self-identify their ethnicity, and to describe how long they had lived in Nova Scotia, and not specifically whether they had immigrated to Canada. In instances where this information emerged in conversation, immigrant status is identified when quoting these participants in following sections.

Representation from rural communities is also complex, since participants were asked only to answer whether they lived inside of HRM or outside of HRM. In some instances, participants who lived in Halifax Regional Municipality (HRM) were from rural communities originally, or spoke about their experiences in small communities within HRM. In other instances, participants who lived outside of HRM
in towns and cities across the province were not necessarily representative of rural communities. Specific efforts were made to include participants from small villages and towns across the province.

2.4 Research ethics
Prior to data collection, the research protocol and interview guide was approved by the Capital Health Research Ethics Board. All of the surveillance data collected was anonymized and aggregated, and therefore impossible to link back to individuals who had been tested. Collection and analysis of these data sets were approved by the Capital Health Research Ethics Board. All information collected by the research team as part of this study, and all copies of the surveillance data were used only for the purpose of this project and were treated as confidential by members of the research team. All data collected was stored in a secure locked cabinet, to be kept for a period of five years after the completion of the project in accordance to Dalhousie University guidelines. Member checking of the transcripts was limited to interested members of the Advisory Committee and the research team, all of whom were required to sign a confidentiality agreement. All research data were maintained by the Principal Investigator and the Research Coordinator.

2.5 Study limitations
There are several limitations of this research that require identification and explanation. This relates to the three specific areas of data collection and analysis: policy, surveillance and interviews.

2.5.1 Policy review limitations
The policy documents reviewed in this report represent a sample of the major documents which are meant to inform the practical and ideal aspects of HIV testing and counselling in the province. These documents were compiled based upon suggestions from the Community Advisory Committee, and were meant to provide a foundation for this research, to show what has already been done, and to help evaluate based upon the findings of this study whether these policy goals have been met. While the review is not exhaustive, it provides a thorough overview of some of the main issues pertaining to HIV testing and counselling in Nova Scotia that were important in this study.
2.5.2 Surveillance limitations

The surveillance data represent approximately 71% of tests, and it is unknown if tests conducted outside CDHA follow similar age and sex distributions. Further examination of the lab data from outside of CDHA would be required in order to assess whether the trends are similar throughout the entire province.

Further investigation is also required to know the testing rates by community, in terms of rural or urban populations, or communities of diverse ethno-racial identities. Indication for testing is not available for the majority of HIV tests conducted. Risk information is only available by self-report from newly diagnosed HIV positive cases and from anonymous testers. While the majority of anonymous testers reported no identifiable risk for HIV exposure, it is unknown whether risk of exposure is truly low or individuals are not fully disclosing possible risks. While testing demographics can be assessed for those being screened for HIV infection, it is not known whether those being tested are representative of those at risk of HIV infection. Understanding risk of infection for different populations would require much more complex details of sexual networks and associated sexual behaviours.

The probable prenatal screen definition may underestimate the true proportion of HIV screening tests performed as part of a prenatal testing algorithm, as the definition applied does not include prenatal HIV screening tests for which specimens were collected on a day other than the day on which specimens were collected for other prenatal tests.

2.5.3 Interview limitations

A major goal of this research was to include representation from a broad range of individuals, including participants of various sexes and gender identities, ethnicities, ages, and geographic locations in Nova Scotia. While this is certainly a strength of the research, it is necessary to acknowledge that this study does not represent each of the diverse social groups. Instead, it was important to give voice to the study’s participants, from many different backgrounds, and not exclude these perspectives.

The research question and research goals for this project were intentionally quite broad. This enabled the researchers to explore numerous and differing experiences and perceptions about HIV testing and counselling in Nova Scotia. Due to the open nature of the questions, it is beyond the scope of this research to identify with great specificity and generalizability the issues affecting each group. The research itself can be classified as an exploratory study to examine the experiences and perceptions of individuals throughout Nova Scotia. The purpose of this research was to offer evidence about some of the issues, barriers and challenges to HIV testing policy and practice faced by communities throughout the province. We offer an overview of these issues, including the voices of diverse participants, in order...
to provide a foundation for further research. Future research may focus more specifically on the issues faced by each community (based on the needs/desires/input of members of the community).

There were also a number of challenges in regards to the recruitment of participants for this research study. Due to ethics restrictions, participants needed to self-select and volunteer to be interviewed. This non-randomly selected study population may not be representative of the sub-communities described in this study. The recruitment process relied heavily upon the cooperation and collaboration of various community-based organizations and word of mouth. Although recruitment posters were distributed widely across the province, most interviews were set up through a community contact. In addition to this, there were also some limitations as far as the amount of travel possible to different rural communities; however, the inclusion of telephone interviews assisted with this process.

The recruitment process was structured this way to ensure that various groups did not feel that they were being “targeted” by the researchers, and also to ensure that participation was completely voluntary. There were of course some challenges to these ideal research conditions, which included the offer of a $15 honorarium (which may have been a motivator for some individuals) and professional or personal involvement with community contacts (which may have influenced their decision to participate, as well as the nature of their responses). It was ultimately important to adhere to ethical practices, although this limited which methods of recruitment were available.
3 FINDINGS

The findings of this research study correspond to the three types of data collected and analyzed, including secondary data sources (policy documents, HIV surveillance data), and primary data (in-depth interviews). The following section includes a description of findings from each data source.

3.1 Policy review

For this study, we reviewed Nova Scotia Government policy documents in addition to HIV/AIDS policy and research to assess how the current policies approach HIV counselling and testing for Nova Scotians. The documents reviewed included: Department of Health and Health Promotion and Protection statements of mandate, Department of Health business plan, and policies on cultural competence and statements related to culturally safe health care services for Aboriginal People (2009/2010); the provincial HIV/AIDS strategy (2003); the blood borne pathogen standards (2004); reports produced for the ‘pre-natal screening project’ commissioned by the NSACA(2007); and the report produced for the NSACA on a ‘strategic approach’ to increase HIV screening in Nova Scotia (2008).

3.1.1 Nova Scotia government policies

**Department of Health Statement of Mandate**

Prior to examining HIV-specific policy, it is important to look at general health mandates in Nova Scotia. The Department of Health’s 2010 statement of mandate focuses on three specific goals:

1) To provide timely access and high quality, safer health care for Nova Scotians;
2) To provide value for money through effective and efficient use of public resources; and
3) To improve the health status of Nova Scotians (DOH, 2010a).

These three goals emphasize the quality of care, efficiency of services provided, and the overall health status of Nova Scotians, which are important factors in the delivery of effective HIV prevention strategies, such as HIV counselling and testing.

**Department of Health Promotion and Protection Mandate**

The Department of Health Promotion and Protection also has a statement of mandate, which includes four strategic outcomes. The four strategic outcomes HPP seeks are:

1) Improved health outcomes for children and youth;
2) More Nova Scotians taking an active role in promoting and protecting the health of individuals, families and communities;
3) Safer citizens, populations and communities; and
4) Reduced health disparities (HPP, 2010).
These strategic directions emphasize the health of Nova Scotia’s youth, active involvement of Nova Scotians in their own health, increasing safety for individuals and groups and reducing health disparities.

**Department of Health Business Plan**

In the 2009 Department of Health Business Plan, they state six strategic priorities, goals and performance measures:

1) Enhance the quality-focused integrated service delivery system;
2) Develop a comprehensive primary health care system for all;
3) Ensure a high quality health system workforce;
4) Strengthen governance and accountability across the continuum;
5) Create comprehensive Information Technology and Management Systems; and
6) Engage Nova Scotians in the health system (DOH, 2010b).

These strategic priorities, goals and performance measures have their emphasis on quality, inclusion, accountability, collaboration and engaging the general public in Nova Scotia. These are all pertinent goals in regards to HIV counselling and testing in the province.

**Cultural competence**

A major component of providing quality health care to all Nova Scotians is the notion of cultural competence. Cultural competence refers to “the attitudes, knowledge, skills, behaviours and policies required to better meet the needs of all the people we serve” (Health team Nova Scotia, 2008a). Culture itself refers to a group or community (including those that we are born into such as race or sex, and those that we become, such as religion or education), and the shared, common experiences of these groups that shape the way they understand the world (Health team Nova Scotia, 2008a). A culturally competent approach can help to:

1) Reduce disparities in health services;
2) Address inequitable access to care; and
3) Respectfully respond to the diversity of Nova Scotians (Health team Nova Scotia, 2008a).

Cultural competence in primary health care:

1) Provides health care to patients with diverse values, beliefs and behaviours, including tailoring delivery to meet patients’ social, cultural, and linguistic needs;
2) Requires an understanding of the communities being served as well as the cultural influences on individual health beliefs and behaviours; and
3) Devises strategies to identify and address cultural barriers to accessing primary health care. (Health team Nova Scotia, 2008b)
It is important for practitioners within the health care system to work collaboratively with these communities to develop culturally appropriate and specific ways of delivering care. This includes providing cultural competence training, providing language interpreter services, and including cultural competence at all levels of planning and practice (Health team Nova Scotia, 2008a).

**Cultural safety**

Culturally safe care is also important, specifically in the context of Aboriginal populations in Canada. The National Aboriginal Health Organization (NAHO) suggests that a culturally safe approach to health care can improve the experience of health care both from the provider’s and recipient’s perspective, in addition to improving the ability of health care providers to meet the needs of diverse communities (NAHO, 2008). As mentioned previously, Aboriginal populations are over-represented in the HIV/AIDS epidemic in Canada (WHO, 2010); it is therefore imperative that the needs of Aboriginal communities, as well as the historical context of these needs, are recognized and valued at all levels of health care planning and delivery, specifically in regards to HIV/AIDS strategies.

### 3.1.2 Nova Scotia Strategy on HIV/AIDS

The Nova Scotia Strategy on HIV/AIDS, which was released in 2003, identifies a number of key areas of importance in regards to the state of HIV testing, counselling, prevention and treatment in the province. It is based on an extensive consultation process which included input from community-based AIDS organizations, government stakeholders, and individuals throughout the province. The strategy is organized into four strategic directions; the third direction is perhaps most relevant to the examination of HIV testing and counselling policy and practice in Nova Scotia.

Strategic direction 3 focuses on building a coordinated approach to HIV prevention and harm reduction across the province. This includes education about healthy sexuality for youth, adopting a province-wide continuum of services including expanded anonymous testing, and promoting public education and awareness about HIV/AIDS (PHASSC, 2003). Recommended action 3.4 examines ways in which public health and community-based organizations in Nova Scotia can collaborate to develop and implement a comprehensive approach to HIV prevention and treatment for diverse communities in various service settings. It promotes anonymous HIV testing in multiple settings across the province, such as correctional institutions and community health centres, to increase access for more vulnerable populations (such as men who have sex with men, women, aboriginal persons, injection drug users, youth, and prison inmates) (PHASSC, 2003). Recommendations include creating an integrated network of anonymous testing sites, providing discrete access to barrier prevention methods, needle exchange
and methadone services, coordinating delivery of services, promoting peer-based prevention and education, ongoing evaluation of services and training on harm-reduction and sensitivity to affected populations (PHASSC, 2003). Recommended action 3.5 suggests the development and delivery of a collaborative awareness campaign to provide the public about HIV/AIDS, which was identified as a priority action for implementing the strategy in Nova Scotia (PHASSC, 2003).

3.1.3 Standards for the Blood Borne Pathogens Prevention Services in Nova Scotia

The blood-borne pathogens prevention services standards were developed with the help of various stakeholders across the province in 2003 and 2004. In 2003, the Department of Health established the Blood Borne Pathogens Coordinating Committee (PBBPCC) which developed prevention standards in these categories: health education and social marketing, methadone maintenance treatment, needle exchange services, and blood borne pathogens counselling, testing and referral services (PBBPCC, 2004).

For our purposes in this report, it is most relevant to examine the strategy pertaining to counselling, testing and referral.

The HIV counselling, testing and referral standards encourage increased counselling in combination with testing in order to strengthen prevention and risk reduction efforts. Anonymous testing sites provide a model for expanded counselling, testing and referral services in Nova Scotia. These services are meant to be provided in a safe, supportive environment. The standard statements highlight the following points (PBBPCC, 2004):

- District Health Authorities (DHA) provide access to counselling, testing and referral services for BBPs (HIV and hepatitis);
- Counselling services include information on transmission, prevention and testing options, assessment, implications of testing, and risk reduction strategies;
- Testing services include informed consent, qualified staff, timely transportation of samples to the lab, and communication of test results to the client;
- Referral services include primary health care, addictions, mental health, health promotion, disease prevention, education and a variety of other health services, screening tests and confirmatory tests are done;
- Technologies used are endorsed by the provincial lab and meet public health standards; and
- Services follow legislated positive test reporting and partner notification requirements (as reflected in the Health Protection Act – HPP, 2004).
Implementation of the BBP Prevention Standards requires collaboration between the Department of Health, the Department of Health Promotion and Protection, District Health Authorities, and Community-based organizations, each responsible for different aspects of the implementation process (such as leadership, planning and evaluation).

### 3.1.4 Increasing HIV Screening in Pregnancy (literature/document review)

Research for the project “Increasing HIV Screening in Pregnancy” (commissioned by the NSACA in 2007) examined the experiences and perceptions of women in regards to pre-natal HIV screening, produced a literature review and made recommendations for a communication strategy. The literature/document review was intended to act as a reference point for looking at how to increase update of prenatal screening for HIV in Nova Scotia. (Extreme Group, 2007). This document is divided into six sections:

- **Review of case studies and initiatives to encourage pregnant women to be screened** – including posters and websites from Alberta, Ontario, Newfoundland and Labrador, USA, Sweden, UK, Brazil and Australia;
- **Summary of relevant social marketing initiatives** – e.g. opt-in/opt-out, social awareness campaigns using print and broadcast media, update/inform healthcare providers, target different cultures/languages, collaborative effort of all healthcare professionals, information essential for allowing an informed decision regarding testing;
- **Where, how and from whom women get care and information** – health care professionals, pamphlets, brochures and other materials (e.g. in UK information mailed to women), pre-and post-test counselling, Aboriginal, immigrant and rural women have higher rates of testing and counselling, rural concerns such as confidentiality and gossip;
- **Awareness, attitudes and perceptions** – low awareness of treatments, low perception of risk, many thought testing was mandatory, baby’s health was the main motivator for testing, lack of knowledge about testing and about transmission, etc; and
- **Barriers to testing** – including lack of time, new doctors, lack of discussion, lack of perceived risk, fear, uncomfortable questioning doctor, doctors refusing testing to those perceived to be not at risk, lack of information/choice, fear of stigma of being “high risk”, living in smaller communities, barriers for Aboriginal populations (e.g. reserves are often small communities, and travel to seek out anonymous testing can be a problem).
Increasing HIV Screening in Pregnancy (focus groups)

The second document produced, “Toward Development of a Communication Strategy to Increase Awareness and Screening of HIV in Pregnancy (Phase 1),” suggested that increasing awareness and screening of HIV in pregnancy is a priority in Nova Scotia (Thinkwell Research, 2007). It outlined the findings of focus group research conducted to learn more about women’s experiences with prenatal HIV testing in Nova Scotia. The focus groups were aimed at soliciting both actual and perceived challenges and opportunities in regards to women’s knowledge, attitudes and behaviour around prenatal testing. Intending/pregnant women, new mothers and marginalized women participated in these focus groups. The following themes emerged from the focus groups:

- **Information about prenatal care** – participants were proactive in seeking out care and prenatal care information, although they did have a few worries, including inconsistent care providers, wait times, and accuracy of information about prenatal care;

- **Lack of awareness of HIV** – indicated by the words participants associated with HIV and its related stigma, sources of information on HIV, perception of vulnerability to HIV, awareness of HIV testing methods, and awareness of HIV treatment;

- **Awareness of prenatal HIV testing** – related to participants’ experiences, the ideal, doctor’s responsibility to initiate conversation, and HIV testing done while not pregnant;

- **Messages to other pregnant women** – participants’ messages were encouraging for other pregnant women to have HIV testing done;

- **Preparation** – participants felt that having a package of information about prenatal testing, including an HIV test, sent to them prior to visiting their doctor would answer a lot of questions and increase their uptake of information; and

- **Concept testing** – when comparing a poster about prenatal “opt-in” HIV testing from Ontario and “opt-out” from Alberta, participants responded more positively to the idea of opt-out testing, and the Alberta poster promoting it, because it made the test seem more routine.

The results of this study suggest that prenatal HIV testing was regarded as a routine test for most women, and was perceived in a positive light. Specifically, many of the women interviewed suggested that HIV testing was not a “big deal.” HIV was not considered to be a pressing issue for many of the women interviewed. However, many of the women who participated in the focus groups were not certain whether or not they had received prenatal HIV testing. It was reported that in most cases, there was little if any discussion with health care providers about HIV and other prenatal tests conducted.
The Nova Scotia Advisory Commission on AIDS (NSACA) had intended to spearhead development of a prenatal social marketing campaign throughout Nova Scotia, but postponed it to conduct a wider exploration of the issues that emerged from the prenatal project research findings given the broader implications for HIV testing in Nova Scotia. This is expanded upon in the following section.

3.1.5 A Strategic Approach to Increase HIV Testing in Nova Scotia

Based on the research findings of the prenatal HIV testing project, the Commission engaged Pyra Management Consulting Services (PMCS) to “explore and recommend options for increasing the provision, quality, and awareness of HIV testing services in Nova Scotia” (PCMS, 2008). This report included a literature review as well as interviews with key stakeholders to inform various recommendations to increase access to HIV testing in Nova Scotia. Most of the stakeholders suggested that nominal, non-nominal and anonymous testing should be available throughout the province, but they believe that testing is not equitably distributed and application of the counselling and informed consent guidelines for HIV testing vary significantly among health care providers. Populations not accessing HIV testing services included injection drug users, rural populations, youth, Aboriginals and women (PMCS, 2008). Barriers to accessing testing include (but are not limited to) real/perceived lack of confidentiality and privacy, stigma and discrimination, lack of awareness of risk for HIV, cultural norms of hostility towards HIV, fear of adverse consequences and personal isolation, cost, lack of transportation, and for youth, lack of testing available in youth-friendly settings. The largest barrier identified was the continued reliance on a single (and unchanged since the 1980s) voluntary HIV testing and counselling model for all people in the province. Alternatives included rapid point-of-care testing, routine testing, streamlined counselling, opt-out models, increasing awareness, increasing number of rural testing sites, creating a network of drop-in centres, increasing outreach services, and making testing part of regular screening services (PMCS, 2008). The key messages identified include:

- HIV testing is an important public health issue that needs ongoing attention;
- HIV issues in general, and HIV testing in particular, has a very low profile in Nova Scotia;
- The Standards for Blood Borne Pathogens Prevention Services in Nova Scotia have not been implemented consistently across the province;
- The current model of service provision is not being implemented effectively in terms of making HIV testing equitably accessible to all Nova Scotians (particularly those most at risk);
- There is support and willingness on the part of various stakeholders to do things differently;
- Several different strategies may need to be tried in order to increase testing; and...
• One approach will not work with all communities, and these communities must be engaged in finding solutions that work for them.

Actions steps to increase HIV testing in Nova Scotia include:

• Commit resources to address HIV testing (Department of Health, HPP and DHAs);
• Allocate responsibility for implementing Standards for Blood Borne Pathogens Prevention Services to a dedicated person in public health who has the time to manage the issue;
• Implement and fund the Standards for Blood Borne Pathogens Prevention Services supported by persons dedicated to this task in each DHA, making increased HIV testing the first priority;
• Provide point-of-care rapid testing as an option in addition to the available 3 testing options;
• Implement a social marketing campaign for diverse audiences with information encouraging people to seek HIV testing, and providing information about where to get tested; and
• Implement a pilot test of routine screening in various primary care practices, and assess the impact on number of tests, number of positive tests, and time impact for patient and physician.

Summary of policy

The current provincial policies on HIV counselling and testing in Nova Scotia promote HIV and AIDS as an important public health issue. A review of these select documents rendered several key themes:

• Provide quality, efficient, effective and culturally-competent health care to Nova Scotians;
• Strengthen the harm-reduction health care model (to decrease the impact of risk behaviours);
• Increase awareness about HIV in Nova Scotia, as well as awareness about the HIV testing and counselling options that are currently available;
• Build on existing HIV counselling and testing services in Nova Scotia by expanding options for HIV testing (including anonymous and rapid point-of-care testing);
• Ensure quality and equitable access to services by developing and implementing various HIV testing strategies for diverse communities and their unique needs;
• Increase clear communication between physicians and patients via pre-and post-test counselling, including a discussion of the nature of the test, the testing process, and the potential risks and benefits of being tested for HIV;
• Ensure cross-disciplinary collaboration beyond the health sector in increasing visibility, access and uptake of HIV counselling and testing; and
• Work collaboratively with the Departments of Health and Health Promotion and Protection, Public Health, District Health Authorities, and Community-based organizations to enhance the implementation of the Blood Borne Pathogens Prevention Standards.
3.2 Surveillance

Surveillance data were collected by the Department of Health Promotion and Protection in conjunction with the Capital Health Laboratory. This section of the report includes an overview of HIV testing rates across the province (in 2008), number of tests per year over time (1999-2008), various identified risk factors of those being tested and the setting of testing (2009), as well as an overview of demographic information for those who have accessed anonymous testing in Halifax (2006-2010).

3.2.1 HIV testing across the province in 2008

HIV tests performed at the Capital District Health Authority (CDHA) laboratory represent approximately 70% of all HIV screening tests and 100% of all confirmatory HIV tests in 2008. Five other laboratories across Nova Scotia reported conducting HIV screening tests; the remaining areas that do not conduct HIV screening tests regionally send these specimens to the CDHA laboratory for testing. Specimens that test positive on screening tests outside of the CDHA laboratory (including specimens from other DHAs) are forwarded to CDHA for confirmatory HIV testing. Table 1 presents the number and proportion of HIV tests performed by each district health authority in 2008. Number of tests approximates number of individuals tested for that time period; however, numbers of tests includes a small proportion of repeat tests for various reasons including confirming a positive screen or retesting if initial test is deemed too soon for antibody detection. All testing data presented beyond Table 1 are based on tests performed at CDHA laboratory, and represent approximately 70% of all HIV screening tests in Nova Scotia. It is unknown how closely the information not presented here mirrors tests performed at CDHA laboratory.

Table 1. Estimated number and percentage of HIV tests performed in 2008 by district health authority and IWK Health Centre, Nova Scotia

<table>
<thead>
<tr>
<th>District</th>
<th>Number of tests</th>
<th>Percentage of tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Shore District Health Authority*</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>South Western District Health Authority</td>
<td>1000</td>
<td>4.5</td>
</tr>
<tr>
<td>Annapolis Valley District Health Authority*</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Colchester-East Hants Health Authority</td>
<td>1441</td>
<td>6.4</td>
</tr>
<tr>
<td>Cumberland Health Authority</td>
<td>1050</td>
<td>4.7</td>
</tr>
<tr>
<td>Pictou County Health Authority</td>
<td>715</td>
<td>3.2</td>
</tr>
<tr>
<td>Guysborough Antigonish Strait Health Authority*</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Cape Breton District Health Authority*</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Capital District Health Authority**</td>
<td>16120</td>
<td>71.9</td>
</tr>
<tr>
<td>IWK Health Centre</td>
<td>2100</td>
<td>9.4</td>
</tr>
<tr>
<td><strong>NOVA SCOTIA</strong></td>
<td><strong>22426</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

*Districts that do not process their HIV screening tests send specimens to CDHA laboratory for testing.  
**CDHA tests include screens and confirmatory tests, while all others are screening tests only.
3.2.2 HIV screening tests at CDHA laboratory and provincially-reported HIV cases – number of tests and cases between 1999 and 2008

The number of HIV screening tests submitted to the CDHA lab has increased between 1999 and 2008 from 12277 to 15933 tests (Figure 1). Tests per month ranged from around 1100 to 1500 tests in 2008.

Figure 1. Number of HIV screening tests by year, CDHA laboratory, 1999-2008

![Number of HIV screening tests by year, CDHA laboratory, 1999-2008](image)

Between 1999 and 2008, the number of newly diagnosed and reported HIV cases in the province ranged from 14 to 33 per year, with an average of 20.6 new cases per year.

3.2.3 HIV screening tests at CDHA laboratory and provincially-reported HIV cases – sex and age characteristics

Of the 15,518 HIV screening tests performed by CDHA laboratory between April 16th 2009 and April 15th 2010, 95% had age and sex recorded (14750). Figure 2 presents HIV screening tests by sex and age group, with females divided into two groups: probable prenatal HIV screening test and not probable prenatal HIV screening test.
Approximately 64% of HIV screening tests performed at the CDHA laboratory with known sex was for females. Although data regarding whether tests were submitted for prenatal screening is not routinely available from laboratory data, an estimate can be made by examining data from females aged 15 to 44 years whose specimen for the HIV screen was collected on the same day as specimens for both syphilis and rubella (this combination of tests would be unusual outside the context of prenatal screening). Using this surrogate estimate, a large proportion of female tests were likely conducted as part of a prenatal screening algorithm. Considering tests other than those classified as probable prenatal screens, the female to male ratio of HIV screening tests conducted at CDHA laboratory was close to one to one (1.2:1, 54.8 versus 45.2%).

The 25-29 year age group accounted for 20% of HIV screening tests at the CDHA laboratory, and was also the age group that accounted for the highest percentage of tests when probable prenatal tests were excluded (19% of tests). The age distribution of HIV screening tests followed the same pattern for males and females, with a peak in testing in those aged 20-34 years, and with tests in that age group accounting for 53% of all tests. The demographics of anonymous testers are collected separately by HPP. The age and sex distribution of anonymous testers follows a similar pattern to that shown in Figure 2 for non-anonymous tests conducted at CDHA laboratory.

In contrast to the HIV screening tests, most of the recently reported HIV cases were male (Figure 3). Between 2005 and 2009, males accounted for 83.7% of all newly diagnosed and reported HIV cases. Cases reported between 2005 and 2009 typically followed an older age distribution compared to the HIV
screening test distribution (Figures 2 and 3). There was a peak in the number of reported HIV cases in the 40 to 44 and 45 to 49 year age groups, which accounted for 19.4% and 18.4% of all cases, respectively. Additionally, 55.1% of all HIV cases were reported for those 35 to 49 years of age. It appears that newly reported female cases followed a younger age distribution compared to the male cases; however, female case numbers were low.

**Figure 3. Newly diagnosed HIV cases by sex and age group, Nova Scotia, 2005-2009**

![Bar chart showing HIV cases by sex and age group over 2005-2009](image)

**3.2.4 HIV screening tests at CDHA laboratory – setting of test**

Requisitions for HIV screening tests were submitted from 1,081 physicians over the time period from April 16th 2009 – April 15th 2010. The majority of specimens were initiated from physician offices in CDHA (Table 2). Twenty percent of specimens were submitted from outside of CDHA. Nearly five percent of tests were from anonymous testing sites over the time period. Smaller proportions were for specimens collected from individuals in the Queen Elizabeth II (QEII) Emergency Room, QEII inpatients, and QEII outpatients in Halifax.
Table 2. Number and percent of HIV screening tests performed by CDHA laboratory by test setting, Nova Scotia, April 16th 2009 – April 15th 2010

<table>
<thead>
<tr>
<th>Test Setting</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDHA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physician, nominal</td>
<td>9939</td>
<td>64.0</td>
</tr>
<tr>
<td>Anonymous Testing Site</td>
<td>730</td>
<td>4.7</td>
</tr>
<tr>
<td>Physician, non-nominal</td>
<td>393</td>
<td>2.5</td>
</tr>
<tr>
<td>QEII Emergency Room</td>
<td>254</td>
<td>1.6</td>
</tr>
<tr>
<td>QEII Inpatient</td>
<td>468</td>
<td>3.0</td>
</tr>
<tr>
<td>QEII Outpatient</td>
<td>565</td>
<td>3.6</td>
</tr>
<tr>
<td>Outside CDHA</td>
<td>3169</td>
<td>20.4</td>
</tr>
<tr>
<td>TOTAL TESTS AT CDHA</td>
<td>15518</td>
<td></td>
</tr>
</tbody>
</table>

While female HIV screening tests outnumber males tests requisitioned in the physician office setting, more screening tests are conducted on male specimens non-nominally, from QEII inpatients, and from QEII outpatients (Figure 4). Females had higher numbers of tests than males in the QEII Emergency Room (Figure 4).

Figure 4. Number of HIV screening tests by sex and test setting, CDHA laboratory, April 16th 2009 – April 15th 2010
3.2.5 Anonymous HIV tests and newly diagnosed HIV cases – HIV exposure type

While type of possible exposure to HIV is routinely collected for reported HIV cases, this information is not available for the screening tests performed at the CDHA laboratory. As an alternative, the exposure type reported for anonymous HIV tests conducted by the Halifax Sexual Health Clinic and AIDS Coalition of Cape Breton can be examined. However, it must be noted that those who utilize these anonymous testing services might not be representative of all those who are screened for HIV in the province.

From 2005 to 2009, the majority (71.8%) of anonymous HIV tests were conducted for those reporting no identified risk (NIR and NIR-Het, Figure 5). In contrast, the exposure type most commonly reported for newly diagnosed HIV cases was men who have had sex with men (MSM), accounting for 45% of all cases during this time period. A lower proportion of anonymous testers identified injecting drug use (IDU) as their exposure type (2.6%) compared to the HIV cases (14.3%). As well, a higher proportion of HIV cases reported having heterosexual contact with a person at risk (Het-Risk, 11.2%), compared to those having an anonymous test (0.4%).

Collection of exposure type data relies on patient self-report. As a result, it is possible that exposure type can be misclassified (e.g. if the patient does not fully disclose their risk behaviours, or if the risk associated with their partner(s) is not known). Additionally, patients may be reported as NIR if HIV exposure information cannot be collected. Those classified as NIR in this report may thus actually have a known exposure type, and so the true distribution of exposure type for these HIV cases and anonymous testers may differ from what is presented here.

Figure 5. Percent of anonymous HIV tests/HIV cases by exposure type, 2005-2009
3.2.6 Anonymous HIV testing at Halifax testing site

Information about anonymous HIV tests was provided by the Halifax Sexual Health Centre. This includes the total number of anonymous tests conducted per year, as well as demographic information (sex, age and ethnicity of those being tested). This data was adapted from the Anonymous HIV Testing Statistics from 2006 to 2010, and serves as a non-representative example of who is accessing anonymous testing and counselling services as they are currently available in Nova Scotia.

The total number of anonymous HIV tests from April 2006 to March 2007 was 522, with 502 the following year, 374 the year after that, and 419 to the end of March 2010. Most years the tests were almost evenly split between men and women, with women representing a slight majority of those tested for the first three years, and men representing the majority in the most recent year. Table 3 shows the distribution of anonymous tests by sex and the year they were tested.

Table 3. Sex (self-identified) of anonymous tests by year, 2006-2010

<table>
<thead>
<tr>
<th>SEX (SELF-IDENTIFIED)</th>
<th>NUMBER OF TESTS PER YEAR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>April 06 to March 07</td>
</tr>
<tr>
<td>Female</td>
<td>284</td>
</tr>
<tr>
<td>Male</td>
<td>234</td>
</tr>
<tr>
<td>Not Identified</td>
<td>4</td>
</tr>
</tbody>
</table>

The age group tested most frequently was consistently 20 to 29 year olds (accounting for over one third of tests done) followed by 30 to 39 years of age. Table 4 shows the range of anonymous tests based upon the age group of the person being tested and which year they were tested.

--

5 Self-identified gender is used in the HSHC statistics to describe a person’s sex.
Table 4. Age group of anonymous tests by year, 2006-2010

<table>
<thead>
<tr>
<th>AGE GROUP</th>
<th>NUMBER OF TESTS PER YEAR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>April 06 to March 07</td>
</tr>
<tr>
<td></td>
<td>April 07 to March 08</td>
</tr>
<tr>
<td></td>
<td>April 08 to March 09</td>
</tr>
<tr>
<td></td>
<td>April 09 to March 10</td>
</tr>
<tr>
<td>19 and under</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>84</td>
</tr>
<tr>
<td></td>
<td>(19-20) 22</td>
</tr>
<tr>
<td></td>
<td>24</td>
</tr>
<tr>
<td>20-29</td>
<td>305</td>
</tr>
<tr>
<td></td>
<td>244</td>
</tr>
<tr>
<td></td>
<td>(21-30) 195</td>
</tr>
<tr>
<td></td>
<td>230</td>
</tr>
<tr>
<td>30-39</td>
<td>120</td>
</tr>
<tr>
<td></td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>(31-40) 92</td>
</tr>
<tr>
<td></td>
<td>86</td>
</tr>
<tr>
<td>40-49</td>
<td>39</td>
</tr>
<tr>
<td></td>
<td>36</td>
</tr>
<tr>
<td></td>
<td>(41-50) 44</td>
</tr>
<tr>
<td></td>
<td>44</td>
</tr>
<tr>
<td>50-59</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>(51-60) 15</td>
</tr>
<tr>
<td></td>
<td>20</td>
</tr>
<tr>
<td>60 and over</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>(61-70) 5</td>
</tr>
<tr>
<td></td>
<td>15</td>
</tr>
<tr>
<td>Not Identified</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>(78) 1</td>
</tr>
<tr>
<td></td>
<td>n/a</td>
</tr>
</tbody>
</table>

Caucasian individuals accounted for the large majority of those tested for all three years, followed distantly by African Nova Scotian individuals. Middle Eastern, East Indian, Asian, First Nations, Hispanic and other or unknown ethno-racial identities were less represented. First nations were represented the least of all two out of three years, and second least in the other year. Table 5 shows the number of anonymous tests for individuals of various ethno-racial identities (which were self-identified).

Table 5. Ethno-cultural identity (self-identified) of anonymous tests by year, 2006-2010

<table>
<thead>
<tr>
<th>ETHNO-CULTURAL IDENTITY (SELF-IDENTIFIED)</th>
<th>NUMBER OF TESTS PER YEAR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>April 06 to March 07</td>
</tr>
<tr>
<td></td>
<td>April 07 to March 08</td>
</tr>
<tr>
<td></td>
<td>April 08 to March 09</td>
</tr>
<tr>
<td></td>
<td>April 09 to March 10</td>
</tr>
<tr>
<td>Caucasian</td>
<td>448</td>
</tr>
<tr>
<td></td>
<td>434</td>
</tr>
<tr>
<td></td>
<td>316</td>
</tr>
<tr>
<td></td>
<td>373</td>
</tr>
<tr>
<td>African Nova Scotian / Black</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>15</td>
</tr>
<tr>
<td>Middle Eastern</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>9</td>
</tr>
<tr>
<td>East Indian</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>8</td>
</tr>
<tr>
<td>Asian</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>4</td>
</tr>
<tr>
<td>First Nations</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>0</td>
</tr>
<tr>
<td>Hispanic</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>10</td>
</tr>
<tr>
<td>Unknown</td>
<td>n/a</td>
</tr>
<tr>
<td></td>
<td>n/a</td>
</tr>
<tr>
<td></td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>n/a</td>
</tr>
</tbody>
</table>

This data shows a consistent trend in anonymous testing rates at the Halifax location. The populations accessing this service at the Halifax Sexual Health Centre the most are: Caucasian populations and individuals aged 20-30. There was a relatively even split between male and female individuals seeking testing, however there were slightly more women than men each year, except in 2010.
Summary of surveillance

The surveillance data shows that the number of HIV screening tests has increased over time and that over 1000 physicians from across the province sent specimens for HIV screens. Approximately equal numbers of males and females were being tested when prenatal tests were excluded (prenatal screening guidelines do not call for testing of partners), and the age distribution of tests was also similar for males and females. Newly reported HIV cases were predominantly male, and tended to have an older age distribution (ages 40-44) compared to the HIV screening test distribution (ages 25-29). The most commonly reported HIV exposure type for newly diagnosed HIV cases was men who have had sex with men (MSM), while the majority of people who went for anonymous HIV tests did not have any identified risk (NIR) for HIV infection. Age and sex distribution of anonymous tests was similar to that for all tests at CDHA lab, and the anonymous testing service at the Halifax Sexual Health Centre were accessed predominantly by Caucasian individuals aged 20-30, equally split between men and women.
3.3 In-depth interviews

In-depth interviews were conducted with 50 participants from across the province of Nova Scotia in order to learn more about individuals’ experiences and perceptions of HIV counselling and testing. Specific efforts were made to include the voices of diverse communities in these conversations. Both individuals who had been tested in the past year (with a positive or negative result) and those who had not been tested in the past year were asked open-ended questions to explore some of their issues and concerns in regards to HIV counselling and testing. The goal of the in-depth interviews was to learn more about the experiences and perceptions of HIV counselling and testing in Nova Scotia of both individuals who had and had not been tested in the past year. Accordingly, different questions were asked of those who had been tested and those who had not in order to best allow for an open conversation about their experiences and perceptions.

The themes that emerged from the analysis of the interviews examine the experiences and perceptions about HIV testing and counselling, as well as the salient barriers and facilitators to accessing testing in Nova Scotia. In addition to these general themes, there were many sub-themes explored. The process of thematic analysis assisted the research team in determining where experiences of HIV testing and testing behaviours differ and why. Experiences of those who had not been tested in the past year included: those who had never been tested and either did or did not consider it, and those who had been tested before the past year, and had or had not considered begin tested again. Various reasons for being tested or not, or considering testing or not are provided for each group. The barriers to testing included: low awareness of HIV and HIV testing in Nova Scotia, lack of information or misinformation about HIV and HIV testing, stigma and discrimination about HIV and HIV testing, and accessibility and acceptability of testing options and testing sites. Experiences of those who had been tested in the past year included: initiating the test (pre-test counselling), waiting for the test results, and receiving the results (post-test counselling). Some identified facilitators to testing included: increased education, availability of testing options (anonymous and rapid), and accessible and supportive services.

Participants included a wide-range of men and women of various ages who were from diverse communities and had various ethno-racial identities:

- **Sex** – Interviews were conducted with 30 women, 19 men, and 1 trans-gendered person.
- **Age** – Participants ranged in age from 17 to 64 years old, including 6 teenagers, 6 in their 20s, 20 in their 30s, 5 in their 40s, 10 in their 50s, and 3 in their 60s.
• **Ethno-racial identity** – Participants included 12 Aboriginal, 16 African Nova Scotian (including some immigrant), and 22 Caucasian individuals.6

• **Tested or not** – 17 participants had been tested for HIV in the last year (5 were tested anonymously and 12 were tested nominally or non-nominally), and 33 had not been tested in the last year (16 had been tested previously for HIV, and 17 had never been tested).

• **HIV / Hep C status** – 3 participants indicated that they were HIV positive and 4 indicated that they were Hepatitis C positive.

• **Education** – 11 participants had less than grade twelve, 8 had grade twelve, 25 had college or university, and 6 had master’s degrees.

• **Relationship status** – 12 participants were married, 5 were divorced or separated, 11 were in a relationship, and 22 were single or unmarried.

• **Location** – 29 participants lived inside HRM and 21 lived outside HRM.

• **Family doctors** – 46 participants had general practitioners while 4 did not.

• **Language** – 46 participants spoke English as their first language, while 4 spoke other languages primarily (including French, Mi’kmaq and an African language). All spoke English fluently.

• **Children** – 30 participants had children and 20 did not have children.7

### 3.3.1 Experiences of those who had not been tested

33 of the participants had not been tested for HIV in the past year, although 17 of these participants had been tested for HIV prior to the past year; the other 16 had never been tested for HIV. Participants who had not been tested in the last year were asked whether or not they had ever considered HIV testing and why or why not. Of those not tested in the past year, 5 had never been tested and did not consider testing; 8 had never been tested but considered testing; 5 had been tested before and considered being tested again; and 15 had been tested before but did not consider being tested again.

#### 3.3.1.1 Reasons for not being tested for HIV in the past year

Participants who had not been tested for HIV in the past year provided the following reasons:

1. Were not involved in risk activities or had the perception of low risk activities;
2. Did not think much about HIV or hear much about HIV testing in NS;
3. Were involved in a long-term monogamous relationship;
4. Felt fear of learning the HIV test result (fear of positive test);
5. Believed that symptoms would have shown up by now if they were HIV positive;

6 As mentioned previously in the methods section, multiple ethnicities (including immigrant status) were self-identified; however, to protect the identity of the participants, more general ethno-racial categories were used.

7 See Appendix D for charts of this information.
6. Believed that knowing their HIV status wouldn’t change their health outcomes; 
7. Were only tested while pregnant (as per Nova Scotia’s prenatal screening guidelines); 
8. Perceived stigma attached to HIV testing; 
9. Believed that Canada is an “HIV-free environment” due to lower rates of infection; 
10. Felt fear about waiting for the test results; 
11. Felt fear about the prospect of telling partners the HIV test results; 
12. Was advised against HIV testing by their doctor; 
13. HIV test was not suggested by their doctor or included with other tests; 
14. Did not know where to go for HIV testing; and 
15. Had fear or difficulty with having blood drawn.

For those who had not been tested before and had not considered testing, the main explanations had to do with perception of low risk or no risk activities, fear of knowing the result, or the assumption that if something was wrong symptoms would have shown up by that point in their life. For those who had been tested prior to the last year, but did not consider being testing again, the main reasons were a lack of risk activities (particularly sexual activity), involvement in a long-term monogamous relationship or marriage, only having been tested routinely (while pregnant), do not know where to go for testing, or do not think about HIV testing (because they did not consider HIV testing to be “standard” in Nova Scotia). For those who had been tested before and considered being tested again, the main reasons for not going to be tested were the stigma attached to HIV testing (particularly in marginalized communities), Canada having lower HIV infection rates (the perception that it is an HIV-free environment), fear of waiting for the test results, and fear of the prospect of having to tell former partners the results of the test. For those who had not been tested before but would consider testing, the reasons cited for not actually being tested were fears about the results, not knowing many people who get tested or talk about HIV in their community, not giving much thought to HIV, not wanting to know if they are going to die, and the perception that knowing wouldn’t change their health outcomes. Participants also described being advised against HIV testing, and not being offered HIV testing along with other STI tests. Finally, some cited difficulty or fear with having blood drawn as a reason for not seeking HIV testing.

**Perception of monogamy – no need to be tested**

Some of the participants (particularly those who did not consider themselves to be at risk) suggested that it is generally important to be tested for HIV, but that in their particular circumstance it was not
necessary. Especially those in monogamous relationships (either marriages or long-term relationships) said that they trusted their partners and did not feel that they were at risk of contracting HIV.

“Yeah, don’t get me wrong; if I had any suspicion that something like that was going on I would be tested, but personally like I said I strongly believe that I’m in a monogamous relationship, so...” (Female, 30s, Caucasian, College, Outside HRM, Not Tested)

“It’s not an issue for me cause I’ve been married for [over 20] years so... like I say, not for me. We just celebrated our wedding anniversary.” (Female, 40s, Caucasian, College, Outside HRM, Not Tested)

“I’m not at any risk factors, I’m in a loving relationship so... no, I haven’t put myself at risk so why would I want to do that? I get tested for everything, but not even a remote thought about HIV testing.” (Male, 60s, Caucasian, University, HRM, Not Tested)

The perception of risk among those in monogamous relationships differed somewhat depending upon the length of the relationship and whether the participant was dating or married to their partner. The perceived risk of contracting HIV for married participants was consistently very low.

3.3.1.2 Reasons for considering being tested for HIV in the past year

Participants who had not been tested in the past year but had considered being tested provided various reasons as to why they had considered seeking an HIV test:

1. Involvement in risk activities
2. Perception that people should be tested because it is the “smart thing to do”
3. Perception that it is better to know than not
4. Perception that HIV testing is important
5. It had been a while since the last test
6. Tested for other STIs – considered HIV as similar or a part of that

For those individuals who had never been tested before but had considered testing, the reasons cited for considering testing were risk behaviours (sexual activity or drug use), that it is the “smart thing to do,” and it’s better to know than not to know. For individuals who had been tested before and would consider being tested again, the main reasons for considering being tested again is the perception that HIV testing is important, participants had engaged in risk behaviours, the notion that people “should” be tested, and it had just been a while since the last test.

3.3.2 Barriers to accessing HIV testing

A number of barriers to accessing HIV testing emerged from these conversations. These include: low awareness of HIV and HIV testing in Nova Scotia; misinformation or lack of information about HIV and
HIV testing; stigma and discrimination; and the accessibility and acceptability of the testing site. Each of these barriers will be discussed in more detail.

### 3.3.2.1 Low awareness of HIV and HIV testing in Nova Scotia

Several participants who had not been tested said that they could access this service if they wanted to, but they did not feel the need, did not want to, or simply didn’t think much about it.

“I just really never got around to actually making an appointment to go to my doctor to get one done. It’s not that I didn’t want to, it’s just sometimes it’s not the first thing that you think about.” (Female, teens, African Nova Scotian, some high school, HRM, Not Tested)

“I could probably be able to find it somewheres if I needed it, I just haven’t thought about it... doesn’t like climb in my head every day.” (Male, teens, Aboriginal, some high school, HRM, Not Tested)

“Just never occurred to me. Sometimes it’s very difficult for you to want to know something... I don’t know, it never occurred to me, it’s the least thing I think about.” (Female, 50s, African-Nova Scotian Immigrant, Master’s, HRM, Tested prior to past year)

“It’s not a priority. I’m not really worried about it, like I say it would be to rule things out so if I was going there you know for another reason, then I’m sure I would do it at the same time, but I haven’t gone there so. It’s not something that’s sort of, it’s ah, not higher on the list right now.” (Female, 30s, Caucasian, Master’s, HRM, Not Tested)

Other participants mentioned the fact that they never hear about HIV, or that it is not talked about.

“I’m sure it’s still a big issue, an important issue, but we just don’t seem to hear that much anymore about... people having it and how many people have it and those sorts of things, as we used to, it doesn’t seem like it anyway, as far as awareness. Maybe more workshops could be done.” (Female, 50s, Aboriginal, High School, HRM, Not Tested)

“They just don’t talk about it. It’s like... something you don’t really want to talk about. I remember when I first heard of it, when I was a kid... I was happy that they came into the schools and told us about it, be safe and this and this, but as soon as I started hearing about it actually growing in my community, like I heard there’s so many cases, it was scary. But people don’t talk about it.” (Female, 20s, Aboriginal, University, HRM, Tested)

“You know people back years ago, HIV started and everybody... it was such a quiet thing you know, people wouldn’t talk about it, it was a disgrace and all those other things, it doesn’t matter, it’s a disease and you’ve got to learn to live with it...” (Male, 60s, Caucasian, University, HRM, Not Tested)

One participant from a rural community mentioned her perception that HIV testing is not talked about where she is from, particularly not among her high school age group. She also had the perception that people are not tested very often as well.

“Where I’m from you don’t, for kids my age in high school you don’t really, I mean I don’t think people really talk about it anyway, but it just doesn’t seem like it’s a thing, it doesn’t seem like people do it very often, like get tested but maybe that’s just me but...” (Female, teens, Caucasian, in high school, Not Tested)
These descriptions clearly speak to the idea that HIV is not perceived as something that people talk about, and HIV testing is also perceived as something that people do not actually do.

3.3.2.2 Lack of information or misinformation about HIV and HIV testing

Some of the participants had misinformed ideas about HIV risk factors. When asked what she considered to be behaviours that might put her at risk for contracting HIV, one respondent said:

“Kind of like touching like something, like drinking somebody else’s bottle of water that could be contaminated with HIV or any of that... cause you don’t know what their saliva has and they could drink backwash into their water and then drink into yours. And then you could get infected by it very quickly.” (Female, 20s, Caucasian, High School, Outside HRM, Tested Anonymously)

A number of participants mentioned a lack of symptoms as a reason for not being tested.

“I had to have a blood transfusion and it was right after that there was the big scandal with you know the blood transfusions... but because there was never any symptoms or anything you know at that point in time I never did... and I think that by now I think I would have noticed if there was a problem.” (Female, 40s, Caucasian, College, Outside HRM, Not Tested)

Another participant who had also received a blood transfusion over twenty years ago spoke about the fact that she always considered the possibility that she might have HIV (realizing that there can be no symptoms for many years) but was never tested because she continued to feel healthy.

“When I passed the 10 year mark I thought okay, I think I’m out of the woods... It did cross my mind for several years... but I never did get tested and probably because I didn’t have any kind of symptoms, and I was healthy and I was feeling okay.” (Female, 50s, African Nova Scotian, College/University, Outside HRM, Not Tested)

She went on to suggest that her fear of knowing kept her from being tested, and even though she considered it, she put it to the back of her mind.

“I thought at any point in time I could go to the doctor’s, get routine blood work and maybe I would test positive. So I was really nervous and on edge and afraid like and I think it was the fear of knowing what could possibly be wrong that prevented me from getting the test. I didn’t want to know. So I just said okay, I’ll just put this to the back of my mind and just keep doing what I’m doing and hope and pray for the best.” (Female, 50s, African Nova Scotian, College/University, Outside HRM, Not Tested)

Several of the participants also asked questions about HIV during the interviews.8

8 In these instances, participants were generally referred to the list of organizations, phone numbers and websites included with their consent form for more information.
“I don’t know if people can get HIV from kissing or not. I think it’s just sexual intercourse, is it?” (Female, 20s, Aboriginal, High School, HRM, Tested)

“I just think that everybody should know as much information as possible and you know. Is there a cure for HIV?” (Female, 30s, African Nova Scotian, Some high school, HRM, Tested)

“Have they found a cure for that already or...?” (Male, teens, Aboriginal, Some high school, HRM, Not Tested)

“Well I just don’t really... what happens, happens, so it’s going to be whether I like it or not, I don’t really want to know about it... I don’t even know if there’s any signs or anything but... is there signs...?” (Male, teens, Aboriginal, Some high school, HRM, Not Tested)

A number of the participants said that they would not want to know their HIV status because they equated a positive result with the end of their life.

“What if I did really catch HIV? What would happen, cause I know that they can’t cure it so my life would be over.” (Female, 20s, Aboriginal, High School, HRM, Tested)

“Personally if I had HIV I probably would try to jump off a bridge. Your life is over, there’s no cure, you’re going to die from it, you just don’t know when you’re going to go.” (Female, 20s, Aboriginal, High School, HRM, Tested)

“I don’t really want to find out if I’m going to die in four years or whatever so... if it happens, it happens... I wouldn’t want to know I’m going to die in 10 years or whatever the heck it is.” (Male, teens, Aboriginal, Grade 10, HRM, Not Tested)

“I think that’s the first thing people think about is oh if I have it, I don’t want to know. I’ll live longer if I just don’t know, if I do I’ll just kill myself or I’ll just stress myself out and die faster. I think that’s how people look at HIV testing.” (Female, teens, African Nova Scotian, Some high school, HRM, Not Tested)

“I’d be scared, I wouldn’t know what the outcome would be, I wouldn’t know how bad it would progress or what it would do to me personally. The worst part would be the fact of me dying at a young age, that’s what I worry the most about.” (Female, teens, African Nova Scotian, Some high school, HRM, Not Tested)

One participant who did not want to know his status stated that he was aware of treatment possibilities for HIV, however his perception remained that it was something that would bring his life to an end and that he would not be able to get over an HIV-positive diagnosis.

“I would feel that my life would come to an end, to a sudden halt, what’s the good of dealing with it? I know there’s counseling... there’s all sorts of things that can help you even if you have HIV these days but there’s this sense that something is hanging over your head that you can’t... I would imagine not being able to get over, that makes me not want to know”. (Male, 20s, African-Nova Scotian, University, HRM, Tested prior to past year)

Another participant said that even though people can live for a long time after being diagnosed with HIV, she perceives a broader societal view that HIV remains a death sentence.
“It’s like a death sentence for people, or that’s how they see it. Even though to this day... there are people who live for years and years even with full-blown AIDS, but there’s this stigma, people are afraid of it.” (Female, 20s, Aboriginal, University, HRM, Tested)

Another participant expressed uncertainty about what the test itself involves. When asked what kind of pre-test information she would like, she suggested that she would want to know what to expect if she were to go for an HIV test.

“Just maybe what to expect or... is it just a simple blood test that they do or... I don’t even know. I guess I’d want to know what to expect.” (Female, 50s, Aboriginal, High School, HRM, Not Tested)

Another potential barrier or concern about testing mentioned by some participants was the prospect of having to go back to former partners to tell them.

“A lot of it is... one basic thing is that you have to go back and tell people that’s a really big barrier, major barrier because yeah... that’s... I just wouldn’t want to do that.” (Female, 30s, Aboriginal, High School, HRM, Tested prior to past year)

“Finding out the results, letting your partners know would be a traumatic thing to do. And it’s not just the one you’re with, you’d have to go back to I have no idea how long you’d have to go back and let them know but that would be an awful lot of shitty calls to place.” (Male, 30s, Caucasian, College/University, Outside HRM, Tested prior to past year)

Another participant stated that he did not want to know because he had been tested involuntarily prior to coming to Canada, and he found this process to be very stressful.

“The first HIV testing that I went to was not voluntary... throughout that process I was constantly freaked out, even knowing that I haven’t put myself at risk. But it’s this perception that when you go to the doctor it’s going to come back with bad news... I think a lot of people would rather not want to know, ignorance is bliss I guess.” (Male, 20s, African-Nova Scotian Immigrant, University, HRM, Tested prior to past year)

In some instances, participants did not directly ask for HIV testing, but assumed or were informed after the fact that they had been tested.

“I just had some blood work done about a month ago, I’m fine... I think my family doctor would let me know... when they do everything at the [hospital] they test for everything.” (Male, 30s, Aboriginal, College, HRM, Tested)

“I’m not sure if I was actually tested for HIV but I’m pretty sure cause I went to the doctors with my girlfriend and she was getting blood work done and the doctor asked me if I wanted to get blood work done and to check me to see if I had any STDs or something like that and they told me that I didn’t have HIV or any STDs or anything when I got my blood work back so...” (Male, teens, Caucasian, Some high school, HRM, Tested)

In another instance, a participant described the situation where she had asked her doctor to be tested for HIV but her doctor advised her against it.
“She asked me have you thought that you were exposed to the virus and I said no, and she said why do you want to get tested? And I said well I’m getting blood drawn I may as well. Then she advised me against it stating that possible like health coverage with jobs or anything like that might not cover me as fully or as readily if they found in my record that I had been tested for HIV. And so I appreciate her giving me that insight, that’s not something I know, but I also think like definitely left me with a bad taste in my mouth that a health care provider was encouraging me not to get tested for something...” (Female, 20s, Caucasian, University, HRM, Not Tested)

A couple of participants mentioned their concern about STI testing in general, since HIV testing was not included or at least discussed as a part of this testing:

“‘I was being tested for other STIs and it was just a general kind of thing... and I was kind of surprised that my family physician didn’t suggest testing for HIV. I mean to me it kind of seems like it’s part of the whole continuum, you know. If you’ve exposed to possibly Chlamydia and gonorrhoea and things, you’ve possibly been exposed to HIV. I mean it seems a little odd that we separate it.’ (Female, 30s, Caucasian, Master’s, HRM, Not Tested)

“It’s a very specialized test whereas a lot of the other STI tests... they get one sample and they can do a broad range of tests for that. But I think where HIV is so specific, like you get tested for HIV/AIDS and... it’s in its own little category. It’s easier to be stigmatized cause you can’t just say, oh I just got tested for STIs.” (Female, 20s, Caucasian, College/University, HRM, Not Tested)

“I know somebody who... was treated for a sexually transmitted disease but was never tested for HIV/AIDS... that person is at risk for HIV/AIDS... your patient may not be cognizant of the risks that they engage themselves in, or cognizant of the need for testing, and it’s always good for the health care provider to advocate... to encourage their client to have testing for HIV/AIDS.” (Male, 30s, African-Nova Scotian Immigrant, Master’s, Outside HRM, Tested prior to past year)

It becomes clear in reviewing these excerpts that the participants who mentioned HIV testing as a part of general sexual health check up felt that it would be a helpful way to incorporate HIV into a more general, or potentially less stigmatized group of tests.

### 3.3.2.3 Stigma and discrimination about HIV and HIV testing

Stigma and discrimination was discussed by several participants as a major barrier to testing, in regards to perceptions about HIV/AIDS, what it means to have HIV, and negative and stigmatized associations with different groups.

“It’s just I guess not wanting people to find out. I suppose that’s a barrier, feeling the stigma and discrimination about it... That for me would be one of the biggest barriers of why people probably don’t get tested.” (Trans, 30s, Caucasian, Some College/University, Outside HRM, Not Tested)

“It’s like having leprosy. People just, okay, even though you cannot have it by touching me or by sitting beside me, well they will run from you... already because you are Black people don’t really associate enough with you anyway and then if you have that out, that is... it’s a tough thing and I know that’s why people don’t just stand up and say I’m going to do it.” (Female, 50s, African-Nova Scotian Immigrant, Master’s, HRM, Tested prior to past year)
“I mean HIV... it’s an illness, it’s an infection that people get in many different ways, you know, not always under their control... you know, people aren’t going out searching to you know for these illnesses... It seems odd to me that you, that you know oh somebody has the clap, oh that’s just them sowing their wild oats, but if you get HIV oh they’re horrible people or something.” (Female, 30s, Caucasian, Master’s, HRM, Not Tested)

One participant who had previous experience with another STI related her feelings at that time to HIV and her perception of a lack of social acceptability and stigma related to HIV testing.

“If I were in a position where I had to get tested... I think I’d be judged... whether they say it or not, they judge you know so, yah. Cause I go back to my past experience where yeah I felt like nobody knew and I just, you harbour all these feelings of being judged and guilt and everything. You harbour it and you don’t tell people and you feel like you’re not being, you can’t be honest with people or you know what I mean and then you can’t share part of your life with them either because, because you know that that’s not acceptable...” (Female, 40s, Caucasian, College/University, Outside HRM, Tested prior to past year)

Some participants spoke about their perceptions of HIV stigma within their particular communities. It is important to reiterate that members of diverse ethno-racial communities are represented in this research, but a necessary limitation of this research is that it does not provide a representative or comprehensive overview of the issues faced within these communities. With this in mind, it is still important to report the perceived barriers discussed by members of these communities. One woman spoke of her perceived stereotypes about HIV in her black community.

“If I talk about my Black community... it goes with all the stereotypes that if you have HIV that you must ... have gotten it because you’re having a homosexual relationship. It’s not a secret within our Black communities that homosexuality is not accepted in some of the churches or in most of the church because they feel that it’s a major sin. So if you’re an avid church-goer you wouldn’t want that to come out because then you’re going to get labeled. Nobody is going to ask the question how you got the HIV they’re just going to make the assumptions and then... you almost become an outcast.” (Female, 60s, African Nova Scotian, Some College/University, Outside HRM, Not Tested)

Another participant spoke of the church in his African-Nova Scotian community, and how this could potentially be used as a means of distributing information about HIV/AIDS.

“Use existing networks within communities, so you can use organizations that are regarded as credible organizations within this part of the community... they have networks... that can be useful if you want to distribute information on HIV and AIDS, or information relating to testing. So you can use existing networks, do some partnering there. The African Nova Scotian community church plays an important role in holding certain communities together, it’s the glue that binds and so the church can be used as an avenue for dissemination information about HIV and AIDS.” (Male, 30s, African-Nova Scotian Immigrant, Master’s, Outside HRM, Tested prior to past year)

Another woman spoke about her perceived HIV stigma, particularly from her experiences on her Aboriginal reserve.
“The stigma that goes with HIV... like I’ve had multiple partners and for me to go back and tell them, they’ve had partners, and... especially on the reserve it’s kind of like a lot of people sleep with everybody and then they go and sleep with somebody else and... a lot of times it’s unprotected sex and... I guess how I grew up and if I have to go and get tested... I wouldn’t want to do it.” (Female, 30s, Aboriginal, High School, HRM, Tested prior to past year)

One participant spoke of the difficulty experienced as a gay or transgendered person, in particular due to the stigma and discrimination that is attached to risky behaviours and HIV/AIDS.

“I think that’s one of the big problem is that a lot of people being gay or transgendered or being involved in risky behavior, they don’t have the support mechanism, they don’t want the stigma or discrimination attached to them.” (Trans, 30s, Caucasian, Some College/University, Outside HRM, Not Tested)

One participant mentioned the stigma she perceived towards being tested for HIV and what it means to be tested for HIV.

“I was telling [someone] that I was coming to this interview and I said yeah the criteria is pretty loose, it’s just if you... have/have not/have considered being tested. And she just gave me this look, and you’re the have not been tested, right? And so, just the thought that like... just being tested for HIV means something.” (Female, 20s, Caucasian, College/University, HRM, Not Tested)

Stigmatized language surrounding HIV also came up in a number of the interviews. Specifically, the notion that having HIV means a person is dirty and not having HIV means a person is clean appeared regularly throughout the interviews. The word “clean” was used very frequently by participants to describe their test results, and this was the language they said practitioners used as well. Although this is not necessarily specific to HIV (this terminology is often used regarding other STIs or in relation to IDU) it is important to note the stigmatized language as it is used in this context.

“I just think it’s important but I mean that’s... there’s still so much stigma and discrimination around... that it’s dirty and that it’s you know... that it’s just gays...” (Female, 40s, Caucasian, College/University, Outside HRM, Not Tested)

“When you hear HIV, I think most people think dirty word... that’s a bad misconception, because I don’t think it has anything to do with being dirty or anything like that.” (Male, 30s, Caucasian, College/University, Outside HRM, Tested prior to past year)

“... if I was with someone I knew was really dirty, or I didn’t know and found out afterwards then I might go get checked...” (Male, Teens, Aboriginal, Some High School, HRM, Not Tested)

“I think if I was to you know say here is my test results, I’ve been tested and I know I’m clean, I would want to be able to say you know have you done the same thing, are you clean...” (Female, 40s, Caucasian, College/University, Outside HRM, Not Tested)

“She gave me the paper and she said it all came back negative, you’re very, very clean.” (Female, 20s, Caucasian, High School, Outside HRM, Tested Anonymously)
3.3.2.4 Accessibility / acceptability of testing options and testing sites

Accessibility and acceptability of HIV testing options, including the type and location of the test, emerged as an important theme amongst the participants. The location of HIV testing sites was described as a significant barrier to some of the participants.

“I would think that a lot of testing sites would be clinics in hospitals and doctor’s offices and those other testing sites that are offered in the community like through [ASO] and things like that. Most centrally located so to speak of [HRM] and I don’t know if enough is being done to basically bring testing to those other communities in Nova Scotia, who may not easily access those other sites so the physical location may be a barrier.” (Male, 30s, African-Scotian Immigrant, Outside HRM, Tested prior to past year)

Another participant stated that for herself and her friends who had immigrated to Canada, there is a discomfort accessing services that are explicitly linked to their sexual health, or that could identify the reason for their visit. For example, she said that going to access HIV testing at a Sexual Health Centre would be undesirable due to the visibility of the reason for being there. Testing at the hospital was preferred in this case because individuals can go to the hospital for a wide range of issues, not necessarily related to sexual health. Even with the assured anonymity of the counselling and testing services offered, the decision to go to a clinic that deals specifically with sexual health issues was seen as a major deterrent for this participant in seeking out HIV testing services.

“Taking an immigrant woman to get testing, even if the doctor has 100 other things ticked off, she knows everybody knows that this is what she’s coming in for. It’s a mental state and there’s not a whole lot you can do about it other than holding her hand… there’s a lot of fear and stigma especially for women of color who already have so much crap that they’re dealing with.” (Female, 50s, African-Scotian Immigrant, HRM, Tested)

She went on to suggest that going to the hospital allows you to obscure the reason for the test – it can be done among many other things, de-emphasizing the HIV test itself.

“I don’t like the idea of going in just for an HIV test because it becomes so easily public knowledge. This is Nova Scotia, it’s a very small town and everybody knows each other.” (Female, 50s, African-Scotian Immigrant, HRM, Tested)

Linked to the accessibility of the testing site is the issue of confidentiality. Concerns about confidentiality were discussed by several participants as a potential barrier to testing.

“Nova Scotia is such a small community if I were to go for an HIV testing in Nova Scotia, the initial fear would be somehow this information will get out… you might end up in a hospital or at a doctor’s office and someone you know from the community is working at that particular place and it might be one of the people that are administering this exam to you or have access to the result.” (Male, African-Scotian Immigrant, College/University, HRM, Tested prior to past year)
“The biggest concern is... the confidentiality of the information... I don’t know what statutes are in place to mandate that health care providers share information about HIV and AIDS and test results... how information is going to be used and how it’s given back to you.” (Male, African-Nova Scotian Immigrant, Master’s, Outside HRM, Tested prior to past year)

Access to services in rural communities was also discussed by a number of participants from both inside and outside of the Halifax Regional Municipality (HRM).

“But rurally... you’ve got a runny nose you have to go to emergency... there’s no such thing as a clinic to go to here, so it would have to be family doctor or emergency. Those are the only two access points and it’s a big bone of contention of course rurally or in this area.” (Female, 40s, Caucasian, College/University, Outside HRM, Tested prior to the past year)

“I’ve worked occasionally in some small areas and everybody knows what’s going on... even in [HRM], you know [HRM] isn’t that big and then when you meet somebody from your home town here, it’s like where are you going? So that people... in rural areas might feel even more exposed and you know, there’s a lack of resources there and things like that, so yeah I can’t imagine what it would be like in rural areas at all.” (Female, 30s, Caucasian, Master’s, HRM, Not Tested)

“Yeah, and access in terms of travel was difficult but also the fact... living with my parents also made it difficult to kind of talk... my mom, like I rarely go to the doctor and so if I requested to go to the doctor, she was like what’s going on... and so, that would have been difficult as well so the fact that I lived in a rural community, and I lived in a rural community and I was still living with my parents and as wonderful as they are, trying to talk about this stuff would have been definitely difficult.” (Female, 20s, Caucasian, College/University, HRM, Not Tested)

One participant from a rural community mentioned that she would feel awkward going to the hospital in her town to be tested for HIV because she knows a number of the people who work there.

“I think I would probably just ask at the hospital, but then I know a lot of people who work at the hospital so that would kind of be awkward... I would be kind of nervous to do that.” (Female, Teens, Caucasian, High School, Outside HRM, Not Tested)

The same participant went on to suggest that having to go to the hospital would deter her from being tested due to the waiting period in the hospital and her discomfort with hospital settings in general.

“I don’t want to wait for three hours to get tested, and if you go to the ER that’s what’s going to happen. You’re going to have to sit there for three hours around people who are coughing or throwing up and broken arms, it’s just not something I would want to do... if you have to wait in the emergency room that would discourage me a lot.” (Female, Teens, Caucasian, High School, Outside HRM, Not Tested)

Another participant mentioned she did not feel comfortable talking to her doctor about HIV testing.

“My relationship with my family physician is not one where I can really bring up things and she’ll go along with it always.” (Female, 30s, Caucasian, Master’s, HRM, Not Tested)

One man from a rural community suggested that access to a family doctor in Nova Scotia could also be problematic for individuals seeking HIV testing.
“Not everybody has a family doctor to go to... when you have to go to emergency, and if you had been sleeping around with somebody and felt that you may be at risk of contracting the HIV virus, then it would probably be pretty hard for you to go to an emergency department and sit there for twelve hours or six... and then go see a complete strange doctor.” (Male, 30s, Caucasian, College/University, Outside HRM, Tested prior to past year)

The relationship participants had with their family doctor (or whether or not they had a family doctor) was a significant issue in terms of whether or not they felt comfortable accessing HIV counselling and testing. Participants had diverse experiences with this issue suggesting that it is important for HIV-related health services be offered in equally diverse ways to provide equitable access.

3.3.3 Experiences and perceptions of testing in the past year

17 participants had been tested for HIV in the past year (5 of these at anonymous testing sites). Approximately half of the participants who had been tested in the past year cited sexual activity as their main reason for being tested. Following sexual activity, other reasons were also discussed by several of the participants: regular testing, “just to be sure,” previous experience with an STI, injection drug use (IDU), doctor suggestion, assumed testing, and experience of undiagnosed symptoms.

3.3.3.1 Initiating test (pre-test counselling)

Most of the participants who had been tested for HIV in the past year initiated this process by approaching their family doctor and asking to be tested for HIV (opt-in testing).

“I just asked for can I have HIV also tested and they’re like yeah sure and they took the extra blood. They didn’t say anything about... anything about anything.” (Female, 20s, Aboriginal, College/University, HRM, Tested)

Some participants described the counselling they received:

“Basically the guy gave me some brief lecture. Okay, if we find some HIV positive stuff it’s not the end of the world... he just walked me through the different programs, to help face... basically go through the phase of accepting and stuff like that so it was okay.” (Female, Teens, African-Nova Scotian, High School, HRM, Tested)

There were a small number of participants, however, who had been approached by their doctor about HIV testing (opt-out testing).

“I don’t usually walk in and say hi can you test me, it’s usually offered to me. They ask me if I’d like to be tested, sure...” (Male, 50s, Caucasian, Some High School, HRM, Tested)

“I guess they just wanted me to test, cause I guess you can get infections and stuff when you’re pregnant and they just wanted to check me out and see if I had any STDs, AIDS and HIV, and
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gonorrhea, all the other ones, so I just got some paper work down there... I guess they felt that I should be tested...” (Female, 20s, Aboriginal, High School, HRM, Tested)

Some of the participants who had been approached by their doctor about HIV testing refused or decided not to be tested. In one instance, the participant was aware that it was a standard test, but had been tested before and did not want to go through the painful waiting period again.

“When I went to get a physical or whatever just to get checked down there and everything and [the health nurse] just wanted to run all the basic tests including that one but I refused it... I knew it was routine so that was it, I just asked her questions on it and I didn’t want to get it done.” (Female, 30s, Aboriginal, High School, HRM, Tested prior to past year)

Another participant brushed it off when she was approached, because she said that wanted to get the Pap test and blood work she had originally gone to receive and then go home.

“She asked... had I ever gone for an HIV test before and I told her no and then she asked me would I like to and I kind of never answered her, just brushed it off.” (Female, Teens, African-Nova Scotian, Some High School, HRM, Not Tested)

One man said he would feel singled out if he were a healthcare provider suggested an HIV test to him.

“Yeah, they could suggest it, but you know if my health care professional suggested me to get testing, well why do you think I need to get a test? That’s the first thing that would come to my mind... I’d feel like I’ve been singled out for some reason.” (Male, 30s, African-Nova Scotian, Master’s, HRM, Not Tested)

One woman said that she had never been asked if she needed a test, but suggested that she would like to have her doctor bring it up with her due to her perception that HIV is not talked about enough.

“I would rather that they suggest it to me to get this all, the tests that I need every time I’m in, not every time but at least once a year. They don’t... like, I find nobody talks about it, not as much as they should be...” (Female, 20s, Aboriginal, College/University, HRM, Tested)

Another participant suggested that it would be easier to encourage people to be tested by offering routine testing, rather than putting the onus on the individual to ask for testing.

“I think the best way to do it is to approach the people with it as opposed to people approaching you with it. I think that it makes it a lot easier when things are available for people to go get tested... I don’t know how you would actually word it so that it didn’t come out as testing for HIV... a softer way to put it to entice people to come get tested.” (Male, 30s, Caucasian, College/University, Outside HRM, Tested prior to past year)

In other cases, participants went to be tested at anonymous testing sites. This process was described as a good experience by those who received this form of testing. In particular, the experience with the nurses was cited as very professional but also comforting. The importance of relationships with nurses and practitioners in the HIV testing process will be discussed further.
3.3.3.2 Waiting period to receive test results
When asked about their feelings while waiting for the results of their HIV test, most of the participants noted that they felt anxious or worried to varying degrees. In fact, one woman suggested that the fear and anxiety she had experienced waiting for her test results actually deterred her from going back to be tested again.

“I asked him if my results came in and I was prepared... but he goes no you’re okay. So that was a big relief. It was scary for those couple of weeks.” (Female, 30s, Aboriginal, Some high school, HRM, Tested)

“And then we have done it with one of my exes... I heard he had it so I went to get tested and he came back and it was like two weeks – the most miserable two weeks – and then I had another test when my daughter was born and that was still another miserable two weeks.” (Female, 30s, Aboriginal, High School, HRM, Tested prior to past year)

“How did it make me feel? Very anxious, very nervous, very worried, very stressed out, wow... it was a roller coaster of emotions during that whole entire period, waiting for the results and actually meeting with him. Yeah I was scared. I was obviously really scared.” (Male 30s, African-Nova Scotian, College/University, HRM, Not Tested)

Other participants said that they did not think about it very much, since they did not consider themselves to be at risk, and were having the test done mainly as a routine. It is possible that their lessened fear was due to the fact that they considered the test to be routine, or because they did not consider themselves to be at risk, and therefore did not fear the results.

3.3.3.3 Receiving test results (post-test counselling)
Participants who had been tested for HIV in the last year received the results in various ways. Some participants received the results of the test in the mail, while others received this news from doctors or nurses in-person or over the phone. All participants tested at the hospital had to make another appointment or call their doctor to receive the results. In some instances, the participants said that they received their test results from their doctors in a fairly nonchalant way, and did not include any substantial post-test counselling.

“She just casually told me. She said you always worry about this, worry about that, every little thing... she said you’re already in menopause, your blood pressure’s excellent, everything is great, you know your HIV tests came back negative, just kind of threw it in there...” (Female, 50s, Aboriginal, College/University, HRM, Tested)

“Certain times when I had blood work done everything would be fine so no call, right. Other times she’d call when I had blood work... then I’d specifically ask about HIV and she’d go you’re good, right... Sometimes I just come out and ask her cause I really want to know about that.” (Female, 30s, African-Nova Scotian, Some High School, HRM, Tested)
“I just called to see, to just check in, and they’re like oh yeah your irons are low and I’m what about the other, and they’re oh they’re all fine, we would have called you.” (Female, 20s, Aboriginal, College/University, HRM, Tested)

“... the first appointment I had the form that I brought in to the clinic with the checked things that they wanted to test me for, so when they have their own form with the result it’s kind of HIV negative, this, with my blood level, I don’t know what they call it the red blood cell count and all that stuff, so it was just there after each one they tested me for.” (Female, Teens, African-Nova Scotian, High School, HRM, Tested)

Some participants mentioned that they would have desired a more detailed conversation or some reading materials during the waiting period, to have a better idea of what different results would mean.

“I think they should talk to you about it a little bit more thoroughly, at least give you a pamphlet to read while you’re waiting and then afterwards tell you a little bit about it... but if there’s that rapid testing, they could explain that and say you know, hey if it comes back positive we’re going to sit down with you and talk about it. Everything will be okay. It’s not the end of the world. You’re not going to die tomorrow or anything.” (Female, 20s, Aboriginal, College/University, HRM, Tested)

Another participant said that he would not desire additional counselling when receiving the results of his HIV test, due to a negative experience he had when tested for HIV prior to coming to Canada. His doctor did not deliver the results of the test first, but rather spoke to the participant for 15 minutes before announcing that the test had come back negative. None of the participants who had been tested in Nova Scotia during the past year described having this experience.

“I got tested for absolutely everything, and everything went off the way it was supposed to, until I got to the HIV test and [the doctor] just decided to go into a huge conversation for about 15 minutes and I’m sitting there shaking in my boots and I wondered what’s going on... then he just pats me on the back and says let’s not do this again.” (Male, 30s, African-Nova Scotian, College/University, HRM, Not Tested)

A number of participants said that they were not aware of pre- and post-test counseling when being tested for HIV, since they had only been tested through their doctor, or they had not been tested before.

“They didn’t mention anything about it at the hospital, the ones that did the blood tests, the nurses or whatever... they didn’t offer any counseling or whatever after I got tested, but I don’t know I never really thought about it. But they never mentioned anything and my doctor said it was alright so...” (Female, 50s, Aboriginal, College/University, HRM, Tested)

“I didn’t hear anything about counselling, like since I’ve never been to a testing site... is it just okay, come in, draw the blood, test you, you’re positive, and that’s it? Do they also have counsellors who talk to you before you do the test, and after the test, especially if you turned out to be positive?” (Male, 30s, African-Nova Scotian, Master’s, HRM, Not Tested)
Another participant mentioned that she was unsure what kind of counselling would be offered through her family doctor, but had the perception that it would be insufficient.

*I would suspect with my family physician her counselling would be very brief. I’m not sure if she would direct me elsewhere, it’s possible but again that would be, there may be a waiting period I’m not sure where you go, a lot of question marks around it.* (Female, 30s, Caucasian, Master’s, HRM, Not Tested)

### 3.3.3.4 Reasons for being tested for HIV in the past year

Participants who had been tested for HIV in the past year described the following reasons for why they went to be tested:

1. Involvement in risk behaviours (such as sexual activity or drug use)
2. Believed in personal responsibility for
3. Believed that despite being monogamous, there is still risk
4. Were tested as a part of a routine health regimen
5. Were tested “just to be sure”
6. Had previous experience with STIs
7. Their doctor suggested an HIV test
8. Experienced unexplained symptoms

**Perception of monogamy – still need to be tested**

Several participants who spoke of being in a monogamous relationship with a partner they trusted still expressed that it was important to be tested. None of the participants in this situation were married, but they were in committed, monogamous dating relationships. Some participants said that they did not tell their partner that they got tested to avoid creating feelings of mistrust. Still, going to be tested for HIV was described as a necessary precaution.

“Because again just knowing about my own past, sexual relationships, you don’t know, you only know what people tell you and it’s that one encounter you have with an individual you can only take what they tell you, you don’t know what you don’t know and so...” (Female, 40s, Caucasian, College/University, Outside HRM, Not Tested)

“The test came back negative but I’m going to go again just to be sure cause like I said I’ve been with him for [several] months, but when I met him he was a stranger to me... he told me he wasn’t with anyone... but then there are people they’ll tell you things and... he’s a pretty nice guy but you can never be sure, you know.” (Female, 50s, Aboriginal, College/University, HRM, Tested)

“You’ve just got to protect yourself. There’s no guarantee that the other person that you’re with is not doing something... nobody else is going to look out for you so you’ve got to look out for yourself,”
to take care of yourself, that’s all there is to it.” (Female, 30s, Aboriginal, College/University, HRM, Tested prior to past year)

“I think people who... are in a relationship think they don’t have to get this done because oh, they trust their partner. I trust my partner, but you know like I said you can’t be around them 24/7... You don’t know until you get tested, and then you really find out.” (Female, 30s, Aboriginal, College/University, HRM, Tested prior to past year)

The same participant went on to suggest that going to be tested for HIV must be confidential, since learning about the test can send the wrong message to a monogamous partner, which was a sentiment reflected by other participants as well:

“You know, it could send the wrong message too if you go and get tested your partner is like, we don’t need to. They might think that you’re doing something, like I’m doing something, but I’m only getting it done to make sure that I’m protected, that’s all...” (Female, 30s, Aboriginal, College/University, HRM, Tested prior to past year)

“Well I guess as a married man I wouldn’t want anybody to know that I was you know getting tested... just because I’m married and you know, neither one of us should be running around and all that should have been tested before or we should know that stuff by now.” (Male, 30s, Caucasian, College/University, Outside HRM, Tested prior to past year)

Perceptions of monogamy were shown to be significant to the participants in terms of the message going for an HIV test might send to a partner (including lack of trust, or infidelity) and the consequent desire for confidentiality.

Perceptions of responsibility

Amongst the participants, there was a popular notion that the individual is responsible for his or her own health. In the case of HIV transmission, several participants frequently cited the individual as being responsible for the health of anyone he or she may have a sexual relationship with. As an example, one participant said going to be tested for HIV is: “being responsible, you’re taking responsibility for your actions” (Female, 40s, Caucasian, College/University, Outside HRM, Not Tested). This notion is reflected further in the following quotations:

“I think everybody has a responsibility... to make sure that they are not getting involved in risky behavior, and also I think if you’re getting involved with someone, I think I have a responsibility to make sure that... you know, I haven’t contracted HIV.” (Male Trans, 30s, Caucasian, Some College/University, Outside HRM, Not Tested)

“I have a deceased relative that was bad off in another prison, was an intravenous drug user and through the grapevine I heard he had AIDS, but he OD’d and died so I kind of like... people are responsible for their own actions and choices in life.” (Male, 30s, Aboriginal, High School, HRM, Tested prior to past year)
“Protect yourself is the only advice I can give, always use protection and if you’re going to drink and do drugs use caution, be aware. That’s my way of thinking but I can’t force another person to think that way. Everybody is responsible for their own lives, so you can only wish for the best for them, and pray for them. But I’ll look out for number one though…” (Male, 30s, Aboriginal, High School, HRM, Tested prior to past year)

Tied to the notion of personal responsibility, many participants stated that they would want to know their HIV status because of the kind of person that they are. This further represents the perception that individuals are responsible for their health and HIV status.

“I’d have to know, period... I have to know.” (Male, 60s, Caucasian, College/University, HRM, Not Tested)

“If it were a case of me needing to know or feeling that I had to know I would just have to know, that’s just the type of person that I am.” (Female, 40s, Caucasian, College/University, Outside HRM, Not Tested)

“Yeah, for me I want to know like if you’ve got a rapid test give it to me right now, like I say I had unprotected sex, and usually I use protection, make sure they use protection and things like that you know, it’s just one of those things, but I want to know right away. That’s just the person I am.” (Female, 50s, Aboriginal, College/University, HRM, Tested)

“I think maybe just for my own awareness that you know you’re doing o.k., everything is alright, you know from that standpoint, starting a clean slate, choices that I make from here on in, getting this knowledge for myself, so I can make better choices from this point.” (Female, 40s, Caucasian, University, Outside HRM, Not Tested)

“I have friends who won’t get tested cause they’d rather not know. I’d want to know right away. There’s so many... there’s medicine, there’s stuff out there... I’d have to know, that’s the way I am.” (Female, 20s, Aboriginal, College/University, HRM, Tested)

**Routine testing – as part of a health regimen**

Several participants described being tested for HIV as a part of their usual health care routine. In most instances, participants described going for blood work, or a routine check up, and just adding an HIV test to the list of other tests being done at that time.

“I just think it should be done every year, I just think it should be. You know it’s not like it’s something that’s excruciating pain, it’s just a blood test, that’s all there is to it. If you want to live healthy then that’s part of that, you’ve got to get it done.” (Female, 30s, Aboriginal, College/University, HRM, Tested prior to past year)

“I get tested for everything, like diabetes, anything that could possibly show up, I always want to make sure that... I’m trying to maintain my health the best that I can... I’m not getting any younger... and that’s the only way to get that testing is to get your blood work done.” (Male, 30s, Aboriginal, College/University, HRM, Tested)

“There’s so many medical problems on each side of my family that I always think... I got this, I got that, and [my doctor] goes so far so good you don’t have any health problems... there’s [many]
people with health problems, something’s got to be passed down to me... I mean... you never know. So I want to be sure I’m healthy.” (Female, 50s, Aboriginal, College/University, HRM, Tested)

“I just wanted to know, just in case... Like I always... go for a physical every year, and I always get... the full test. You just never know.” (Female, 20s, Aboriginal, College/University, HRM, Tested)

3.3.4 Facilitators to accessing HIV testing

3.3.4.1 Increased education

Over half of the participants mentioned access to information and increased education about HIV in general, and HIV counselling and testing services offered in Nova Scotia. Increased education was cited as a potential facilitator to testing, in that it would alleviate fear and give people a better understanding of HIV risk factors and treatments, and what an HIV test entails. Proper education about HIV and sexual health in general was also discussed as important for individuals in making healthy sexual decisions.

“There should be a lot more going on in the high schools. They should be giving more information... I didn’t really know a lot when I was that young... I think people should be getting educated at a younger level so they can know about it, because I know that there’s a lot of peer pressure there, like people did it to me, like people lose their virginity at a younger age, these days they don’t like to wait...” (Female, 20s, Aboriginal, High School, HRM, Tested)

“I just think they should be educated more to know that... you can prolong your life, you can live a healthy life. I mean there’s women who have it and get pregnant and have healthy babies that don’t have it... more education should be going into teaching teenagers that age.” (Female, 30s, Aboriginal, College/University, HRM, Tested prior to past year)

“Just more information on people that are living with it and things that they go through. I mean that’s... everything basically not just like dealing with the sickness but... yeah just basically as much information as they can provide really... about HIV and somebody living with it.” (Female, 30s, African-Nova Scotian, Some High School, HRM, Tested)

“I think in school they should have classes about it, I think here they should have classes about HIV and just stuff like that. I think people need to be educated about that kind of stuff, cause you never know... a lot of people are just like, so what, right? Oh it won’t be me, until it is you, right?” (Male, Teens, Caucasian, Some High School, HRM, Tested)

Another participant mentioned the importance of having information about HIV and HIV testing available to educators, community health nurses and so on, such that they can pass along this information:

“Just have the information available, have the workers of these institutions well aware too yeah... educators, community health nurses, representatives, people involved in addiction services, just like have them educated about it as they can be so they can help pass on that knowledge to the people that need it.” (Female, 20s, Caucasian, Outside HRM, College/University, Not Tested)
A participant from a rural community specified that she felt even though there is a lot of information available to her, people do not always seek it out, particularly when HIV is not commonly talked about in her community. She suggested that the best way to learn is to have someone else teach you.

“There’s tons of things out there like all those pamphlets and stuff and if you really, I mean you can go and you find all this information but I think the best way to learn about these things is to have someone tell you about them or do that way, rather than… I don’t think people will always go out and read all these things…” (Female, Teens, Caucasian, Some High School, Outside HRM, Not Tested)

Another participant spoke of the importance of targeted HIV-related messages and ensuring that information is adequately and appropriately delivered to various communities:

“Having targeted messages; not just generalized messages, but target demographics. Think about how receptive they will be to certain types of information and then think about the avenue… how is the information packaged? Their response to that information… is dependent on how they receive it, how it was packaged. So I think targeted prevention programs should be in place.” (Male, 30s, African-Nova Scotian Immigrant, Master’s, Outside HRM, Tested prior to past year)

### 3.3.4.2 Availability of HIV testing options

The availability of various HIV testing options and testing sites emerged as a potential facilitator to testing for various participants in this study. Specifically, this referred to anonymous HIV testing, and also rapid point-of-care testing. Though questions about anonymous HIV testing were not overtly asked of participants, conversations about anonymous testing emerged in conversation, both with those who had or had not been tested anonymously or otherwise. In general, those who spoke about anonymous testing or who had themselves experienced anonymous testing were advocates of having this option more widely available for Nova Scotian populations.

“I think people would be a lot more willing to go get tested if they could get tested anonymous. More so than just walking in and you know they come out with the two sets of gloves on and call your name out… yeah, I think if it was anonymously done that nobody knew who you were there would probably be more testing done.” (Female, 40s, Caucasian, College/University, Outside HRM, Not Tested)

“When are we going to have more anonymous testing in rural areas, especially in Nova Scotia? Will we ever get to the point... when are we going to have enough programs in place all over Nova Scotia? Because how does like... somebody from [a rural town] get to [HRM], especially if you’re below the poverty line, and I would think in the rural areas that’s a big concern.” (Trans, 30s, Caucasian, College/University, Outside HRM, Not Tested)

“I think that anonymous testing right now is what seems most attractive to me if I was to pursue getting tested for HIV and so I guess just knowing more resources in Nova Scotia to get anonymously tested would kind of be a pro I would think.” (Female, 20s, Caucasian, College/University, HRM, Not Tested)
“I think just generally speaking, anonymous testing is a really good idea because I think it’s opening doors for all kinds of people to be tested who normally wouldn’t be tested.” (Female, 50s, Caucasian, College/University, Outside HRM, Tested Anonymously)

“Testing anonymous is a lot faster and a lot easier... you can just come in and they’ll just get you and have you sign papers, give you your blood work and then you’re out. But if you get it done at a hospital it takes a lot longer and you’ve got to sit there and wait...” (Female, 20s, High School, Outside HRM, Tested Anonymously)

The majority of participants who were asked about rapid testing had never heard of it before. Rapid point-of-care testing for HIV is not currently offered in Nova Scotia. When asked what they would prefer (rapid or standard testing) there was a mixed response, but most participants stated they would rather know their HIV test results sooner, and would be interested in learning more about rapid testing. Those who preferred the standard test said this was because they were uncertain of the accuracy of a rapid test, or they associated it with home testing (as opposed to point-of-care rapid testing).

The main reason cited in favour of rapid testing is in lessening the waiting period, which some participants mentioned was a stressful, even painful time. One participant said that the waiting period was the main reasons she didn’t want to be tested again. For those who said they would prefer rapid testing, they explained that finding out the results of their test as soon as possible would help decrease the stress of the waiting period.

“Well faster would always be better, accuracy is the point and if there’s not a problem with accuracy in the results, well faster would always be better I would think.” (Male, 50s, Caucasian, Some High School, HRM, Tested)

“It’s like... instant knowledge... Wouldn’t have to wait that week or two period.” (Male, 30s, African-Nova Scotian, College/University, HRM, Not Tested)

One woman suggested that she would like rapid testing if it was explained well, and would like to see rapid testing happening in rural or Aboriginal communities, explaining her perception that rapid testing might be an effective way to reach communities that don’t know or don’t want to know their HIV status.

“I think if they explain it to you, that we’re going to know something right away, give you the heads up about stuff, then yeah I think it’s acceptable. I think they should put that in like... more small communities, like Aboriginal communities, where you know it’s growing and people don’t really know and nobody wants to get tested. I think they should have those clinics there.” (Female, 20s, Aboriginal, College/University, HRM, Tested)

Several participants mentioned difficulty or discomfort with having blood drawn, which is not necessary with rapid testing (although for positive test results, a confirmatory blood test is required).
“I can’t see no way to improve it unless they had some kind of those little things that they can prick you quickly and take blood cause they have... in both arms trying to get blood out of me I was here for about a half hour.” (Male, 40s, Caucasian, Some Elementary School, Outside HRM, Tested Anonymously)

“I don’t like having my blood tested yeah, that’s probably, I really, they have a lot of trouble drawing my blood, I have a lot of issues where they try, they have to leave so that’s probably my biggest anxiety actually the fact it’s being as blood testing.” (Female, 30s, Caucasian, Master’s, HRM, Not Tested)

“I guess the reason I haven’t gotten tested because one I’m really, really afraid of needles and will avoid them at any cost so the thought of getting blood drawn is kind of a turnoff for me.” (Female, 20s, Caucasian, College/University, HRM, Not Tested)

As stated before, the majority of participants had never heard of rapid testing before, and several suggested that they might prefer standard testing mainly because it is what they are used to. Those who had mixed feelings or no preference in regards to rapid testing often asked questions about the accuracy of the rapid test.

“I would prefer the standard testing because I know everything should be accurate, they took the time to check and re-check, with the rapid test... are you sure there’s nothing wrong with your machine?” (Female, Teens, African-Nova Scotian, High School, HRM, Tested)

The only instance where participants reacted negatively to the idea of rapid testing was when the rapid test would be done at home (i.e. not point-of-care). These participants emphasized the need for caring health professionals to be there when finding out the results of an HIV test. Overall, rapid testing was received well by the participants and most desired more information about this testing option.

3.3.4.3 Accessible and supportive services

The relationship with doctors, nurses and practitioners was described as quite important by several of the participants. Multiple participants noted that they had a good or close relationship with their doctor; a number even mentioned that they had the same doctor for their entire life, or that their doctor had delivered all of their children. The importance of building rapport and support given by the individual doing the testing was described by a number of participants.

“I just went... she called me... [in] and she was really cool about it you know, just me and her.” (Male, 30s, Caucasian, Some High School, Outside HRM, Tested Anonymously)

“If you test positive the counselor will just encourage and empower you that you are not the only one. There are ways that you can help yourself. It doesn’t mean that’s the end of the world and that doesn’t mean you are dying now. It’s just understanding of all those things... you cannot say to yourself. If you have it, you still need somebody to empower you.” (Female, 50s, African-Nova Scotian Immigrant, Master’s, HRM, Tested prior to past year)
One participant described his experience when diagnosed with Hepatitis C:

“Just talking to me... just telling me... you’re going to lead a normal life, all that sort of stuff. She was talking as if she was my best friend. She was pretty good.” (Male, 40s, Caucasian, Some Elementary School, Outside HRM, Tested Anonymously)

A few participants stated that they would feel comfortable accessing HIV testing at a clinic which offered specifically sexual health services, rather than going to a hospital or clinic to be tested. This preference was explained as a means of avoiding discomfort or a judgmental reaction from the practitioner.

“Places maybe that were set aside for just testing, or even maybe in the hospital but a room that was set aside just for that sort of testing, just so that... I wouldn’t have to say this is what I’m here for, because I think that would be an uncomfortable discussion...” (Female, Teens, Caucasian, High School, Outside HRM, Not Tested)

“Cause some doctors... they’re snobby sometimes and they’re very judgmental... and I think going to a clinic, they kind of understand because you get a lot of patients that are from neighborhoods like this, or the doctors live in neighborhoods like this, so they’re not working only for the money, but they’re working for their patients too, to see that their needs are met.” (Female, Teens, African-Nova Scotian, Some High School, HRM, Not Tested)

“In terms of any kind of counselling, I would not be comfortable through my family doctor... if I actually thought there was a possibility I would test positive, I’d want to go through a [sexual health centre]... there’s not the supports there through the family doctor...” (Female, 30s, Caucasian, Master’s, HRM, Not Tested)

One participant mentioned that she would be more comfortable accessing HIV testing general sexual health services due to the fact that for women in particular, pap testing and other sexual health services offered are perceived as being routine.

“I don’t know if men would be as comfortable going. I don’t know, it’s a supposition... but being female, because there’s such a range of other services offered there, I guess I wouldn’t attract attention if I was concerned about that... it’s just like any other possible infection you might get... it’s just on the range.” (Female, 30s, Caucasian, Masters, HRM, Not Tested)

Alternatively, others said that they would prefer to access HIV testing in a location where the reason for their visit was obscured.

“I don’t feel like going there and sitting around waiting to be tested, everybody knows what you’re there for so it’s like well you know... so I felt for me it was easier to have it done under the auspices of a bunch of other things.” (Female, 50s, African-Nova Scotian Immigrant, HRM, Tested)

“You don’t have to tell people why you’re going to the hospital, you can just tell them you’re going for blood work... and when you go in, the doctor can give you the form to fill and choose which test you would like that and HIV can be one of the tests on that form and you can check it without you specifically asking.” (Male, 20s, African-Nova Scotian Immigrant, College/University, HRM, Tested prior to past year)
A suggestion made by a number of participants was the idea of mobile HIV testing or open house HIV testing as a potential way to make HIV testing available and accessible to various communities.

“I don’t know if they can do that, but go to different places and have like a... something to set up that they’re testing people, they don’t do that, only in big cities, like I’ve only heard of that. I’ve never... they don’t really go around, they don’t push it. And now you have to ask for it, they don’t...I’ve never... nobody has ever asked me if I needed a test, you know.” (Female, 20s, Aboriginal, College/University, HRM, Tested)

“Almost like an open house or something. It’s like come on in, just come in; you don’t necessarily think you have it, just a baseline kind of thing... almost like a mass testing effort to kind of get people used to thinking about HIV.” (Female, 30s, Caucasian, Master’s, HRM, Not Tested)

“There should be more... testing sites that can go into communities thereby ending the need for physical structures to be built... So I think a concerted effort should be put in place to ensure that the information that people need to know about HIV and AIDS is made aware to them so take that information to the people that are waiting for them to come.” (Male, 30s, African-Nova Scotian Immigrant, Master’s, Outside HRM, Tested prior to past year)

It is clear from the participants that diverse populations experience equally diverse barriers and/or facilitators to testing, which require innovative solutions to ensure equitable access to quality health care services.

**Summary of interviews**

The findings from the interviews provide an overview of the experiences and perceptions of a diverse sample of those who had and had not been tested for HIV in the past year about HIV counselling and testing in Nova Scotia. While many participants had accessed HIV testing services (and did not experience significant barriers to access) others either did not view HIV testing as “their issue” or did not feel comfortable accessing this service. Some barriers included low awareness about HIV and HIV testing, misinformation about HIV and HIV testing, stigma and discrimination, and inaccessibility of services. Participants offered their own perspectives on how feelings of fear or discomfort could be mitigated through decreased waiting times for test results, more in-depth discussion with their doctors, or assured anonymity and confidentiality. For those who did access HIV testing, many did not receive counselling or experienced minimal discussion about the test and their results. Individuals who accessed anonymous testing sites spoke very highly of this experience and of the relationship developed with the nurses. The facilitators to accessing testing included: increased education, availability of testing options, and accessible and supportive services. Suggestions about how to mitigate the barriers and promote facilitators to testing are offered in the following discussion and recommendations section.
4 DISCUSSION

The data in this report examined provincial HIV testing policies and research, provincial testing rates, and the experiences and perceptions of the research participants. Some key issues to emerge in this study are: who is seeking testing and who is testing positive; knowledge about HIV and HIV testing (on the part of the patient and the practitioner), provision of adequate sexual health services for diverse communities, and testing options (including anonymous and rapid point-of-care testing).

4.1 Who is seeking testing and who is testing positive?

The laboratory testing data show that the number of HIV screening tests has increased over time, and that a large number of physicians from across the province send specimens for HIV screens. Efforts to increase uptake have been effective to a degree, but continued efforts and further study are needed to track and ensure equitable and timely access to this health care service (as per the DOH statement of mandate, 2010). Our quantitative data suggest that approximately half of the women tested were tested as part of prenatal screening (as per our surrogate marker), but when this group is removed, the number of men and women seeking HIV testing is almost equal. The age distribution of those tested was also similar for males and females. Nova Scotia’s prenatal HIV testing guidelines recommend HIV testing be offered to all pregnant women with appropriate pre-and post-test counselling and conducted with specific informed consent (i.e. opt-in testing approach). Routinely collected surveillance data for HIV tests includes only the number of tests conducted by month; data used in this study was collected for the purpose of specimen testing for clinical management, not for surveillance purposes, and tracks demographic information pertaining to the person’s age and sex.

Individuals testing positive in the province have been predominantly male, between the ages of 40 and 44, although those most commonly accessing testing are individuals aged 25-29. The most commonly reported HIV exposure type for newly diagnosed HIV cases was men who have had sex with men (MSM). It is important to understand the characteristics of those testing positive for HIV, but also to be mindful of the fact that there are HIV positive persons not represented in the provincial statistics. This may be due to the fact that individuals have been tested outside of Nova Scotia and later move to the province, or may not have been tested at all. Provincial statistics measure HIV incidence (new diagnoses) rather than prevalence (Nova Scotians living with HIV), which means that the number of newly diagnosed HIV cases in Nova Scotia (ranging from as low as 10 to as high as 33 new infections each year since 2003) do not necessarily represent the full burden of HIV in Nova Scotia.
4.2 Provision of accessible HIV testing services for diverse communities

The findings of this study suggest that not all individuals feel comfortable accessing HIV testing or sexual health services in the same way, and there is a need to provide diverse sexual health services (in terms of location and method of testing) in order to meet the needs of diverse communities. Both the surveillance and the interview data suggest that most people access HIV testing through a family doctor or a clinic, not through anonymous testing sites (which may be due to the fact that these sites are limited throughout the province). Information about who accesses which service is not readily available, outside of the non-representative data provided by the Halifax Sexual Health Center.

It also becomes clear that in order to meet the needs of diverse communities, ensuring a culturally competent approach to HIV counseling and testing is required. HIV testing could be framed in a different context other than sexual health, such as general health and wellness, in order to meet the needs of various populations. Several interview participants stated that they would feel comfortable accessing HIV testing at a clinic which offered specifically sexual-health related services, rather than going to a doctor or the hospital to be tested. The reason for this preference was described as avoiding an uncomfortable discussion, and avoiding a judgmental reaction from the practitioner. This reflects the continued importance of the harm-reduction philosophy promoted in Nova Scotia’s HIV/AIDS policy documents (PBBPCC, 2004; PHASSC, 2003) and the need for a culturally competent approach to service provision (Health team Nova Scotia, 2008a & 2008b).

One participant stated that both for herself and her friends who had immigrated to Canada, there is a discomfort accessing services that are explicitly linked to their sexual health, or that could identify the reason for their visit. For example, she suggested that going to access HIV testing at a Sexual Health Centre would be undesirable due to the visibility of the reason for being there. Testing at the hospital was preferred in this case because individuals can go to the hospital for a wide range of issues, not necessarily related to sexual health. Even with the assured anonymity of the counselling and testing services offered, the decision to go to a clinic that deals specifically with sexual health issues was seen as a major deterrent for this participant in seeking out HIV testing services.

Strategic direction 3 of the provincial HIV/AIDS strategy examines the ways in which public health and community-based organizations in Nova Scotia can collaborate to develop and implement a comprehensive approach to HIV prevention and treatment for diverse communities in various service settings (PHASSC, 2003). It promotes anonymous HIV testing in multiple settings across the province, such as correctional institutions and community health centres, to increase access for more vulnerable populations (men who have sex with men, women, aboriginal persons, injection drug users, youth, and
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Recommendations include an integrated network of anonymous testing sites, discrete access to barrier prevention methods, needle exchange, methadone services, coordinated delivery of services, peer-based prevention and education, ongoing evaluation of services, and training on harm-reduction and sensitivity to affected populations (PHASSC, 2003). Additionally, it is imperative that health care practitioners at all levels receive cultural competence training in order to ensure that they are equipped with the tools necessary to provide equitable services to all populations (Health team Nova Scotia, 2008a & 2008b), particularly those that do not perceive HIV testing as their issue, or that feel uncomfortable seeking out these services. The necessary model of primary health care would make HIV testing equitably accessible to all Nova Scotians, recognizing that one approach will not work with all communities, and also recognizing the necessity of engaging these communities in finding solutions that work for them (Health team Nova Scotia, 2008a; PMCS, 2008).

4.3 Anonymous and rapid point-of-care testing options

Anonymous testing

Anonymous HIV testing sites provide a model for enhanced counselling, testing and referral services in Nova Scotia. These services are meant to be provided in a safe, supportive environment (PBBPCC, 2004). It is widely accepted that wherever possible, having access to a consistent health care professional both before and after the HIV test is recommended when delivering pre-and post-test counselling (PBBPCC, 2004; MMWR, 2001). The anonymous counselling, testing and referral strategy encourages increased counselling in combination with testing in order to strengthen prevention and risk reduction efforts.

The surveillance data shows that the majority of people who went for anonymous HIV tests in Nova Scotia did not have any identified risk (NIR) for HIV infection. Age and sex distribution of anonymous tests was similar to that for all tests at CDHA lab, and the anonymous testing service at the Halifax Sexual Health Centre were accessed predominantly by Caucasian individuals aged 20-30, equally split between men and women.

Interview participants who were tested through their family doctor generally had to first go to their doctor, then to the hospital (where a technician took their blood), and then back to their doctor to receive the results (though some participants were able to call or were contacted by mail). This involved three visits and two practitioners, as opposed to the participants' experiences of anonymous testing, which commonly involved the same nurse, and required only two visits. The importance of building rapport with the individual doing the testing was often described by participants who were tested anonymously.
Several participants noted that they had a good or close relationship with their doctor; a number even mentioned that they had the same doctor for their entire life. However, not everyone in Nova Scotia has a family doctor, or would said that they would feel comfortable accessing the services that are currently available to them (hospitals and clinics in small or rural communities). Anonymous testing sites have the potential to address concerns of confidentiality, and provide increased testing options for various populations across the province.

**Rapid point-of-care testing**

The majority of participants who were asked about rapid testing had never heard of it before, likely due to the fact that rapid point-of-care testing for HIV is not currently offered in Nova Scotia. When asked what they would prefer (rapid or standard testing) there was a mixed but mostly positive response to rapid testing. Those who preferred standard testing said this was because they were uncertain of the accuracy of a rapid test, or they associated rapid testing with home testing (not point-of-care testing). This reflects a concern identified by stakeholders (PMCS, 2008). Several research studies have been conducted to test the accuracy of rapid testing; based on the results from four CDC studies, it was found that the performance of rapid tests is similar to or sometimes even better than conventional tests (Delaney et al., 2006). There are concerns about the quality of pre-and post-test counselling offered with rapid testing, and it is essential for rapid testing to occur at the point of care (not in the home) and to maintain counselling as a priority (Canadian Legal AIDS Network, 2000).

The main reason cited by participants for liking the idea of rapid testing is because it would lessen the waiting period for test results (which can often last up to 2 weeks), which for individuals who feel they might be at risk for contracting HIV, can be a stressful, even painful time. One of the participants cited the waiting period as her main reason for not wanting to be tested again. For those who said they would prefer rapid testing, they explained that finding out the results of their test as soon as possible would help decrease the stress of the waiting period. Another participant suggested that she would like rapid testing if it was well-explained, reflecting the concern that quality pre-and post-test counselling remains a part of rapid point-of-care HIV testing (Canadian Legal AIDS Network, 2000). The same woman said she would like to see rapid testing happening in rural or Aboriginal communities, explaining her perception that rapid testing might be an effective way to reach communities that don’t know or don’t want to know their HIV status. Rapid testing has been shown to increase uptake of HIV testing in rural communities, by removing logistical barriers (Morin et al, 2006).
As stated before, the majority of participants had never heard of rapid testing before, and several suggested that they might prefer standard testing simply because it is what they are used to. Those who had a mixed response or no preference regarding rapid testing questioned the accuracy of the test. The only instance where participants reacted negatively to the idea of rapid testing was when the rapid test would be done at home. They emphasized the need for caring health professionals to be there when finding out the results of an HIV test. Overall, the idea of rapid testing was received well by the participants who were asked about it. It is clear that at the very least most of the participants would desire more information about rapid testing as an option in Nova Scotia.

The PMCS report recommends alternatives to the continued reliance on a single model (unchanged since the 1980s) of HIV testing and counselling for all people in the province; new methods include the introduction of rapid point-of-care testing (PMCS, 2008). Their suggestions also included opportunities for routine testing, streamlined counselling, opt-out models, increasing awareness about HIV and HIV testing, increasing number of rural testing sites, creating a network of drop-in centres, increasing outreach services, and making testing part of regular screening services (PMCS, 2008).

4.4 Information and education about HIV and HIV testing

Lack of information about HIV and HIV testing emerged as one of the most central themes in the interview data, and has been shown to be a consistent trend in Nova Scotia (PMCS, 2008; Thinkwell/Extreme, 2007; PSASC, 2003). HIV testing is an important public health issue that requires ongoing attention, particularly in light of the fact that HIV issues in general, and HIV testing in particular, has a very low profile in Nova Scotia (PMCS, 2008). One suggestion was to implement a social marketing campaign for diverse audiences with information encouraging people to seek HIV testing, and providing information about where to get tested. The Nova Scotia Advisory Commission on AIDS (NSACA) had intended to initiate a prenatal social marketing campaign throughout Nova Scotia, but decided to postpone this action due to findings of this study. Instead, they initiated a wider exploration of the issues emerging from the prenatal research study, which is examined in the PMCS report (PMCS, 2008). The results of this study add to the findings of this report, suggesting that the state of education and general knowledge regarding HIV and HIV testing in Nova Scotia remains quite low and needs to be addressed through culturally-competent educational and social marketing initiatives.

Many participants suggested that increased education would be helpful to them specifically, and their community in general, particularly due to the common view that HIV is not talked about in the community. One participant specified that even though there a lot of information is available, people do
not always seek it out; instead, she suggested that the best way to learn is to be taught by someone else. This reinforces the recommendation that further outreach activities are needed in order to increase visibility of HIV and HIV testing and counseling services in diverse communities across Nova Scotia (PMCS, 2008). The need for these outreach activities needs to be identified by the community.

**Patient knowledge about HIV**

Lack of general knowledge about HIV was indicated during the interviews when several participants asked questions about HIV, such as whether or not there are symptoms, if there is a cure, or what is entailed in an HIV test. This desire for information is reminiscent of the findings from the “Prenatal HIV Testing Project” focus groups and literature review (Extreme Group, 2007; Thinkwell Research, 2007).

A number of participants also indicated an assumption that testing positive for HIV would mean the end of their life. This assumption and potential lack of awareness about treatment options for HIV reflects the findings of other provincial research (Extreme Group, 2007; PMCS, 2008; Thinkwell Research, 2007) regarding prenatal HIV testing, which included general misperceptions about HIV and low awareness of HIV treatments, risk factors, testing procedure and transmission (Extreme Group, 2007; Thinkwell Research, 2007).

Some participants suggested that informing former partners of their HIV status acted as a barrier to testing. Nova Scotia’s legal policy surrounding confidentiality and HIV reporting and partner notification states that if an individual tests positive for HIV, their test results will not be given to others without their consent, and that if a public health official or physician notifies their partner(s) on their behalf (because they do not wish to do so), they cannot use the individual’s name (HPP, 2009b, HPP 2004). Partner notification is promoted as important for those who receive a positive test result to prevent further spread of HIV and can be done on behalf of someone who has tested HIV positive by a public health nurse without using their name; however, despite these facts, it may still act as a barrier to testing for individuals who fear they are at risk for having contracted HIV.

As a separate but related issue, it is a criminal offense in Canada to be aware of one’s HIV status and not inform a potential sexual partner prior to sexual activity that could lead to the transmission of HIV. Actual transmission of HIV does not have to occur in such cases; the law is based on the exposure of another person to a “significant risk” of HIV transmission. Criminalization has the potential to further deter people from effective public health initiatives (such as counselling and testing), to create a false sense of security for those who feel that the law will protect them, and to counteract the message that individuals are responsible for their own sexual health (Canadian Legal HIV/AIDS Network, n.d.).
**Patient knowledge about HIV counselling and testing**

In some instances, participants did not directly ask for HIV testing, but assumed or were informed after the fact that they had been tested. This reflects a similar experience of pregnant women who were not certain whether or not they had received prenatal screening (Thinkwell Research, 2007). These findings combined show that in some circumstances, there is a serious lack of communication about HIV and HIV testing between patients and their doctors or practitioners.

A number of participants stated that they were not aware of pre- and post-test counseling when being tested for HIV, since they had only been tested through their doctor, or they had not been tested before. This shows that in some instances, there is a lack of knowledge about the range of testing options available in Nova Scotia, or a lack of communication between doctors and patients about the various testing options available to patients (including the risks and benefits of being tested).

Some participants suggested that they would accept or even desire their doctors to discuss testing with them, which speaks to a desire for increased knowledge and awareness about HIV testing; however, one participant did not like this idea since he had been tested involuntarily before. This reflects the argument that testing can have human-rights implications if the “3 Cs” (informed consent, confidentiality and counselling) are not followed (Canadian HIV/AIDS Legal Network, 2005; Medical News Today, 2006). Opt-out testing often entails diminished or no pre-and post-test counseling, although the benefits of opt-out testing have been argued by the Centres for Disease Control (CDC, 2006). Their argument is that the benefit of identifying HIV infections earlier through increased rates of testing outweighs the benefit of providing prevention counselling in conjunction with HIV testing (CDC, 2006). Alternatively, it has been argued that focusing on the routinization of HIV testing risks the quality of pre-and post-test counselling (Fisher et al., 2006; Medical News Today, 2006).

**Practitioner knowledge about HIV counselling and testing procedure**

In various instances, participants described minimal conversation about HIV testing with their doctors. In another instance, a participant described the situation where she had asked her doctor to be tested for HIV but her doctor advised her against it. A couple of participants were concerned that HIV testing is not included or at least discussed when asking for STI testing. Guidelines for testing and counselling provided by the Canadian Medical Association (CMA, 1995) require that patients are asked about their reasons for testing, and informed about the potential consequences of the test (i.e. the 3 Cs of consent, confidentiality and counseling). The fact that the participant was advised against being tested, rather than being informed about the available options and potential risks and benefits, suggests that the
counselling did not adhere to the recommended practice guidelines. It was not clearly identified whether the doctor was unaware of alternative testing options, or if they just did not mention these testing options to the patient. The expected release of the updated counseling guidelines for testing later this year should provide another opportunity to increase practitioners' awareness.

Knowledge about HIV: A shared responsibility

Amongst the participants, there was a popular notion that the individual is responsible for his or her own health. In the case of HIV transmission, several participants frequently cited the individual as being responsible for the health of anyone he or she may have a sexual relationship with. This focus on responsibility as a concept shows a common perception that it is individuals (and the choices individuals make) that are responsible for the prevention or transmission of HIV. As an example, one participant said going to be tested for HIV is: “being responsible, you’re taking responsibility for your actions” (Interview 4 - Female, 47, Caucasian, College, Outside HRM, Not Tested). Given the prevailing HIV stigma and marginalization of certain populations, it is important to frame sexual health issues not as the sole responsibility of an individual, but rather as a shared responsibility between partners, and also a responsibility of health practitioners, educators and government organizations (such as District Health Authorities and the Department of Health).
5 RECOMMENDATIONS

The following recommendations were created with input from the Community Advisory Committee. Based on the findings of this research, previous research and policy from Nova Scotia, these recommendations are meant to help inform policy that will help to increase equitable access to HIV testing for all people living in Nova Scotia. The recommendations include potential strategies to address the issues identified in the findings and discussion sections of this report (including policy, surveillance and interview data). The recommendations include: integrate and innovate, increase education, standardize patient-appropriate counselling, increase testing options, and conduct further research. These recommendations must be implemented in conjunction with Nova Scotia Department of Health and Health Promotion and Protection mandates and existing strategies (DOH, 2010; PMCS, 2008; PBBPCC, 2004; PHASSC, 2003). Additionally, they will be given more direction and depth when PHAC releases the updated guidelines for HIV counselling and testing.

5.1 Integrate and innovate

Critical to increasing the accessibility to HIV testing services (and other HIV prevention, care, treatment and support services) in Nova Scotia is integrating and linking with broader provincial health care and public health policy and initiatives. This recommendation emphasizes the Nova Scotia Department of Health’s commitment to quality health care for all of the individuals served by Nova Scotia’s health care system (DOH, 2010); and the need for collaboration between provincial partners in the development, refinement, and delivery of HIV prevention, care, treatment and support strategies. In order to achieve these goals, it is important to address the following:

- Integrate HIV prevention, care and treatment and support strategies as per the Department of Health’s statement of mandate (e.g. collaborative practice, provision of quality care, culturally safe and culturally-competent care provision, integrated into existing system);

- Link HIV prevention strategies with Public Health Renewal lead by HPP, providing opportunities for local innovation projects (See report on Public Health Renewal – HPP, 2006). Recent research and discussion on HIV testing in NS, as well as the broader public health renewal process, demonstrate the need for innovation and a willingness to do things differently, adapting to the changing needs and diversity within Nova Scotia communities (e.g. have sexual health / HIV educators in the community, training for outreach workers, information sharing in ways that are useful to communities); and
• Ensure leadership and involvement from diverse communities to make HIV testing and counselling services accessible and relevant to all Nova Scotians (one size does not fit all).

5.2 Increase education

Increased education amongst practitioners, patients, and the general public about HIV testing and counselling options, as well as HIV in general, was identified as an area of importance in this research. This reflects policy suggestions and previous research findings that emphasize information barriers in Nova Scotia (Extreme Group, 2007; PHASSC, 2003; PMCS, 2008; Thinkwell Research, 2007).

5.1.1 Practitioners (offering, requisitioning, doing HIV testing)

Practitioners should have access to information and/or training about the following:

• Testing options available (general process and location of each);
• Pre- and post-test counselling information for patients (see recommendation 5.2 below);
• Referral services – where to go for further HIV information besides a family doctor; and

5.1.2 Patients (seeking or being tested)

Patients should be informed about the following:

• Important questions to ask doctors and providers, such as HIV risk factors, when to be tested, the consequences and benefits of HIV testing, knowing what they are being tested for and when this is happening; and
• Testing options that are available, and where (see pamphlet – HPP, 2009b).

5.1.3 General public / specific groups

Increased public awareness about HIV was identified as important by the participants in this study and in previous research (PMCS, 2008). With leadership and involvement from representatives of diverse communities across the province, strategies should be developed to:

• Provide basic information with targeted messaging reflective of the needs and diversity within the province about HIV (risk factors, when to be tested, types of tests available, reporting and partner notification, and available treatments for HIV); and
• Reduce the stigma of HIV and HIV testing.
5.3 Standardize population-appropriate counselling

The next recommendation relates to the delivery of pre-and post-test counselling for HIV testing. Pre-and post-test counselling was identified as an important aspect of HIV testing in various relevant policy and research documents (PBBPCC, 2004; PHASSC, 2003; PMCS, 2008). Counselling messages need to be simplified so that they can be delivered in a clear, concise, patient-appropriate and cost-effective manner. Although it is important that certain baseline information be conveyed, the delivery of this information needs to be suited to the context of patient needs (discussed in further recommendations).

Some suggestions for ways to facilitate the delivery of effective counselling procedures:

- Provide a pamphlet about pre-and post-test counselling for practitioners (with clear, easy-to-understand information about what patients need to know about the test and outcomes);
- Practitioners must (at minimum) inform patients what they are being tested for and are not being tested for (to avoid false assumptions that they have been tested for HIV);
- Provide HIV counselling as a part of annual sexual health check-up, or provide a general discussion about HIV when patients access testing for other STIs and/or BBPs (promoting awareness – HIV testing does not always have to be provided as a separate service);
- Counselling messages (whether traditional or streamlined) should be standardized, yet appropriate to the needs of the population being served; and
- Pilot targeted group information sessions which could serve as either a public awareness session and/or preliminary pre-test counselling.

5.4 Increase HIV testing options

There has been a consistent push to increase access to various HIV testing options, particularly anonymous testing, in order to address certain barriers (such as concerns about confidentiality in small communities) to testing in Nova Scotia (PBBPCC, 2004; PHASSC, 2003; PMCS, 2008). Increased availability of the following testing options would be beneficial in mitigating these barriers:

- Increase number of locations where anonymous HIV testing services are available (multiple locations across the province, particularly in small or rural communities, where confidentiality and anonymity is a greater concern);
- Introduce rapid point-of-care testing, addressing quality assurance issues and appropriate pre- and post-test counselling to increase benefits (e.g. potential to decrease the waiting period and increase the number of those who receive their test results) and mitigate the risks.
of this form of testing (e.g. how to provide counselling for a reactive test result – or initial positive result – that requires referral for confirmatory testing);

- Design and pilot a comprehensive annual sexual health examination within physicians’ offices, which includes HIV testing for targeted groups of sexually active individuals; and
- Encourage physicians who have a high immigrant base from countries where HIV is endemic to consider HIV (and sexual health in general) as a discussion item during patient visits.

### 5.5 Conduct further HIV-related research

Although a significant amount of HIV-related research has been conducted in Nova Scotia in the past decade, there are nuances and issues emerging from these studies that warrant further exploration. The social inclusion-focused nature of this research necessitated a very broad research approach, and as such this research was limited in its ability to thoroughly assess the needs of a particular community or population. These directions for future research should be community-based, potentially involving a similar framework of community consultations and establishing advisory committees. Some directions for further research inspired by the findings and limitations of this study include:

- Assess community-specific needs for increasing access and uptake of HIV testing (generated by interest in communities and directed by members of communities);
- Assess how to develop an effective social marketing strategy with appropriate messages and communication strategies for diverse Nova Scotian communities (again, with direction and input from members of communities);
- Conduct a sero-prevalence study to better approximate the true prevalence of HIV in Nova Scotia;
- Examine testing rates by geographic communities and ethno-racial populations;
- Understanding risk of infection for different populations would require details of sexual networks and associated sexual behaviours to determine whether those being tested are representative of those at risk of HIV infection;
- Examine the impact of the setting in which HIV testing is conducted on uptake rates and effectiveness of counselling messaged. The setting of testing is not available for the majority of HIV tests conducted; further exploration of testing at the time of other STI testing, or pap smear testing for females, may indicate settings contributing to higher and lower HIV testing uptake; and
- Further investigate why more females than males are being tested in the Emergency Room setting (potential links to research and policy around sexual assault).
6 CONCLUSION

In this report, we discussed the findings of the research study, “HIV Testing and Counselling in Nova Scotia: Implications for Policy and Practice.” This project was carried out in order to better understand the testing rates of people in Nova Scotia, as well as their perceptions and experiences of HIV testing and counselling. The findings and recommendations provided in this report are meant to provide evidence specific to Nova Scotia that will: increase uptake of testing by addressing the barriers to access experienced by various communities throughout the province, and improve experiences of testing by implementing facilitators to access. The Department of Health, Department of Health Promotion and Protection, District Health Authorities, physicians, community-based organizations and members of populations most impacted by these issues are strongly encouraged to work collaboratively to address the recommendations in this report and find ways to increase accessibility to HIV counselling and testing in Nova Scotia. As this report was prepared for the Nova Scotia Advisory Commission on AIDS (NSACA), and was developed in collaboration with other ASOs, it is important to recognize the imperative of collaboration in order to advance the state of HIV prevention, care, treatment and support in Nova Scotia. Further, we must acknowledge and address both the individual and societal impact of barriers to HIV testing in order to realize the provincial mandate of quality and equitable health services for all people in the province. This research report should be used as a basis for action geared toward shifting the HIV-related health policy and programming agendas in an effort to increase access to HIV counselling and testing to meet better the needs of the many diverse populations residing in Nova Scotia.
REFERENCES


Research Study

HIV Testing and Counselling in Nova Scotia:
Implications for Policy and Practice

We are looking for people to take part in a research study looking at the experiences of HIV testing in Nova Scotia.

If you HAVE or HAVE NOT been tested for HIV in Nova Scotia in the past 12 months (whether your test was HIV+ or not), and are between 15-65 years of age, you may be able to take part in a private and confidential one-on-one interview with a member of our research team. The interview will take approximately 1 hour. A $15 honorarium will be provided.

For more information, please contact Janice Fuller:

494-6620 or 1-877-654-9340

Principal Investigator: Jacqueline Gahagan, School of Health & Human Performance, Dalhousie University, 6230 South St., Halifax, NS B3H 3J5; Tel: (902) 494-1155; Fax: (902) 494-5120; Email: Jacqueline.Gahagan@Dal.Ca

Research Coordinator: Janice Fuller, School of Health & Human Performance, Dalhousie University, 6230 South St., Halifax, NS B3H 3J5; Tel: (902) 494-6620; Email: Janice.Fuller@Dal.Ca

Study Funding: The Nova Scotia Advisory Commission on AIDS
Appendix B – Interview guides

Demographic Survey for In-Depth Interviews

1. How long have you lived in Nova Scotia?
2. Do you currently live in HRM or outside HRM?
3. What is your current marital status?
4. Do you have any children? If so, how many?
5. How old are you?
6. What is your highest level of completed education?
7. Do you have a general practitioner?
8. How often do you see your GP (family doctor)? Why?
9. What is the primary language you speak at home?
10. What do you consider to be your ethnicity? (e.g., Aboriginal, Caucasian, African Nova Scotian, etc.)

In-Depth Interview Guide for Participants

Who Have Been Tested for HIV in the Last 12 Months

The following questions ask about your experiences with HIV testing in Nova Scotia. Feel free to provide as much information related to your experience as you feel comfortable. Your answers will remain confidential and no identifying information will be reported.

1. Can you tell me where you went to be tested for HIV?
2. Can you tell me when you were tested for HIV?
3. Can you tell me why you decided to get tested? Have you been tested before now? Why did you decide to get tested now? (Probes Re. perceptions of risky behaviours, misperceptions of risky behaviours, etc).
4. What was the result of the test?
5. Was there a time delay between getting tested and receiving your results? How did you feel about this?
6. How was this news given to you?
7. How do you feel about rapid-testing vs. standard testing? (Note: Rapid-testing can be done with saliva or a dried blood spot and the screening results are available in 15 minutes, though a confirmatory test is still mandatory. A routine/standard test requires blood being drawn and involves two screening tests and one confirmatory test and the results take 2 weeks).
8. Can you describe the process before the blood test took place? Were there issues of accessibility?
9. Can you describe the process after the blood test?
10. Did you meet with/speak to the same person before and after your test?
11. What were your experiences with counselling before and after your test?
12. Would you have preferred more time for pre- and/or post-testing counselling? Or less time?
13. Where would you prefer to get counselling and who would you prefer to get counselling from?
14. Based on your experiences, what would you suggest could be changed about the testing process?
15. Do you have any other observations about your testing experiences you would like to share?
Demographic Survey for In-Depth Interviews

1. How long have you lived in Nova Scotia?
2. Do you currently live in HRM or outside HRM?
3. What is your current marital status?
4. Do you have any children? If so, how many?
5. How old are you?
6. What is your highest level of completed education?
7. Do you have a general practitioner?
8. How often do you see your GP? Why?
9. What is the primary language you speak at home?
10. What do you consider to be your ethnicity? (e.g., Aboriginal, Caucasian, African Nova Scotian, etc.)

In-depth Interview Guide for Participants
Who Have Not Been Tested for HIV in the Last 12 Months

The following questions ask about HIV testing in Nova Scotia. Feel free to provide as much information related to your experience as you feel comfortable. Your answers will remain confidential and no identifying information will be reported.

1. Can you tell me if you have ever thought about being tested for HIV? Can you tell me why?
2. Is access to testing an issue?
3. How acceptable is HIV testing for you? (Probes Re. fear of knowing status, coping strategies, trust in partner, not feeling at risk, do not want to know status, legal liability).
4. Has an HIV test ever been suggested to you by your health care provider?
5. Do you know if there is HIV testing available where you live?
6. What do you think would encourage you to be tested for HIV?
7. Can you tell me what your biggest concern is about HIV testing?
8. Are there any other observations about HIV testing in Nova Scotia that you would like to share?
Appendix C – Consent form

STUDY TITLE: HIV Testing and Counselling in Nova Scotia: Implications for Policy and Practice

PRINCIPAL OR QUALIFIED INVESTIGATOR: Dr. Jacqueline Gahagan, School of Health and Human Performance, Dalhousie University, 6230 South Street, Halifax, NS B3H 3J5; Tel: (902) 494-1155; Fax: (902) 494-5120; Email: Jacqueline.Gahagan@dal.ca

STUDY SPONSOR: Nova Scotia Advisory Commission on AIDS

PART A.
Research Studies – General Information

1. Introduction
You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you don’t understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

- Discuss the study with you
- Answer your questions
- Keep confidential any information which could identify you personally
- Be available during the study to deal with problems and answer questions

We do not know if taking part in this study will help you. You may feel better. On the other hand it might not help you at all. It might even make you feel worse. We cannot always predict these things. We will always give you the best possible care no matter what happens.

If you decide not to take part or if you leave the study early, your usual health care will not be affected.

PART B.
Explaining the Study

2. Why Is This Study Being Done?
This research study recognizes that understanding HIV testing behaviours is of critical importance in the prevention of the HIV epidemic in Nova Scotia. The primary purpose of the study is to examine HIV testing rates and behaviours in Nova Scotia, including who is going for HIV testing in the province and
why. The results of the study will offer evidence-based recommendations for existing testing and counselling services and policies in Nova Scotia.

3. Why Am I Being Asked To Join This Study?

Individuals between the ages of 15-65 who have been tested for HIV in Nova Scotia in the past 12 months (with either HIV+ or HIV- results) or people who refuse to be tested are being asked to join this study.

A trained interviewer hired to work on this project will be conducting the interviews. The interviewer will review the information on this sheet and obtain individual consent at the time of the interview.

4. How Long Will I Be In The Study?

The interview will last approximately 1.5 hours. The interview will be done at a location which is both convenient and comfortable for the participant.

5. How Many People Will Take Part In This Study?

This study is taking place only in Nova Scotia. It is anticipated that approximately 50 in-depth interviews will take place across the province.

6. How Is The Study Being Done?

In-depth interviews will be conducted across Nova Scotia with individuals who have sought an HIV test in the last 12 months (both those who have tested positive, as well as those who have tested negative), and those who have not sought testing. It is hoped that the results of these interviews will help to understand HIV testing rates and behaviours and develop a better understanding of the experiences of persons who have been tested and had a negative result; tested and received a positive result; and those who are contemplating or refusing testing.

7. What Will Happen If I Take Part In This Study?

During the interview you will be asked to discuss your experiences with HIV testing in the past 12 months in Nova Scotia. With your permission, the interviews will be audio-taped for accuracy purposes. We will ask some participants to review their own interview transcripts to make sure the information has been typed up accurately (known as “Member checking”). If you do not want the interview audio-taped, you may still be interviewed and the interviewer will take notes in order to capture your responses. You may stop the interview at any time and withdraw from the study if you choose to do so during your interview.

8. Are There Risks To The Study?

The risks associated with this study are minimal and include loss of personal time or possibly, some discomfort with the questions asked. You can refuse to answer any question or stop the interview at any time. If you experience uncomfortable feelings or memories, the interviewer can refer you to someone local who can assist you.

Taking part may not have an immediate or direct benefit to you; however the outcomes of this project will help inform both provincial HIV testing and counselling policies and programmatic responses to
identified gaps in the current provision of HIV testing and counselling services, programs, and information strategies.

You are free to not answer questions with which you are not comfortable. With your permission, we will record the interviews (audio-tape) to ensure that we analyze and report details correctly. Only the research team will have access to the tapes (and/or notes) and when the tapes are typed out (transcribed), names will not be used in the transcript. The tapes will be destroyed after being typed out and the paper copies of the transcripts will be stored in secure cabinets in the research office for five years after we publish the findings and then they will be shredded. No one will be identified in any presentations or reports of the study findings. The electronic copies of the transcripts will be stored on password protected CDs and kept in a secure cabinet in the research office or the Principal Investigator’s office for the 5 years after publication and then destroyed. The CD formats of the data will not include any potentially identifying information. Consent forms will be stored in a secure cabinet, separate from any transcripts, for 5 years and then destroyed.

9. What Happens At The End Of The Study?

The participant will receive a copy of the study results if they would like one. Please inform the interviewer if you would like a copy.

10. What Are My Responsibilities?

As a study participant you will be expected to:

- Follow the directions of the Interviewer

11. Can I Be Taken Out Of The Study Without My Consent?

Yes. You may be taken out of the study at any time, if:

- There is new information that shows that being in this study is not in your best interests.
- The Capital Health Research Ethics Board or the Principal Investigator decides to stop the study.

You will be told about the reasons why you might need to be taken out of the study.

12. What About New Information?

It is possible (but unlikely) that new information may become available while you are in the study that might affect your health, welfare, or willingness to stay in the study. If this happens, you will be informed in a timely manner and will be asked whether you wish to continue taking part in the study or not.

13. Will It Cost Me Anything?

Compensation/Reimbursement: You will not be paid to be in the study. You will be provided with $15.00 to offset travel or other costs associated with taking part. The investigators have no financial interest in the study.
**Research Related Injury:** If you become ill or injured as a direct result of participating in this study, necessary medical treatment will be available at no additional cost to you. Your signature on this form only indicates that you have understood to your satisfaction the information regarding your participation in the study and agree to participate as a subject. In no way does this waive your legal rights nor release the Principal Investigator, the research staff, the study sponsor or involved institutions from their legal and professional responsibilities.

**14. What About My Right to Privacy?**

Protecting your privacy is an important part of this study. A copy of this consent will be put in your health record.

When you sign this consent form you give us permission to:

- Collect information from you
- Share information with the people conducting the study

**Access to records**

The Principal Investigator and members of the research team will have access to the consent forms that records that identify you by name. Other people may need to look at the consent forms that identify you by name. These might include:

- Project Coordinator and Research Associates (all of whom will sign a confidentiality agreement)
- the CDHA Research Ethics Board and Research Quality Associate

**Use of records**

The research team will collect and use only the information they need to complete the study. This information will only be used for the purposes of this study.

This information will include your:

- information from study interviews and questionnaires

Your name and contact information will be kept secure by the research team in Nova Scotia. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

After your part in this study ends, we may continue to review your health records.

The electronic copies of the transcripts will be stored on password protected CDs and kept in a secure cabinet in the research office or the Principal Investigator’s office for the 5 years after publication and then destroyed. The CD formats of the data will not include any potentially identifying information. Consent forms will be stored in a secure cabinet, separate from any transcripts, for 5 years and then destroyed.

You may also be contacted personally by Research Auditors for quality assurance purposes.
**Your access to records**
You may ask the Principal Investigator to see the information that has been collected about you.

15. What If I Want To Quit The Study?
If you chose to participate and later change your mind, you can say no and stop the research at any time. If you wish to withdraw your consent please inform the Principal Investigator. All data collected up to the date you withdraw your consent will remain in the study records, to be included in study related analyses.

16. Declaration of Financial Interest
The sponsor is paying the Principal Investigator and/or the Principal Investigator’s institution to conduct this study. The amount of this payment is sufficient to cover the costs of conducting the study. The Principal Investigator has no financial interests in conducting this research study.

17. What About Questions or Problems?
For further information about the study call Dr. Jacqueline Gahagan who is in charge of this study at Dalhousie University (she is the “Principal Investigator”). Dr. Gahagan’s work telephone number is (902) 494-1155.

The Principal Investigator is Dr. Jacqueline Gahagan
Telephone: (902) 494-1155

The Research Coordinator is Janice Fuller, MA
Telephone: (902) 494-6620

18. What Are My Rights?
After you have signed this consent form you will be given a copy.

If you have any questions about your rights as a research participant, contact the Principal Investigator, Dr. Jacqueline Gahagan at 494-1155.

*In the next part you will be asked if you agree (consent) to join this study. If the answer is “yes”, you will need to sign the form.*
PART C.

21. Consent Form Signature Page

I have reviewed all of the information in this consent form related to the study called:

HIV Testing and Counselling in Nova Scotia: Implications for Policy and Practice

I have been given the opportunity to discuss this study. All of my questions have been answered to my satisfaction.

This signature on this consent form means that I agree to take part in this study. I understand that I am free to withdraw at any time.

__________________________________  ______________________  ____  /  ____  /  _____
Signature of Participant  Name (Printed)  Year  Month  Day*

__________________________________  ___  /  ____  /  __________
Witness to Participant’s Name (Printed)
Month  Day*
Signature

__________________________________  ______________________  ____  /  ____  /  _____
Signature of Investigator  Name (Printed)  Year  Month  Day*

__________________________________  ___  /  ____  /  __________
Signature of Person Conducting
(Printed)
Month  Day*
Consent Discussion

Thank you for your time and patience!
### Appendix D – Demographic information

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<th>AGE</th>
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<tr>
<td>20-29</td>
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<table>
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<th>TESTED OR NOT</th>
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9 Some participants had immigrated to Canada or had multiple ethnicities.
### HIV Testing and Counselling in Nova Scotia: Implications for Policy and Practice

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