



Nova Scotia Advisory Commission on AIDS

Review of Nova Scotia's Strategy on HIV/AIDS:

*Looking Back &
Moving Forward*

Full Report

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I express sincere appreciation to everyone who contributed their time and wisdom. The information supports and guides the way forward in reducing the spread of HIV and improving the lives of those who are most affected in Nova Scotia.

Michelle Proctor-Simms, Director
Nova Scotia Advisory Commission on AIDS

Executive Summary

Introduction

For over 30 years, the human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) have been serious public health concerns for Nova Scotia, Canada, and the entire world^(1,2,3,4). While the overall reported incidence of new HIV infections and AIDS diagnoses have decreased, the virus continues to spread, particularly among marginalized populations^(4,5,6). The number of new diagnoses has decreased; however, the estimated number of people living with HIV/AIDS (PHAs) in Canada has risen by 11.4 per cent—from approximately 64,000 in 2008 to 71,300 in 2011⁽⁷⁾. This change has been attributed to both new infections and fewer HIV/AIDS-related deaths as treatments increase the survival of those already diagnosed. An estimated 25 per cent (17,980) of those living with HIV (71,300) were unaware of their HIV infection in 2011⁽⁷⁾.

Factors like stigma, discrimination, living in rural/remote areas, and poverty help explain why some communities and individuals are more strongly affected by HIV and have more difficulty accessing prevention, testing, treatment, and support services⁽⁴⁾. There is still no cure or vaccine for HIV/AIDS.

Nova Scotia's Strategy on HIV/AIDS (the Strategy) was released in December 2003⁽¹⁾. This document—*Review of Nova Scotia's Strategy on HIV/AIDS: Looking Back and Moving Forward* (the review)—assesses the implementation and outcomes of the Strategy.

Background to the Strategy

The Strategy is a provincial plan made up of 19 recommended actions under four strategic directions and four overall goals⁽¹⁾. It is based on a comprehensive consultation and strategic-planning process undertaken by the former provincial HIV/AIDS Strategy Steering Committee. A population health approach was the foundation for the Strategy. Integrating a gender and social inclusion approach was a major focus and priority for implementation. Ownership and accountability for the Strategy is shared among many stakeholders and partners, with the Nova Scotia Advisory Commission on AIDS (the Commission) as the coordinating agency for implementation, monitoring, and evaluation.

In 2004, the Commission established and provided secretariat support to four inter-sectoral working groups to facilitate the development of action plans to address the Strategy's recommended actions. Participation in the working groups gradually diminished, and they eventually disbanded. Since 2008, the bulk of the work has been carried out by project-specific committees led by either the Commission or another organization. Issues related to the implementation process are addressed in the main report of this document.

The Commission produced and disseminated annual updates on implementation activities up to the end of 2010⁽⁸⁾, after which it began planning the review. An evaluation framework⁽²⁾ for the Strategy was developed in 2007 and was the foundation for the design and implementation of this review.

Purpose and Priorities of the Review

The purpose of the review is to

- document and assess the outputs and outcomes of the key implementation activities associated with the Strategy
- determine the areas and key elements of success
- identify gaps and unmet needs as well as any implementation processes requiring revision

The logic-model components of the evaluation framework were based on the Strategy's four strategic directions and were used to structure and design the implementation plan. Priorities were selected from across the following components:

- **Care, treatment, and support**

- Availability and coordination of care for PHAs
- Cultural competency
- Availability of income and related support for the medical and non-medical needs of PHAs
- PHA workforce participation
- Stigma and discrimination

- **Health promotion, prevention, and harm reduction**

- Access to harm-reduction services (e.g., needle exchange, methadone maintenance treatment, anonymous testing, barrier protection)
- Public-awareness initiatives and learning opportunities for media

- **Knowledge development and exchange**

- Mechanisms/capacity to collaboratively identify priorities and conduct research
- Mechanisms to build linkages among researchers across disciplines
- HIV/AIDS surveillance, especially for priority populations

- **Coordination, planning, and reporting**

- Awareness of and stakeholder engagement with the Strategy, including PHA participation
- Integration of gender and social inclusion (GSI) approach
- Sustainable funding for AIDS service organizations (ASOs)
- Responsiveness to new or changing issues/monitoring and evaluation

Approach and Methodology

The review was initiated in the fall of 2012. It was undertaken by the Commission with the assistance of Collective Wisdom Solutions (CWS), a private consulting firm. The report was jointly prepared by the Commission and CWS. This was a review rather than a full evaluation, and a detailed initiative-by-initiative assessment was not undertaken. The focuses were on obtaining an overview of the actions, achievements, gaps, challenges, and issues within the four components of the Strategy and identifying priorities and opportunities for future collaborative action and policy direction. The review is rigorous and extensive, covering a cross-section of key priorities related to many of the recommended actions.

Stakeholder views on processes and outcomes within the four components were gathered by CWS in the following ways:

- Surveys with three stakeholder groups, including PHAs
- In-depth interviews with 15 key stakeholders
- Focus groups with two groups of key stakeholders

This information was consolidated and summarized by CWS to ensure confidentiality.

A document review of a wide variety of types of documents was undertaken by the Commission staff to validate and add more depth to the information gathered from the surveys and interviews and, in some cases, to fill in information gaps.

In the spring of 2012, the Commission partnered with Dr. Denver Lewellen (who was the Canadian Embassy Research Scholar and Fulbright Research Chair in Society and Culture, Sociology and Social Anthropology, Dalhousie University in 2012) to conduct key informant interviews with PHAs in Nova Scotia. An analysis of these interviews was used to support and add depth to many of the findings in this report.

Summary of Findings

Due to the variety of stakeholders surveyed or consulted, there were many viewpoints. On some issues there was a broad consensus, and on others there were differences of opinion.

Progress has been made, including some reduction in HIV stigma (especially within health-care settings) and the establishment and/or expansion of collaborative programs and health services (e.g., Mobile Outreach Street Health, methadone maintenance treatment programs, anonymous HIV testing, needle exchange). However, more work is needed to increase access to such services, particularly outside the Halifax Regional Municipality and in rural areas. There has been some increased capacity for culturally competent services, with some informants suggesting that such services have improved for women, aboriginal people, gay men, and youth. That being said, culturally competent services are often ad hoc and not available equally across the province.

The review reveals significant resource and systemic challenges to addressing the recommended actions in the Strategy. A lack of resources was the biggest challenge identified by an overwhelming proportion of respondents. The Strategy is regarded as underfunded, with inadequate resources and supports for implementation, including stable and sufficient funding for community-based AIDS services and other organizations.

Data from all sources demonstrate the range of complexity and potential difficulties for PHAs and those at higher risk who lack sufficient economic resources and community or social support. Overall, the review suggests that health and social service systems do not respond well to chronic illness, and that stigma continues to be a barrier to service.

There is an overall need to build capacity for culturally competent and holistic approaches to care, increased system coordination/navigation, and advocacy, especially for marginalized populations. More work is needed to increase access to education, testing, and prevention-related services in a way that connects with other related sexual-health and social determinants of health issues and sectors.

As the HIV/AIDS policy landscape is shifting toward integration with other sexually transmitted and blood-borne infections (STBBIs) and/or chronic diseases, a re-examination of the scope of the Strategy and which issues should be integrated and which should be addressed separately is needed. Serious consideration is needed for how to best position the Strategy to achieve greater shared accountability and ownership; multi-stakeholder engagement and partnership; better use and leveraging of existing resources; and increased funding for implementation, ASOs and other community-based service providers, and PHA needs.

The following are identified as **priorities** for the future:

- **Address the issue of integration.** Respondents reflected on the need to address how HIV/AIDS is nested within these other issues while also noting the importance and necessity of HIV/AIDS-specific needs, especially around the issues of testing, treatment, and stigma. There are mixed views around whether treating HIV/AIDS as exceptional increases or decreases stigma and isolation.
- **Reflect on and reimagine the role of the Strategy.** Given the changing context in which HIV/AIDS work will be happening, respondents are asking many questions about the role of the Strategy, accountability, stakeholder engagement, role clarity, resources, and funding.
- **Expand access to prevention, testing, and treatment.** Continue to increase the accessibility to testing and needle exchange services and treatment that is culturally relevant and person-centred across the province, especially in rural areas.
- **Increase education and address stigma.** Invest in promoting sexual health through a harm-reduction approach, the education of medical doctors and other health professionals on HIV and HIV and aging and increasing public awareness around stigma.
- **Increase social inclusion and cultural competency.** Continue to ask, Who is missing and how can we best serve diverse and/or marginalized populations? This could be facilitated by increasing the use of tools such as intersectionality research and analysis⁽⁹⁾, expanding training to enhance inclusion and cultural competency, increasing outreach to diverse groups, and enhancing the collection and reporting of ethno-racial data in HIV/AIDS surveillance.

A more nuanced picture of progress and the areas for improvements is provided in the main report of this document.

Concluding Remarks

This review provides direction for a revisioning and renewal of the provincial Strategy for HIV/AIDS within a changing policy, service, and funding context. Stigma and marginalization remain key drivers of the epidemic—creating barriers to services—and must be addressed.

The review makes nine recommendations. The Commission will address the fundamental questions within the first two recommendations—questions related to integration, accountability, stakeholder engagement, resources, and funding. This will pave the way to addressing the remaining seven recommendations. Moreover, addressing these questions will foster shared commitment and ownership that is necessary to address the root causes and reduce the impact of HIV/AIDS in this province.

Recommendations

1. **By March 2015, the Commission and the Department of Health and Wellness (DHW) will convene a process to reimagine and renew the provincial response to HIV/AIDS in Nova Scotia.** This process will include the following:
 - a. *Address the issue of integration.* This includes what a renewed Strategy should be in order to reflect the movement toward integrated funding, policies, and services. Resource/capacity implications for ASOs and other service providers (including those who have not been significantly involved in HIV/AIDS work) and the impact on PHAs and those who are marginalized must be thoughtfully explored and analysed.

Given the prevailing stigma and discrimination and overlap in the populations affected, it is important to determine what issues and services would benefit from an integrated STBBI and/or chronic disease approach and those that would benefit from an HIV/AIDS-specific focus. Further, this work should be linked to and informed by the research project “Exploring the Landscape of Communicable Diseases in Atlantic Canada,” which will be completed in April, 2014.¹

¹ Led by the Atlantic Interdisciplinary Research Network (AIRN) and funded by the Public Health Agency of Canada (PHAC), this project is a collaborative investigation into the current state of communicable diseases, affected populations, and associated service delivery needs in Atlantic Canada.

- b. *Address the issue of accountability and ownership.* This includes determining the roles and responsibilities of various stakeholders and identifying mechanisms to enhance engagement and collaboration and give the Strategy “teeth.” Questions should include the following:
 - i. What should be the role of the Commission given the evolution of HIV/AIDS work?
 - ii. What should be the role of the DHW (e.g., public health, primary care) and other provincial government departments in relation to the Strategy?
 - iii. How can shared ownership across the health, social, justice, and education systems for better-integrated policy and service delivery be achieved?
 - iv. What is the best way to re-establish and/or strengthen linkages with and engagement of ASOs, PHAs, and other stakeholders?
 - v. Given the complexity of issues relative to the social determinants of health, what is the best way to monitor and evaluate the Strategy?
 - c. *Address funding and resource requirements for supporting a renewed Strategy and to increase accessibility to prevention, testing, care, treatment, and support.* This includes increases in funding and support to ASOs and other front-line service providers who assist PHAs and/or those most vulnerable (e.g., people who are street-involved and/or living with concurrent mental-health issues and addictions).
2. Concurrently with recommendation #1, **the DHW and the Commission will convene a review of provincial HIV testing policies (including prenatal screening guidelines) as part of the continuum of quality health care for Nova Scotians that is aligned with the new national guidelines for HIV screening and testing released by the PHAC⁽¹⁰⁾.** This needs to take into account strategies to make HIV/STBBI testing and counselling services accessible to Nova Scotians in all of their diversity, innovations in testing technology (e.g., point-of-care testing), stigma and criminalization, and infrastructure to respond to potential increases in HIV screening and support needs for new diagnoses.

Once the fundamental issues have been resolved through acting on recommendations #1 and #2, the following additional seven recommendations should be addressed:

3. **The Commission, in partnership with the DHW, ASOs, and the Hepatitis Outreach Society, should develop innovative strategies for the coordination and navigation of services for PHAs and people with hepatitis C and/or co-infected, particularly those outside the Halifax Regional Municipality.** Collaboration with the district health authorities (DHAs) and a wide range of health professionals and relevant cultural and/or support organizations is required to ensure access across the province.
4. In keeping with the recommendations of the Episodic Disabilities Network⁽¹¹⁾, other relevant advocacy groups, and other documents completed for the Strategy, **the Commission should work with the Department of Community Services and relevant advocacy groups to improve the structure, coordination, and benefit levels of federal and private sector disability programs and the provincial Employment Support and Income Assistance program.** This includes the development of a common definition of “disability” that takes into account the episodic, reoccurring nature of conditions like HIV/AIDS and allows for part- to full-time work during periods of good health with the option for partial income support.
5. **The Commission should work with the DHW to address specific concerns of diverse PHAs living on assistance or low incomes related to Pharmacare, including copayments, the cost of over-the-counter medications, and coverage of prescribed drugs not on the formulary.**
6. **The AIRN and the Commission should work with the DHW to identify mechanisms that can sustain and facilitate collaboration among academics, community/service providers, and policy-makers in the identification of important research questions and increase uptake of results at the service delivery and policy levels.** There is a need for an intersectional approach to research and policy analysis⁽⁹⁾ to understand the implication of policy decisions on different population groups.²

² Research, policy and programming should also be informed by *The National Consensus Statement on Women, Trans People and Girls and HIV Research in Canada* by J. Gahagan and the *Gathering of Spirits Collaborative* (2013), Halifax, NS, Dalhousie University, Gender and Health Promotion Studies Unit

7. **The DHW and other key stakeholders should invest in and develop education/training and awareness campaigns for key audiences to increase cultural competency and inclusion, reduce stigma, and build awareness of HIV/AIDS as a concern for all Nova Scotians.** This process will include the following:
 - a. The DHW, professional organizations, and universities should identify opportunities (e.g., Continuing Medical Education, professional conferences) to increase the training of medical doctors and other health professionals and/or front-line providers around stigma, cultural competency, harm reduction, and the basics of HIV and HIV and aging.
 - b. The DHW and the Department of Education and Early Childhood Development (DEECD) should increase the capacity and resources of youth-serving organizations (including youth health centres), parents, and educators to address issues related to sexual health, mental health, and addictions.
 - c. The DEECD and school boards should work with the DHW and other relevant partners to monitor, evaluate, and revise as required the sexual-health components of the public school learning outcomes framework⁽¹²⁾ and ensure ongoing access to training and support for teachers responsible for delivering these components.
 - d. The DHW and the Commission, in partnership with ASOs, should develop a public-awareness campaign to increase knowledge of HIV/AIDS and related STBBIs and reduce stigma.
8. **The DHW, the PHAC, the Commission, and other key stakeholders should work together to strengthen and support (including providing funding and increased collaboration) networks and organizations such as the Canadian HIV/AIDS Black African Caribbean (CHABAC) Network, the Health Association of African Canadians, Healing Our Nations, and others to address and make visible HIV/AIDS within their respective communities and increase collaboration with mainstream services and organizations.** Training and other skills-building initiatives need to be supported and expanded in order to increase the cultural competency of providers to more effectively work with and respond to the needs of diverse populations.

9. **The DHW and other key stakeholders should enhance the collection and reporting of HIV and other STBBI surveillance data.** This process will include the following:
 - a. The DHW, NS Public Health Laboratory, and PHAC should work together to facilitate timely access to enhanced surveillance data to better understand trends in HIV/STBBI testing uptake, co-infection, risk factors, and behaviours within diverse population groups.
 - b. The DHW, PHAC, and testing providers should improve the completeness of demographics data collected at the time of testing and during HIV-positive case follow-up, including information related to the social determinants of health.

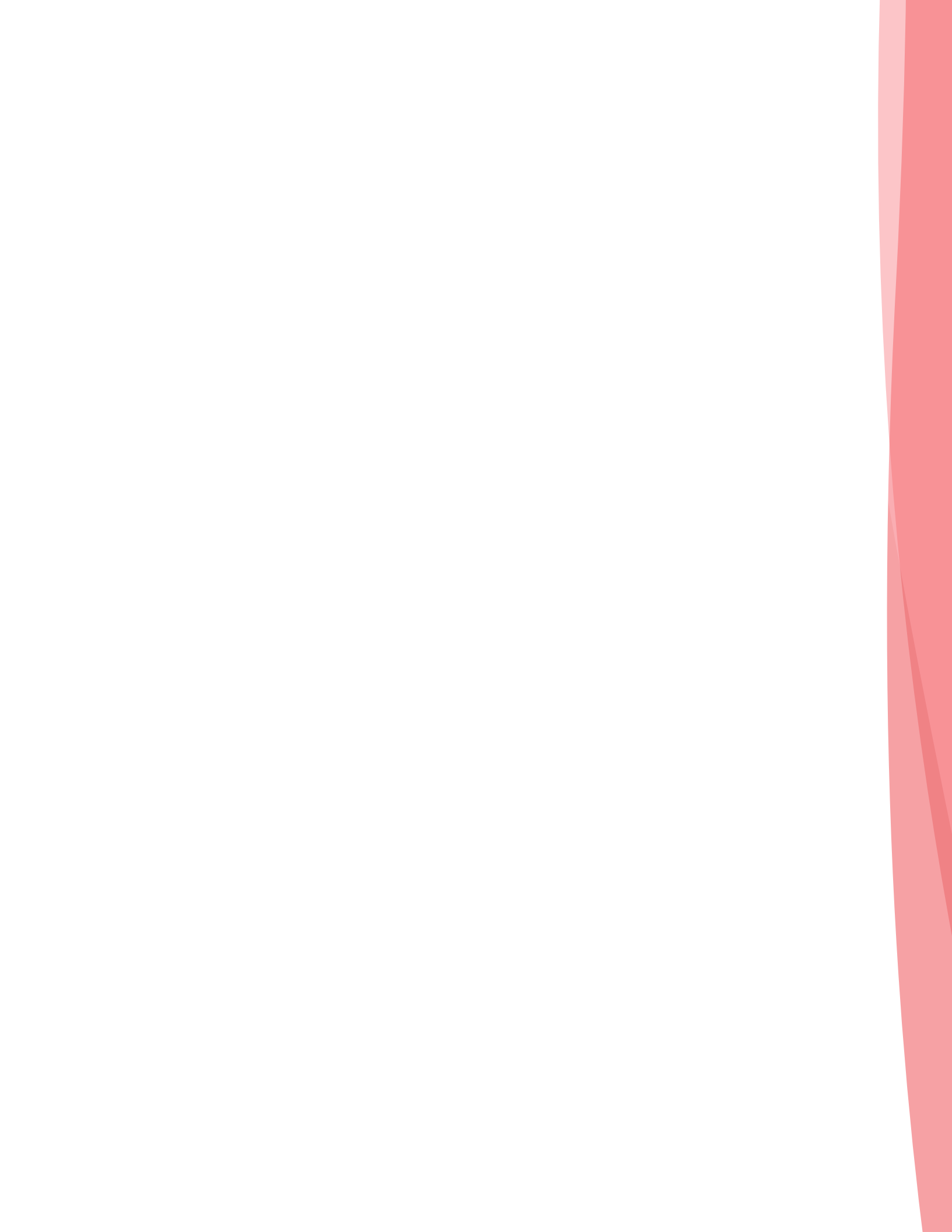


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1.0 Introduction

For over 30 years, the human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) have been serious public health concerns for Nova Scotia, Canada, and the entire world. HIV/AIDS has grown into a global pandemic infecting and affecting millions of individuals^(1,2,3,4). While the overall reported incidence of new HIV infections and AIDS diagnoses have decreased, the virus continues to spread, particularly among marginalized populations^(4,5,6). Factors like stigma, discrimination, living in rural/remote areas, and poverty help explain why some communities and individuals are more strongly affected by HIV and have more difficulty accessing prevention, testing, treatment, and support services⁽⁴⁾. There is still no cure or vaccine for HIV/AIDS.

Nova Scotia's Strategy on HIV/AIDS (the Strategy)⁽¹⁾ was released in December 2003 following a comprehensive consultation and strategic-planning process undertaken by the former provincial HIV/AIDS Strategy Steering Committee that consisted of community-based organizations, people living with HIV/AIDS (PHAs), and provincial and federal government stakeholders. The Nova Scotia Advisory Commission on AIDS (the Commission) acted as secretariat for this process. The 2003 Strategy replaced the *Nova Scotia AIDS Strategy*⁽¹³⁾ released by the Department of Health in 1993 to ensure that the provincial response to HIV/AIDS reflected the current reality of the epidemic and need for a multi-sectoral approach in addressing priorities and “root causes” and that it was aligned with a renewed federal strategy—the *Federal Initiative to Address HIV/AIDS in Canada*⁽¹⁴⁾—that was being developed at that time (and released in 2004).

This document—*Review of Nova Scotia's Strategy on HIV/AIDS: Looking Back and Moving Forward*—assesses the implementation and outcomes of the Strategy. The evaluation framework⁽²⁾ developed for the Strategy was the foundation for the design and implementation of this review. The review was initiated in the fall of 2012. It was undertaken by the Commission and Collective Wisdom Solutions (CWS), a private consulting firm. The report was jointly prepared by the Commission and CWS.

In April 2012, the Commission formed a research partnership with Dr. Denver Lewellen (who was the Canadian Embassy Research Scholar and Fulbright Research Chair in Society and Culture, Sociology and Social Anthropology, Dalhousie University in 2012) for the purpose of conducting key-informant interviews with PHAs in Nova Scotia for the portion of his study that directly related to the care, treatment, and support component of the Strategy. The Commission and Dr. Lewellen collaborated on questionnaire design, recruiting and interviewing PHAs as key informants (via the AIDS service organizations [ASOs] in Nova Scotia), data analysis, and writing of the report entitled *Understanding the Experience of HIV Patients in Nova Scotia*⁽¹⁵⁾. Dr. Lewellen conducted all of the interviews. Analysis of these interviews was used to support and add depth to many of the findings in this report.

1.1 Background to Nova Scotia's Strategy on HIV/AIDS

The Strategy⁽¹⁾ is a provincial plan made up of 19 recommended actions under four strategic directions and with four goals that were identified through the consultation process. The strategic directions are to

1. mobilize integrated action on HIV/AIDS
2. build a broad research and information sharing strategy
3. build a coordinated approach to prevention and harm reduction
4. build a coordinated approach to care, treatment, and support

The overall goals of the Strategy are to

1. integrate HIV/AIDS policy development and service delivery
2. improve knowledge and understanding of HIV/AIDS and related issues that affect the risk of infection
3. reduce the spread of HIV
4. provide Nova Scotians living with and vulnerable to HIV and AIDS with the best possible care, treatment, and support services

A population health approach was the foundation for the Strategy⁽¹⁾, and it was aligned with changes happening within Nova Scotia's health system and development of the current federal strategy⁽¹⁴⁾. Proposed leads and partners were assigned to each of the recommended actions. The Strategy was intended to be a "living document" to address emerging and/or changing needs and priorities and allow adjustment of strategies and actions to respond to these needs and priorities⁽¹⁾.

Ownership and accountability for the Strategy is shared among many stakeholders and partners, with the Commission as the coordinating agency for the Strategy's implementation, monitoring, and evaluation. In 2004, the Commission established and provided secretariat support to four inter-sectoral working groups to facilitate the development of action plans to address the Strategy's recommended actions, which were organized according to the strategic directions. As inclusion was a major theme throughout the Strategy, a gender and HIV/AIDS backgrounder⁽¹⁶⁾ was written, followed by a gender-based analysis (GBA) of the recommended actions⁽¹⁷⁾. A Gender and Social Inclusion Reference Group was struck to

advise the various working groups and assist with capacity building. There have also been many project-specific committees focusing on particular recommended actions. All school- and youth-related recommended actions were to be addressed through the *Framework for Action: Youth Sexual Health in Nova Scotia* by the Nova Scotia Roundtable on Youth Sexual Health⁽¹⁸⁾. Over the years, the majority of these working groups or structures either disbanded or reduced their activity, meeting on an ad hoc basis. Since 2008, the bulk of the work has been carried out by project-specific committees led either by the Commission or another organization. Issues related to the implementation process will be addressed in this report.

Monitoring and evaluation: The Commission⁽⁸⁾ produced and disseminated annual updates on implementation activities up to the end of 2010, after which it began planning the review of the Strategy. In 2005, the Commission established an Evaluation Subcommittee (ESC) to develop an evaluation framework (completed in 2007) to focus and guide an evaluation process for the Strategy⁽²⁾. To help create evaluation questions and matrices, five logic models were developed: One was an overall logic model, and the other four reflected the main categories of activities, called components, of the Strategy⁽²⁾.

The four components were based on the Strategy's four strategic directions as follows.

1. knowledge development and exchange (corresponding to goal and strategic direction #2)
2. health promotion, prevention, and harm reduction (corresponding to goal and strategic direction #3)
3. care, treatment, and support (corresponding to goal and strategic direction #4)
4. coordination, planning, and reporting (corresponding to goal and strategic direction #1 and the implementation plan, including monitoring and evaluation)

The logic-model components were used to structure and design the implementation plan for the current review. Priorities and high-level questions were selected from the original matrices developed for each of the components. The evaluation framework provided a structure that would have seen evaluation of the Strategy occurring on a three-year cycle, with different evaluation activities happening in each of the three years. In year four, the cycle would repeat. However, anticipating that funding and human resources to effectively carry out this plan would be significantly restricted, a mix of priority process/outputs and impacts were identified by the ESC to be assessed either within a three-year cycle or concurrently⁽²⁾. The current review of the Strategy did not begin until 2012.

1.2 Current Context

To move forward strategically, it is important to understand the changing nature of HIV/AIDS in Nova Scotia and Canada as a whole. This section outlines changes in the epidemiology of HIV/AIDS, issues and advances related to prevention and treatment, and the changing policy and programming landscape.

Incidence and prevalence: According to the Public Health Agency of Canada (PHAC)⁽⁶⁾, a cumulative total of 76,275 positive HIV tests and 22,702 AIDS cases were reported in Canada by the end of 2012. In Nova Scotia, a cumulative total of 783 HIV-positive tests were reported by the end of 2012, including 349 diagnosed cases of AIDS and 318 deaths³ due to HIV- or AIDS-related complications^(5,19). In 2012, there were 2,062 new HIV cases reported in Canada⁽⁶⁾ and 17 new cases reported in Nova Scotia⁽¹⁹⁾, representing an overall decrease in the annual reported number of new infections. However, the actual number of people with HIV in Nova Scotia and Canada is likely to be much higher than the reported cases, given that HIV can only be reported when someone tests positive for the virus^(5,6). The reported provincial numbers also do not reflect people who have been tested outside of Nova Scotia but reside in the province^(5,19).

While the number of new HIV diagnoses has decreased, the estimated number of PHAs in Canada has risen by 11.4 per cent—from approximately 64,000 in 2008 to 71,300 in 2011^{4 (7)}. This change has been attributed to both new infections and fewer HIV/AIDS-related deaths as treatments increase the survival of those already diagnosed (further described below). Of significant concern is that an estimated 25 per cent (17,980) of those living with HIV (71,300) were unaware of their HIV infection in 2011. Without testing and diagnosis, this group is not able to receive appropriate care and treatment and/or counselling to prevent further spread of HIV⁽⁷⁾.

³ The numbers for both reported AIDS cases and HIV/AIDS-related deaths have declined significantly since 1996. Fewer AIDS reports could be attributed to the effectiveness of Highly Active Antiretroviral Therapy (HAART), individuals moving outside of Nova Scotia prior to an AIDS diagnosis, and/or delayed reporting or under-reporting of AIDS cases. Similarly, the reduction in reported deaths may be attributed to the effectiveness of HAART, uncertainty about whether a reported death was related or unrelated to HIV/AIDS (e.g., car accident), individuals not residing in Nova Scotia at the time of death, and delayed reporting or under-reporting.

⁴ In addition to annual national HIV and AIDS surveillance reports, the PHAC has been producing national HIV estimates for Canada every three years since 1996. This is because surveillance data do not include people who are untested and undiagnosed.

Anyone who has unprotected sex or shares HIV-contaminated needles or equipment (e.g., for drug use, tattooing, piercing) can become infected with HIV. However, both the reported and estimated numbers show that HIV/AIDS is more prevalent in populations who are more likely to experience economic and social marginalization, such as men who have sex with men (MSM), women, aboriginal people, African-Canadians, people coming from HIV-endemic countries, prison inmates, and people who inject drugs^(4,5,6,7,20). The challenges in addressing this relate to systemic racism, sexism, and homophobia; poverty; complexity of needs; and a lack of access to coordinated and holistic health and social services among marginalized groups in society^(1,2,4, 20).

HIV/AIDS is also increasing among older Canadians^(4,21). The annual incidence and overall prevalence of HIV infection among older Canadians is expected to increase over the next 10 years due to increased life expectancy of PHAs related to treatment as well as new diagnoses. According to the PHAC⁽²¹⁾, 6,036 (9.6 per cent) of all HIV case reports up to the end of 2008 were among Canadians aged 50 years and older, with the annual reported HIV test reports increasing from 10.6 per cent in 1999 to 15.3 per cent in 2008. For Nova Scotia, cases reported between 2002 and 2011 were significantly older (median age: 41 years) than those reported between 1985 and 2001 (median age: 34 years)⁽⁵⁾.

HIV as a manageable chronic disease: Highly Active Antiretroviral Therapy (HAART) was developed in 1996 to prevent or slow the progression from HIV to AIDS^(4,5,15,22,23). As indicated above, many PHAs are living longer and with a better quality of life due to access to better drug treatments, care, and support. HIV/AIDS was once described as a “death sentence,” but now many PHAs are living into their senior years and experiencing health conditions associated with aging^(4,15,21). Because of antiretrovirals (ARVs), HIV is widely considered a manageable chronic disease. It is often experienced as an episodic disability^(24,25). As with other episodic disabilities, periods of good health may be interrupted by periods of illness or disability^(4,15,24,25). It is difficult to predict when these periods of disability/illness will occur and how long they will last^(24,25). PHAs may experience a range of disabilities and co-morbidities as a result of HIV itself, side effects of ARVs, and/or the process of aging. Further, as stated by Dr. Lewellen, “any degree of ‘wellness’ ... will be influenced not just by clinical care and treatment but a wide range of medical, social, economic, and psychological factors”⁽¹⁵⁾.

HAART is also strongly linked to the prevention of new infections^(22,23). Because ARVs can suppress viral load⁽²⁶⁾ to undetectable levels, they lessen the likelihood of the virus being transmitted to a sexual partner^(22,23). Also, while not yet approved in Canada (with certain ethical and logistical challenges to be addressed), HIV-negative people considered at risk (e.g., those in an intimate relationship with an HIV-positive partner) can take ARVs on a regular basis as a preventive measure^(22,23).

Prevailing stigma and discrimination: Many PHAs have experienced stigma and discrimination⁽²⁷⁾ as a result of their diagnosis—either within their communities and/or in accessing health care services^(4,15). HIV-related stigma arises mostly from ignorance or fear about the virus itself and/or negative views or prejudices toward the communities or groups who have been most affected by HIV/AIDS, such as gay men/MSM or people who inject drugs^(4,27). HIV-related discrimination is unfair treatment on the basis of actual or perceived HIV status and, like stigma, may extend toward the communities or groups who have been most affected by HIV/AIDS^(4,27). Stigma and the fear of discrimination often stop people from being tested and/or accessing treatment for HIV. They can lead to isolation and/or prevent PHAs from acknowledging their HIV status with family and friends⁽⁴⁾. The results can be further transmission of HIV, a poorer quality of life, and decreased survival for those infected⁽⁴⁾.

Criminalization of HIV non-disclosure: Canadian criminal law requires PHAs to disclose their HIV status to a sexual partner before engaging in behaviours that pose a “realistic possibility” of transmission unless a condom is used and the PHA has a low viral load^(4,28). PHAs living in Canada have been charged and convicted of different crimes for non-disclosure of HIV status. One of the arguments for criminal prosecution is that it will act as a deterrent against non-disclosure of HIV status and behaviours that pose a risk of transmission, thereby preventing new HIV infections. However, there is no evidence that this is the case. In fact, criminalization may have a number of serious effects, particularly for vulnerable and marginalized populations. These include increasing the stigma faced by PHAs due to media attention given to some cases and portraying them as potential criminals as well as deterring people from being tested, accessing other HIV and related services, and/or being open with health care providers^(4,22,28). This contradicts public health messages to “know your status” at a time when 25 per cent of HIV-positive people in Canada are estimated to be unaware that they have HIV⁽⁷⁾.

A changing policy, programming, and funding landscape: With what is being called the “end of AIDS exceptionalism^(29,30)”, the review of the Strategy has occurred during a time of movement toward an integrated model of HIV/AIDS policy, services, and funding with other sexually transmitted and blood-borne infections (STBBIs) and/or other conditions such as tuberculosis. For example, the PHAC released a new HIV screening and testing guide⁽¹⁰⁾ in April 2013 that recommends the “normalization” of HIV testing and the consideration of an HIV test as part of periodic routine care for all people regardless of risk-group status. The PHAC is also moving to an integrated community grants and contributions funding program for HIV/AIDS and hepatitis C. This is because HIV and hepatitis C (as well as other STBBIs) have common risk factors and behaviours that lead to infection as well as populations affected and/or disadvantaged in a similar way⁽⁴⁾. Disease transmission and the progression of HIV are also more efficient when one or more STBBIs are present (and vice versa)⁽⁴⁾.

While integration is not new within HIV/AIDS work and has significant advantages, the implications of a more formalized integrated framework are not yet clear. Integration may leverage existing resources and avoid duplication of efforts, but there is concern that it could dilute population-specific interventions that are needed to respond effectively to HIV or other STBBIs⁽⁴⁾. It is hoped that this review will facilitate thoughtful and full discussion of the opportunities and challenges (e.g., how HIV-related stigma and discrimination will be addressed) of integrating HIV/AIDS with other STBBIs and, ultimately, a revisioning and renewal of the Strategy for Nova Scotia.

Ongoing relevance: HIV and AIDS continue to be significant health and social concerns for Nova Scotia and across Canada. As previously indicated, new cases of HIV or AIDS are being diagnosed each year, and the number of PHAs is increasing due to the effectiveness of treatment^(4,5,6,7,15,19). In addition, the economic costs of HIV and AIDS are significant. Not including quality of life years lost, the “net present value of the economic loss” related to lifetime health care and lost labour productivity (attributed to people infected with HIV in 2008) is estimated to be \$1.3 million per person, or \$4,031,500,000 in total⁽³¹⁾. This is 22 per cent higher than what was estimated in 2001 after accounting for inflation⁽³¹⁾. Given that the number of PHAs and treatment and other costs are increasing, greater attention and resources are needed for prevention, education, and support, with an emphasis on the factors that create greater vulnerability to HIV and AIDS and other STBBIs (e.g., poverty, addiction, stigma).

1.3 Purpose, Scope, and Limitations

The purpose of the review is to

- document and assess the outputs and outcomes of the key implementation activities associated with the Strategy
- determine the areas and key elements of success
- identify gaps and unmet needs as well as any implementation processes requiring revision

The review is also intended to identify opportunities and priorities for collaborative, integrated action; inform provincial government policy and funding direction and decisions related to HIV/AIDS; and enhance capacity to monitor and evaluate HIV/AIDS and related issues and initiatives within a renewed provincial strategy.

Limitations and challenges to reviewing the Strategy included the following:

- A modest budget and human resources. This required the selection of a cross-section of priorities to be assessed within each of the components. An evaluation of all of the activities and outcomes associated with each of the 19 recommended actions could not be undertaken. However, the review is extensive, covering key priorities related to many of the recommended actions.
- Voluntary participation of stakeholders, with limited time to participate in interviews, focus groups, and/or surveys. While the review successfully engaged a diversity of stakeholders from across Nova Scotia, the findings may not be representative of all stakeholders' perspectives and important information may have been missed.
- PHA involvement was limited to those affiliated with an ASO and/or known to the Commission who were willing to participate in either a key-informant interview and/or survey. Therefore, the findings do not represent the perspectives of all PHAs.

It should also be noted that it is difficult to directly link Strategy initiatives with outcomes because these relationships are complex and difficult to trace as well as impacted by a variety of factors happening outside of the Strategy⁽²⁾. Also, substantial research efforts are required to develop and pilot-test adequate approaches to measuring the complex concepts included in the Strategy, which are beyond the scope of the review⁽²⁾. There has also not been a consistent approach to collecting data about the work being done to achieve the Strategy's goals and strategic directions.

1.4 Priorities of the Review

Priorities were selected from across the strategic directions or components of the Strategy (using those selected in 2007 as a starting point). The priorities of the review are indicated below, as per the four components of the logic model.

- **Care, treatment, and support**
 - Availability and coordination of care for PHAs
 - Cultural competency
 - Availability of income and related support for the medical and non-medical needs of PHAs
 - PHA workforce participation
 - Stigma and discrimination
- **Health promotion, prevention, and harm reduction**
 - Access to harm-reduction services (e.g., needle exchange, methadone maintenance treatment, anonymous testing, barrier protection)
 - Public-awareness initiatives and learning opportunities for media
- **Knowledge development and exchange**
 - Mechanisms/capacity to collaboratively identify priorities and conduct research
 - Mechanisms to build linkages among researchers across disciplines
 - HIV/AIDS surveillance, especially for priority populations
- **Coordination, planning, and reporting**
 - Awareness of and stakeholder engagement with the Strategy, including PHA participation
 - Integration of a gender and social inclusion approach
 - Sustainable funding for ASOs
 - Responsiveness to new or changing issues/monitoring and evaluation

2.0 Approach and Methodology

2.1 Approach

As indicated in section 1.0, the review was undertaken by the Commission and Collective Wisdom Solutions (CWS), an independent consulting firm. A plan for the review process was developed together, covering the four strategic directions of the strategy, outlined in section 1.0.

This was a review rather than a full evaluation, and a detailed initiative-by-initiative assessment was not undertaken. The focuses were on obtaining an overview of the actions, achievements, gaps, challenges, and issues within the four strategic directions of the Strategy and identifying priorities and opportunities for future collaborative action and policy direction. Both processes and outcomes were reviewed. The Strategy was developed by many stakeholders, and its implementation is the responsibility of many stakeholders. Thus it is important to look at both the process aspects (how the various goals have been tackled, who has been involved, and the actions taken) and the outcomes (the results achieved and the goals met and unmet).

2.2 Methodology

Stakeholder views on processes and outcomes in the four strategic directions were gathered on a confidential and impartial basis by CWS in the following ways: surveys of stakeholders to obtain breadth of coverage, in-depth interviews with a smaller sample of stakeholders for rich detail, and two focus groups composed of key stakeholders to broadly explore perspectives and expert opinions. This information was consolidated and summarized by CWS to ensure confidentiality.

A document review of a wide variety of types of documents (both internal and external) was undertaken by the Commission staff to gather additional information about both processes and outcomes in the four strategic directions. This information was used to validate and add more depth to the information gathered from the surveys and interviews and, in some cases, to fill in information gaps.

2.3 Information Gathering

The following three surveys were conducted:

- **Front-line service providers:** Thirty-six front-line service providers were invited to participate in an online survey. Nineteen responses were received: 15 from a variety of service-provider organizations (e.g., ASOs and other community-based providers) and four from government or District Health Authority (DHA) service providers. With regard to their areas of service provision, seven were province-wide, nine were central (Capital Health region), two were northern, and one was eastern.
- **Key stakeholders:** Ninety-six key stakeholders were invited to participate in an online survey. Nineteen responses were received from a variety of stakeholders, including government (all levels), DHAs, academia, not-for-profits, and key individuals (e.g., Commissioners). All regions of the province were represented. Given the low number of survey respondents, the opinions, concerns, and experiences expressed do not fully represent and cannot be generalized to all stakeholders. Important information may also have been missed and, therefore, not captured in the findings. This should be borne in mind when interpreting the results.
- **PHAs:** One hundred and thirty-three surveys (paper and online) were distributed by ASOs to PHAs. Nineteen responses were received, predominantly from the central and Cape Breton regions. Seven of the 19 had also participated in the study undertaken in 2012 by Dr. Lewellen⁽¹⁵⁾. The survey is unlikely to have reached potential participants who are not well connected to ASOs. The low number of survey respondents means that important information may have been missed and that the responses do not fully represent and cannot be generalized to all PHAs in Nova Scotia. Again, this should be borne in mind when interpreting the results.

Interviews were conducted with 15 key stakeholders from a variety of organizations, including front-line service providers, doctors, researchers, and past and present members of the Commission.

Two focus groups were conducted with groups of key stakeholders. One was conducted at the Nova Scotia Department of Health and Wellness (DHW) with provincial and federal government representatives to broadly discuss the successes and challenges of the Strategy and to identify the best ways to move forward in addressing HIV/AIDS in Nova Scotia. The other was with Nova Scotia members of the Executive and Advisory Committees for

the Atlantic Interdisciplinary Research Network (AIRN) to also discuss the successes and challenges of the Strategy and the best ways to move forward, with an emphasis on the knowledge development and exchange component.

The information-gathering instruments are not included in this document but are available upon request from the Commission.

2.4 Document Review

Sixty-six documents related to one or more of the priorities under the four components were reviewed by Commission staff. These included a report prepared by Dr. Lewellen⁽¹⁵⁾; federal and provincial government documents (e.g., surveillance reports, strategies); reports produced by the Commission and other organizations as part of the implementation of the Strategy, including annual updates on the Strategy; Nova Scotia/Atlantic research-related initiatives; and relevant documents produced by national non-governmental organizations (e.g., CATIE; Canadian Working Group on HIV and Rehabilitation; African and Caribbean Council on HIV/AIDS in Ontario [ACCHO]). Each document was reviewed against high-level evaluation questions for each priority area for the purpose of identifying discrepancies and/or corroborating results from other sources and/or filling in gaps or responding to questions that could not be adequately addressed by another method.

3.0 Findings

The findings from the sources described in section 2.0 are consolidated and summarized in this section. Due to the variety of stakeholders surveyed or consulted, there were many viewpoints. On some issues there was a broad consensus, and on others there were differences of opinion.

A number of themes emerged that cut across all of the findings. These include the following:

- Access to some key social determinants of health—a good education, sufficient income, health benefits, a supportive social network and/or vigorous ASOs providing support, and being a resident in or having access to the services available in Halifax (and, to a lesser extent, Sydney and Truro)—is a major determining factor in the well-being of PHAs and those at higher risk and in how well the system provides for their needs. Those with access to these determinants are generally well serviced by the system. Those without are served much less well. At the opposite end of the spectrum are those who are socially and economically marginalized, such as individuals who are homeless and/or those with mental illnesses and with addictions, particularly people who inject drugs. Diverse and marginalized groups also lack access to services, even if services are available.
- HIV-related stigma affects access to and willingness to seek services, including testing and treatment.
- The availability of and resources for services and ASOs are lacking outside of Halifax and Sydney. An ASO based in Truro provides vital links, but local services are limited.
- There is concern about the lack of awareness of the risks of STBBIs and risky sexual and substance-using behaviours among young people.
- ASOs appear to have a crucial role in the system and are relied upon by other service providers to deliver essential support and coordination services, yet their funding is insufficient, uncertain, and short-term, creating insecurity and instability as well as diverting energy to the struggle to find resources.
- Fulsome discussion of the opportunities and challenges associated with integrating HIV/AIDS with other STBBIs (including integrated testing) is needed to understand the implications.
- Revisioning and renewal of the Strategy is needed.

3.1 Care, Treatment, and Support

3.1.1 SERVICE PROVIDERS' KNOWLEDGE OF AVAILABLE SERVICES AND REGIONAL ACCESSIBILITY OF SERVICES

The majority view was that service providers, in general, have a fairly good knowledge of available services, but there were caveats, such as “within Halifax,” “outside of prisons,” and “dependent upon the individual providing the service.” Those working in the HIV/AIDS field are the best informed; those outside of this field (e.g., emergency-room workers and general practitioners/family physicians) may be less so.

Family practitioners have an important role to play, but some service providers and around half of the PHAs stated that many are not well informed of the available services. Therefore, PHAs may have varied experiences across service providers, based on the individual service provider’s knowledge of services.

Respondents were asked to identify the regions where access to services was easiest and most difficult, and the consensus was

- central (HRM): easiest
- western: most difficult
- eastern (Cape Breton): difficult
- northern: neutral (neither easiest nor most difficult)

3.1.2 COORDINATION OF CARE

On the topic of coordination of care, the majority view was that there is coordination between some service areas but not others. Perhaps not surprisingly, PHAs tend to be less satisfied about this than the service providers. It is clear that marginalized groups (e.g., people who are homeless/street-involved or use drugs) encounter poorer coordination of care, although they have a greater need for it. Service providers commented that this situation is not unique for services specific to HIV/AIDS.

“People who have multiple vulnerabilities need service providers to walk with them and support them on their journey.” (Front-line service provider)

ASOs and the HIV Clinic in Halifax (provided through the Infectious Disease Clinic, QEII Hospital) were typically cited as providing examples of good coordination of care.

The data in the Lewellen report⁽¹⁵⁾ indicate that “for respondents in the study, the primary health care model has proven to be a relatively uncomplicated one.” The HIV Clinic facilitates coordination and collaboration between infectious-disease specialists and other health care professionals (e.g., social workers, psychologists) and with family/primary-care doctors. Since 2004, there has been an infectious-disease specialist in Sydney who provides care and treatment to PHAs in Cape Breton. While PHAs in Cape Breton do not have the benefit of a multidisciplinary clinic like the one in Halifax, there appears to be good coordination of basic services and supports (e.g., nutrition, local ASO).

The Lewellen report⁽¹⁵⁾ demonstrates the crucial role of ASOs as vital links between PHAs and services and supports within the community. Direction 180, Mobile Outreach Street Health (MOSH), and Halifax Housing Help (HHH)—all located in Halifax—were also often cited by review participants as examples of good service coordination. Direction 180 established HHH in collaboration with the Housing Coalition to help marginalized populations secure housing. This success attracted federal funding and helped to demonstrate the value of this type of service. Subsequently, the Nova Scotia Department of Community Services (DCS) began investing in housing support workers in the community, which has further increased access to housing for marginalized populations.

Services provided by government departments and the formal health care system (excluding the HIV Clinic) were cited as less well coordinated. Challenges to improved coordination include systemic rigidity, a lack of resources (particularly for ASOs), a lack of services in rural areas, and stigma. Mental-health issues and inadequate mental-health services were a particular concern.

“The system does not respond well to chronic illness.”
(Front-line service provider)

Dr. Lewellen⁽¹⁵⁾ also makes this point strongly: “While reporting a general satisfaction with all of his health care providers, [one key informant] ... commented on what he felt was a fragmented health care system overall:

‘One, once you get a chronic illness, a debilitating illness, you as a patient or client have the option to take more control over your health destiny and not that you’re forced to but you are probably wise to because the health system still is very fragmented, and although you get very good care within each of the specialties I find the specialties are not able to put it all together and I don’t think your family physician has ... the detailed information to be able to put it all together to keep track of things.’

A number of key stakeholders also commented on the issue of providing care to PHAs who are aging. This is an emerging challenge that will increase the treatment and support requirements from a greater variety of health professionals and services. Again, education and capacity building within non-HIV specialists, rehabilitation, and other services is needed.

*“HIV is minor in my health concerns—aging is more my general concern. Has to be seen through an HIV lens; how do service providers provide this level of care?”
(PHA)*

“Do you educate ASOs about aging or people who work in the aging field about HIV?” (Key stakeholder)

3.1.3 CULTURAL COMPETENCY

Opinions were equally divided on the issue of whether PHAs and/or people at higher risk have access to culturally competent care. Like other issues, this one remains population dependent and has regional dimensions. For instance, the two populations that were often cited as receiving culturally competent care were aboriginal people and gay men living with or at risk of HIV/AIDS. (Both have ASOs that serve these populations and that receive some government funding.) The complexities of multiple cultures, ethnicities, experiences, and social determinants make it difficult to provide completely tailored care to each group or to individuals in a small province.

A two-day workshop entitled “Strengthening Capacity of Service Providers to Deliver HIV Prevention Programs to the African Diaspora in Canada”⁽³²⁾ offers one tool to help increase the capacity of mainstream providers to deliver culturally competent HIV/AIDS services to the African Caribbean and Black (ACB) and other diverse communities. The workshop (developed with project funding from the PHAC) addresses the historical and contemporary context of racism and oppression and the impact of and response to HIV/AIDS within these communities. As one of five regional “hubs” formed by the Canadian HIV/AIDS Black, African and Caribbean (CHABAC) network across Canada, the Halifax hub conducted two workshops in 2012 that were well received by ASOs and other service providers in Nova Scotia. The format and content is seen as adaptable to any cultural group.

Healing Our Nations (the ASO serving aboriginal communities across Atlantic Canada) provides workshops and training opportunities on various topics (e.g., two-spirit and

transgender, substance use and addictions, STBBIs, sexuality) to aboriginal communities in the region as well as conducts cross-cultural training workshops for non-aboriginal service providers.

Supporting and collaborating with ethno-racial organizations and networks (e.g., CHABAC, Healing Our Nations) to develop and deliver training could facilitate the provision of culturally competent HIV and related services to ACB, aboriginal, and other diverse communities in Nova Scotia.

Overall, things have improved in Nova Scotia: The provincial government developed a cultural competence guide⁽³³⁾ and guidelines for primary health care providers⁽³⁴⁾; a Special Advisor to the Associate Deputy Minister (of Health and Wellness) on Diversity and Social Inclusion was appointed several years ago; and work is under way to better integrate consideration of diversity and social equity in the provincial government decision-making processes (described further in section 3.4). There is much room for improvement in terms of building capacity for culturally competent services within clinical/medical, government, and community-based services. As stated by a well-informed key stakeholder:

“Supports and guidelines for health care providers to deliver culturally competent care exist. ... But actual services: they are ad hoc, and there is no budget available.”

The Lewellen report⁽¹⁵⁾ suggests that any degree of “wellness” potentially experienced by a person with HIV will be influenced not just by primary medical care but through a wide range of medical, social, economic, and psychological factors.

3.1.4 INCOME SECURITY AND SUPPORT

This section addresses the level of income security experienced by PHAs who participated in the review, the medical care and drug coverage provided, and the supports provided for other basic needs.

Medical care and drug coverage

As previously described, care and treatment for PHAs is provided by the physicians and/or other health care staff at both family doctors’ offices and the HIV Clinic (within the Infectious Disease Clinic) in Halifax or the infectious-disease specialist in Sydney, which is covered by the provincial Medical Services Insurance.

Of paramount importance is that Nova Scotia PHAs without a drug plan have their HAART or ARV medications covered through the provincial government’s Exception Drug Fund program, with approval of the HIV Clinic or an authorized physician^(35,36). PHAs pay a

dispensing fee based on the Pharmacare tariff agreement for each prescription dispensed and any transportation costs incurred for getting the prescription from Capital Health to the client's home (e.g., mail, bus). People on social assistance can submit invoices to their worker to determine eligibility to have these costs reimbursed^(15,35,36).

For other (non-HIV) prescription drugs, coverage is provided either through a private insurance plan (employer/group, individual), the Canada Pension Plan (CPP), a provincial Pharmacare program (including the DCS Pharmacare benefits) for drugs or services listed on the Nova Scotia formulary, or a plan administered by another entity. For PHAs on provincial income assistance, a \$5 copayment is required for each prescription, which may be eligible for reimbursement^(35,36). Over-the-counter (OTC) or non-prescription drugs are not covered by Pharmacare. However, PHAs on income assistance may also get help with OTC medications if they are deemed to be "items of special need"^(35,36).

PHAs who participated in the review reported that Pharmacare is not always adequate to cover needed medications. This may be due to a lack of knowledge on the part of individual PHAs about what additional items may be covered in specific circumstances or variations in interpretation of the rules by individual Employment Support and Income Assistance (ESIA) caseworkers. Some also find it difficult to afford copayments, dispensing fees, or the initial fee for Pharmacare coverage. Marshall⁽³⁵⁾ reported that PHAs on income assistance are sometimes prescribed new or specialized medications that are not on the formulary and, thus, are ineligible for coverage under Pharmacare.

"[Pharmacare is] not always as good at covering dispensing fees for HIV meds. Some offices will not cover it all. Others can be slow to do so." (PHA)

"... they [Pharmacare] don't cover my AIDS meds, some heart meds." (PHA)

Other income security and supports

By far, the area of greatest concern cited by PHAs and others who participated in the review is income security.

"People are happy with the formal health care they are receiving but the income challenges are where many of the problems reside. Basic needs are not met. This has impacts on mental health, access to food, and the neighbourhood you live in." (Key stakeholder)

The main sources of income identified by PHAs who completed the survey were

- Canada Pension Plan/Disability (CPP/D)
- ESIA, DCS
- partner support and/or part-time work
- retirement income

Based on these findings—and echoed in previous research related to the Strategy^(35,37,38)—the consensus is that financial support is insufficient to cover the following needs: rent, food, telephone, heating, OTC medications, transportation (e.g., for medical appointments), alternative therapies, rehabilitation services, dental services, and special needs (e.g., special diets). As stated by a respondent in the Lewellen study⁽¹⁵⁾:

“Basically that’s it, if I could just eliminate the food problem ... As far as medical, I can’t ask for better than in Halifax at the Clinic, they are absolutely great, and my family physician, he’s great, if I’m not feeling very well he’ll see me right away instead of my going into a panic, you know, so he—I don’t have any problems with waiting. So it’s just more or less food and uh a roof over my head, I mean I don’t ask for much.”

A major challenge is that benefits—particularly those provided by the provincial ESIA and CPP/D—are simply inadequate for anyone, whether a PHA or not. These and other income support programs are also not set up to handle episodic illnesses or disabilities (such as HIV) and repeated claims. In addition to inadequate benefit levels for basic needs (well below the poverty line), common barriers to income security for PHAs and/or people living with other episodic disabilities include complexity of the programs and eligibility requirements (e.g., not written in plain language, a maze of regulations and policies); different tests for disability and adjudication processes; and a lack of coordination between programs, including provincial income assistance and CPP/D^(11,25,35,38,39).

The Lewellen report⁽¹⁵⁾ provides a vivid picture of life for PHAs dependent on a government income support system:

“The remaining eight [of 13] respondents reported they did not have enough money to live comfortably and six of these faced the task of providing for themselves on disability payments that were \$1,000 or less per month. After deducting monthly rent costs from that amount, respondents were only left with a few hundred dollars for groceries, transportation and other expenses. Other respondents reported that a large part of their days were taken up by looking for ways to supplement their incomes, primarily for money for food, without setting off a red flag to the administrators of the particular disability program. One of the vital functions of the AIDS service organizations in the province ... is to help in this endeavour. Respondents reported that these organizations helped link them not only to formal disability programs and to agencies such as food banks and visiting nurse organizations, but also helped them by distributing grocery store gift cards and invitations to participate in research studies offering honorariums.”

The Lewellen report⁽¹⁵⁾ also speaks to the need for consistent, accessible support all along the continuum of care (emotional/psychological, financial, educational, advocacy, and peer support). Those who are heavily reliant on the current support system do not have such a continuum of care.

“Those who are hardest hit by HIV are youth, seniors, and injection drug users; they are the least likely to have supportive benefits.” (PHA)

3.1.5 WORKFORCE PARTICIPATION

With the availability of ARVs, PHAs are living longer and, like people who suffer from other chronic diseases, many can continue to work, although the episodic nature of their illness and fear of stigma or actual stigma in the workplace make working or returning to work a significant challenge. Policies and supports exist in theory, but in practice there are many challenges to getting and using these supports, particularly related to stigma and the inability of the available income support programs to respond to episodic illnesses^(11,25,35,39).

PHAs who participated in the review, and documents reviewed on policies related to workforce participation^(11,15,24,35,39), indicate the following:

- PHAs fear that if they return to work in the short term, they will be barred from long-term disability benefits when they become more ill and need them. They also fear the loss of eligibility for health benefits and supports when returning to low-paid, short-term, or otherwise precarious work due to episodic illness.
- PHAs are often unaware of changes to CPP/D (since 2008) that could support their return to the workforce, including a provision to “fast track” subsequent claims during a new period of disability⁽²⁵⁾.
- Some PHAs are not necessarily aware of their rights around disclosure in the workplace, thinking that they need to disclose when they actually don’t.
- The CPP/D definition that a disability be “severe and prolonged” does not accommodate the experiences of many people with episodic illnesses or diseases who can work part-time or intermittently on an ongoing basis but not full-time due to the symptoms of their illness or side effects of medication. CPP/D (and other related programs) does not allow for partial CPP/D income support for times when the recipient is able to work^(25,39).
- Provincial income assistance programs were not designed to serve as disability income supports, but they have become the payer of last resort for people who are without significant workforce attachment and, thus, are ineligible for CPP/D^(25,39). This includes PHAs who are younger and unable to work on a regular basis or who did not have the required amount of time in the paid workforce before leaving due to the effects of HIV.

The Nova Scotia government’s *HIV/AIDS in the Workplace Policy* (2001)⁽⁴⁰⁾ is undergoing revision with advice from the Commission. The objective to be maintained in the revision is creating a workplace environment and culture where HIV/AIDS-related issues are managed effectively and in a compassionate, supportive manner.

3.1.6 STIGMA AND DISCRIMINATION

A little over half of the respondents feel that stigma still exists and remains unchanged, although some feel it has increased while others feel it has decreased. This quote sums up the long-term picture:

“From a long term point of view, we have come a long way since the '80s ... and an understanding of HIV, specifically within the health care services, has greatly improved. The general non-health care sector still has a ways to go ...” (PHA)

Over half of the respondents believe that stigma affects service providers' ability to provide the services needed by PHAs. Stigma about injection-drug use and some types of sexual behaviour can also indirectly affect service provision to PHAs. For example, community opposition to the extension of service provision by Direction 180 to a new area of Halifax caused the service to be provided in a different format (by mobile service rather than in a permanent facility). The effects of stigma on service provision include making PHAs reluctant to access services (especially in rural Nova Scotia or other communities that are not comfortable with or are in opposition to harm-reduction and health-promotion services) or, if they do, to sometimes not tell the whole story.

Lewellen⁽¹⁵⁾ reported on past and relatively recent experiences of PHAs being treated differently, being discriminated against, and/or not being given proper treatment in health care settings because of negative attitudes toward HIV. Negative experiences related to HIV during hospitalizations and from service agencies such as visiting nurse associations were also reported.

Lewellen⁽¹⁵⁾ also reported on stigma-related experiences related to sexual orientation and HIV status in the respondents' communities:

“In two ... cases, respondents reported that they are known in their communities as gay men with HIV and they had subsequently experienced social difficulties, even in the 2000s. One respondent reported feeling he was the subject of hurtful gossip, saying 'I am always defending who I am here and I shouldn't have to,' and added that he thought things would be different if he lived in a metropolitan rather than a rural area. The second respondent reported experiencing harassment either through threats through email or having people scream insults such as 'Faggot!' and 'Go die of AIDS!' in public.” (p. 29)

In the 2007 study of income support, Marshall⁽³⁵⁾ noted that most PHAs reported having experienced forms of insensitivity and discrimination from caseworkers and their supervisors. They also worried that their HIV-positive status would not be kept confidential. On the other hand, some PHAs reported very positive experiences with staff of the DCS⁽³⁵⁾.

PHAs responding to the survey identified a number of obstacles and challenges to obtaining treatment and services caused by stigma, including

- a lack of anonymity
- a lack of sensitivity training on the part of professionals (e.g., legal, emergency-department staff, dentists, ophthalmologists)
- ignorance about HIV among the general population
- general practitioners/family physicians sometimes refusing to take new patients who are HIV positive

Results from two public-opinion surveys on HIV/AIDS—one conducted in 2011⁽⁴¹⁾ and the other in 2012⁽⁴²⁾—give a mixed picture on the issue of stigma within the general public. Both surveys suggest that Canadians are fairly knowledgeable about HIV/AIDS and generally comfortable in situations where they may be in contact with a PHA, such as working in an office with a PHA, wearing a sweater previously worn by a PHA, and shopping in a grocery store where the owner was known to have HIV/AIDS. However, many are uncomfortable with some specific situations involving more perceived direct contact, such as using a restaurant drinking glass once used by a PHA and if a close family member or friend dated someone with HIV/AIDS. While many respondents to one survey⁽⁴²⁾ said they would be comfortable with PHAs serving the public, 20 per cent disagreed that PHAs should be allowed to serve the public in positions like hairstylists and 32 per cent disagreed that PHAs should be permitted to work in positions such as dentists. The other survey⁽⁴¹⁾ noted a similar ongoing discomfort among a decreasing proportion of the population that does not appear to be rooted in a bias against people living with HIV but concerns accidental exposure to HIV transmission. However, concerns about accidental exposure may, in fact, constitute a bias or could lead to bias against PHAs⁽⁴⁾.

Both public-opinion surveys show strong agreement that PHAs have the right to be sexually active but with the important caveat that they inform their sexual partners of their HIV status^(41,42). A majority of respondents in one of the surveys⁽⁴¹⁾ see imprisonment as appropriate for someone who knowingly fails to disclose their status, although there was no consensus on the efficacy of this measure for preventing HIV.

HIV stigma may be exacerbated by several high-profile criminal cases in which people have been charged with exposing others to HIV because they did not disclose their HIV status prior to sexual activity. It is possible that the use of the criminal law—rather than public health powers (e.g., as enshrined in Nova Scotia’s Act to Provide for the Protection of Health)⁽⁴³⁾—to deal with such cases and the resulting media exposure may undermine efforts to increase access to HIV prevention, testing, and care and reinforce stigma toward PHAs and/or populations who have been disproportionately affected by HIV/AIDS^(4,28).

3.2 Health Promotion, Prevention, and Harm Reduction

In surveys and interviews conducted for the review, respondents were asked if access to a number of harm-reduction services had increased, stayed the same, or decreased. They were also asked about accessibility to these services among various priority populations. Most respondents had only partial knowledge and were hesitant to offer opinions outside of their specific areas of knowledge. Even within specific areas of experience, respondents’ views tended to vary, and often there was no strong consensus.

Only a small number of key informants had a good understanding of harm-reduction services in Nova Scotia, and these were almost all current or former Commission members or staff. This indicates the danger that in our silo-based system no one will have this understanding unless there is a focal point for expertise about a complex issue such as HIV and AIDS that affects many areas of life (e.g., social, financial, health).

3.2.1 ACCESS TO HARM-REDUCTION SERVICES

In the community

The majority views of survey and interview respondents include the following:

- Methadone maintenance treatment (MMT): Overall accessibility has increased across the province. This includes Direction 180’s “Bailey Bus,” initiated in January 2013. The Bailey Bus brings low-threshold interim methadone maintenance to where people are located in addition to its fixed site location. To date, the Bailey Bus goes to four sites in the Halifax Regional Municipality (HRM): Fairview, North End Dartmouth, North End Halifax, and (as of February 2014) Spryfield. MMT is also available in Truro and in the Cape Breton Regional Municipality (CBRM).

- Needle exchange: Overall accessibility has increased. In 2003, Mainline Needle Exchange expanded its services to Lunenburg and the surrounding area and then expanded outreach to the northern region. Sharp Advice Needle Exchange works with community groups and a network of volunteers (called “Natural Helpers”) to distribute safe injection equipment and supplies within various communities in Cape Breton.
- Barrier protection (e.g., condoms, dental dams): There were mixed opinions. ASOs have extended access in some regions (through partnerships such as the Northern AIDS Connection Society and Mainline Needle Exchange and condom co-ops) and in aboriginal communities. Barrier protection is also available through youth-health centres and sexual-health centres.
- Anonymous testing: Accessibility has stayed the same reflecting a lack of access to this service in Nova Scotia.

It is important to note that access to anonymous testing did, in fact, increase somewhat since the release of the Strategy in 2003. At the time, the Anonymous HIV Testing Program at the Halifax Sexual Health Centre (formerly Planned Parenthood Metro Clinic), which is located in Halifax, was the sole provider of anonymous testing in the province. In 2007, the AIDS Coalition of Cape Breton began providing anonymous testing in Sydney, with outreach to a few rural communities, and in 2010, prideHealth (Capital District Health Authority) began to provide it to the lesbian/gay/bisexual/transgender (LGBT) community on an outreach basis. It is not clear whether only a minority of the respondents knew about the addition of anonymous testing in Cape Breton and through prideHealth or whether some felt that this had not made a big enough impact on the overall situation.

Despite improvements in availability of anonymous testing and the general availability of confidential HIV testing within the health care system (e.g., doctors’ offices, hospital emergency departments), there are many barriers, including geographic isolation for rural communities, a lack of anonymous testing sites, a lack of cultural competency, racism, homophobia, fear of disclosure, poverty, and the continuing stigma associated with HIV. Two initiatives currently under way are attempting to address these barriers: 1) the Northern Region HIV/STBBI Testing Project, which is exploring testing options in the northern Nova Scotia area, and 2) a Point-of-Care (POC) rapid HIV testing pilot study with members of hard-to-access vulnerable populations who are clients of the Direction 180 mobile service and MOSH. The latter is being conducted as a “proof-of-concept” for the acceptability of POC in higher-risk populations and the ability to diagnose previously unknown HIV infections. The outcomes of both initiatives will be available late in 2014.

In correctional settings

Many survey/interview respondents aren't familiar with the situation in correctional facilities.

In 2010 and 2011, there were some improvements to MMT access in provincial correctional facilities (in response to concerns noted in the report by Marshall⁽⁴⁴⁾) following discussions with Direction 180 and Capital Health. Beyond this, the review did not determine if there have been any significant changes since the Marshall report.

While confidential voluntary HIV testing is offered upon intake to inmates of provincial correctional facilities, inmates have reported concerns about the confidentiality of testing results^(15,44). The Lewellen report⁽¹⁵⁾ illustrates the validity of this concern:

“One respondent was given an HIV test while she was incarcerated in a correction center in the early 2000s. Upon discovering that she was HIV positive the corrections officer made it a point to single her out to all of the other inmates as someone with HIV and this made [her] experience at the center much worse than it otherwise would have been.” (p. 29)

For priority populations

As mentioned in section 1.0, HIV/AIDS is more prevalent in populations that experience economic and social marginalization, including MSM, women, aboriginal people, people from HIV-endemic countries, prison inmates, and people who inject drugs. This is a complex picture; most survey/interview respondents lack knowledge of many priority populations. The categories used to define priority populations⁵ are confusing in themselves because they are not mutually exclusive. One researcher we interviewed stated:

“These categories ... are very screwed up in my opinion. These categories don't exist separately from each other. They all cross over e.g. ‘women at higher risk’—why higher risk—because they are aboriginal, immigrants, injection drug users?”

⁵ In our surveys and interviews, we used the eight priority populations defined by the PHAC, which were adopted in the 2003 Nova Scotia Strategy: people living with HIV/AIDS; gay, bisexual, two-spirit, or other men who have sex with men; people who inject drugs; people in prisons; youth at risk; aboriginal people; women at risk; and people from countries where HIV is endemic. The PHAC acknowledges that these are not mutually exclusive.

Most respondents attempted to comment on the populations they had knowledge of, and some improvements were reported, as follows.

- In 2009, MOSH began activities in the Halifax area. It is a collaborative primary health care team providing accessible primary health care services to people who are homeless, insecurely housed, street-involved, and underserved in the community.
- The Bailey Bus has increased accessibility to MMT for the same populations in some areas of Halifax. MMT service is also available in the CBRM and Truro area. Health Canada's Non-Insured Health Benefits (NIHB) program covers the cost of methadone prescriptions for aboriginal people. Aboriginal treatment centres in Nova Scotia, however, continue to be abstinence-based. Patients on methadone are denied treatment at the centres because they are not considered "abstinent" while on methadone⁽⁴⁵⁾.
- Needle-exchange services have also increased in communities in Cape Breton, through Sharp Advice Needle Exchange and the AIDS Coalition of Cape Breton, and in northern and western regions of the province due to the efforts of Mainline Needle Exchange (often with assistance of local partner organizations). These increases have been achieved without corresponding increases in funding, placing additional strains on resources that are already stretched very thin.
- Since 2009, access to education, needle exchange, and condom distribution has significantly improved for aboriginal communities through Healing Our Nations. Further, the "No Harm in Trying Gathering" project was established in 2012 in response to the interest and conflict about harm reduction from the Atlantic chiefs⁽⁴⁵⁾. The project fell within organizational strategic priorities of the Mi'kmaq Maliseet Atlantic Health Board (MMAHB), including population health, capacity building, integration, and workplace health. The gathering was also an identified need by Healing Our Nations and many partners, as there has been resistance and challenge to reducing the risk associated with HIV/AIDS and hepatitis C. This project maintained a community identity throughout its development and included best and wise practices as well as access issues relative to harm-reduction services⁽⁴⁵⁾.
- In 2013, the AIDS Coalition of Cape Breton received three-year funding for collaborative work with aboriginal communities from the Mental Health and Addictions Community Grants program funded through the provincial government's Mental Health and Addictions Strategy⁽⁴⁶⁾.

- For people in provincial correctional facilities, MMT is accessible if the individual was on MMT prior to incarceration and has continuity of care upon release. All other harm-reduction modalities are either non-existent or largely deemed inaccessible.
- Accessibility to harm-reduction services was considered by most respondents to have improved for MSM.
- Little information was available from the document review or the survey/ interview/focus-group respondents about whether accessibility had meaningfully improved for immigrants and African Nova Scotians. This could be attributed to a limited focus or study on access to services for these communities in this province.
- Information from the document review indicates that increasing attention is being paid to youth and sexual-health issues, as follows.
 - Over the past decade there has been an investment in youth-health centres⁽⁴⁷⁾ in many high schools in Nova Scotia, which helps youth deal with a number of issues that affect their lives, including sexual health, mental health, and addiction.
 - The Department of Education and Early Childhood Development⁽¹²⁾, in its revised learning outcomes framework for the public school system for 2013, describes improved learning outcomes for topics related to sexual health and healthy relationships starting in grade 4 and continuing up to grade 9.
 - In the winter/spring of 2013, the Nova Scotia Association for Sexual Health⁽⁴⁸⁾ hosted full-day workshops for teachers to address the learning outcomes that focus on sexual-health topics in the revised learning outcomes framework, providing teachers with information and skills to address barriers, myths, values, diversity, disclosure, dealing with parents, language, and sexual-health resources. It is not known if such workshops will be ongoing.

These are positive changes; however, there is room for improvement. Results from a comprehensive scoping review of existing policies and programs related to youth and HIV/hepatitis C virus (HCV) prevention in four sectors (health, education, corrections, and community organizations) in Atlantic Canada, conducted by the “Our Youth Our Response” study⁽⁴⁹⁾, revealed significant gaps, including service fragmentation; a lack of awareness of which services diverse youth can use, and where these services can be accessed; and stigma associated with HIV/HCV and youth sexuality.

There are many challenges regarding access to services for priority populations. Issues identified by survey respondents, interviewees, and focus groups include

- inadequate funding causing insufficient resources and long waiting lists, particularly for mental-health services and addiction-related services like MMT, and needle exchange
- government (at the federal level in particular) policies against some harm-reduction services like needle exchange in correctional facilities
- inadequate access to harm-reduction services such as barrier protection for diverse youth
- a lack of provincial harm-reduction standards and/or regulations
- a lack of services and/or barriers to access services in rural areas (e.g., anonymity, confidentiality)
- stigma (People often do not want to access condoms or needles from ASOs because of stigma attached to HIV and gay men and/or to HIV and racial [e.g., black] and/or cultural groups.)
- the history of racism and segregation in Nova Scotia
- language barriers and/or a lack of cultural competence
- insufficient resources for training for service providers who are not HIV specialists to address issues such as stigma, a lack of cultural competency, and a lack of awareness regarding available services for priority populations

3.2.2 PUBLIC-AWARENESS INITIATIVES AND MEDIA

The majority of survey/interview respondents knew of public-awareness campaigns and other initiatives implemented over the past eight years that aim to increase awareness about HIV, related services, related stigma, healthy sexual behaviour, positive attitudes toward PHAs, and public involvement in activities related to HIV/AIDS.

Examples of relevant awareness initiatives often cited by respondents include the following:

- HIV/AIDS Awareness Week (November 24 to December 1), World AIDS Day (December 1), and Aboriginal HIV/AIDS Awareness Week (December 1 to 5) (Events include panel discussions and presentations, annual vigils, and displays of the AIDS memorial quilt hosted across the province by ASOs, the Commission, and other organizations.)
- Annual Pride Parade
- Campaigns aimed at decreasing stigma (e.g., posters targeting the ACB community)
- AIDS Coalition stigma and testing campaigns
- AIDS Walk
- Amazing Race
- HIV Youth Eyes Wide Shut
- Campaigns targeting gay men
- Hepatitis C campaigns for African Nova Scotians

Many respondents made comments similar to the one below:

“I don’t recall the specifics of various campaigns but I know that during the last eight years various education and awareness initiatives have taken place to address HIV prevention for specific populations.” (Key stakeholder)

A media manual entitled *Understanding HIV/AIDS and the Media*⁽⁵⁰⁾ was developed and published in 2008 by the Northern AIDS Connection Society and the Commission and distributed to the media and community-based organizations. There was a tentative plan to hold a half-day workshop with the media; however, after some discussion with the media, they indicated that they no longer have the time for training and development because of cutbacks of resources. Very few survey/interview respondents other than former or current Commission members were aware of the existence of this manual. Follow-up after its dissemination was highlighted by Commission members as a gap.

3.3 Knowledge Development and Exchange

3.3.1 COLLABORATIVE RESEARCH INITIATIVES

Just over half of the service providers and key stakeholders surveyed have been involved in one or more collaborative research initiatives facilitated by the Atlantic Interdisciplinary Research Network (AIRN). AIRN is a network of over 200 individuals and organizations working in the areas of hepatitis C (HCV) and HIV/AIDS in the Atlantic region. AIRN's regional membership includes community-based and AIDS service organizations, people living with HIV/AIDS or HCV, front-line service providers, academic researchers, and federal and provincial policy-makers. Its goal is to coordinate research efforts to support evidence-based decision making to influence policies, programs, and practices to prevent the transmission of HIV and HCV and to improve the quality of life of those affected by HIV and HCV in the Atlantic region of Canada.

The research initiatives conducted via AIRN consist of a wide variety of applied research related to access to and effectiveness of testing, treatment, and harm reduction. One-third of the research projects mentioned were related to people who inject drugs or participate in MMT. Some of the research topics concerned a variety of other priority populations (e.g., women, gay men, emergency-shelter users, youth) and their access to treatment or harm-reduction services. It is important to reiterate that the categories used to define priority populations overlap and are not mutually exclusive. Intersectionality policy analysis and research⁽⁹⁾ that takes into account multiple aspects of identity and the complexity of people's lives could inform the development of policies and services that are accessible and responsive to diverse and/or marginalized populations.

A variety of topics for further research were suggested. The topics most often mentioned (in order) were

- stigma and ways to eliminate it
- population-specific research and cultural competence
- the impact of funding ASOs and the quality of service provision
- addressing the gap between research and policy
- early treatment options

Participating in collaborative research was seen to bring a number of benefits. AIRN members say they have learned that the community needs to be involved: *"It makes*

research accountable because we're all sitting at the table." Priority setting and research is a collaboration between academics, the community, and policy people. However, there are challenges: Participants in collaborative research found that the biggest challenge was not having enough time to participate. This often caused strain on staff with limited resources and time constraints. Another significant concern is the uncertainty of funding and sustainability of AIRN in the long term.

The vast majority of those surveyed found it very difficult to say what the impact of the research results had been. At best, the impact of research on service delivery and policy is seen to be informal, long-term, and indirect, through relationships and building knowledge, trust, and confidence.

"The whole movement of research to policy is not clear cut or even timely. There's no mechanism to translate research results into action at the time the results come out. There is the issue of scale up; we can get funding for a project but not for a program that goes longer term or covers a wider geographical area." (Researcher)

3.3.2 SURVEILLANCE OF PRIORITY POPULATIONS

In 2012, the DHW released the document entitled *Surveillance Report on HIV/AIDS in Nova Scotia: 1983 to 2011*⁽⁵⁾, which examines newly diagnosed cases and trends in Nova Scotia since 1983, focusing on cases reported between 2002 and 2011. It provides an overview of HIV and AIDS reports by year, geography, age, sex, exposure category, and (for the first time) race/ethnicity. This is important because—as with other demographic variables (e.g., age, sex, geography)—looking at race/ethnicity helps us to understand what and how certain factors may increase the risk of HIV infection and to determine how to respond in a culturally competent way. Selected trends relative to some of the priority populations are presented in Table 1 (see page 33). The data presented in this table were taken from Table 1.1, page 11 and pages 19–21 of the above-mentioned surveillance report⁽⁵⁾. For more information, the reader is encouraged to access the full surveillance report on the DHW website

(<http://novascotia.ca/dhw/populationhealth/documents/HIV-AIDS-Surveillance-Report.pdf>).

Table 1: Comparison of selected characteristics of HIV cases diagnosed in Nova Scotia between 1985–2001 and 2002–2011

TIME PERIOD	1985-2001 Number (%)	2002-2011 Number (%)	
SEX			
Male	500 (87.4)	160 (82.5)	
Female	72 (12.6)	34 (17.5)	
EXPOSURE CATEGORY (1)			
MSM or MSM/IDU	390 (68.2)	98 (50.5)	
IDU	53 (9.3)	30 (15.5)	
HET-endemic	22 (3.8)	13 (6.7)	
HET-IR	51 (8.9)	25 (12.9)	
HET-NIR	18 (3.1)	22 (11.3)	
Other	32 (5.6)	0 (.0)	
NIR	6 (1.0)	6 (3.1)	
RACE/ETHNICITY			Estimates Based on 2006 Census: % Visible Minority and Aboriginal Identity in Nova Scotia (2)
Aboriginal	4 (0.7)	6 (3.1)	2.6
Black	37 (6.5)	20 (10.3)	2.0
White	377 (65.9)	154 (79.4)	(not stated)
Other/ mixed race/ ethnicity	3 (0.5)	9 (4.6)	1.6
Unknown/ missing	151 (26.4)	5 (2.6)	(not stated)
TOTAL CASES	572	194	

Notes: (1) Exposure categories: MSM=men who have sex with men, IDU=injection drug use, HET-endemic=heterosexual contact and origin from an HIV-endemic country, HET-IR=heterosexual contact with a person at risk for HIV (e.g., HIV+ partner), HET-NIR=no risks other than heterosexual contact, Other=cases in which the mode of transmission is known but not captured in major exposure categories (e.g., blood transmission), NIR=no identified risk. (2) All population counts used in the 2012 surveillance report were obtained from Statistics Canada and are estimates based on the 2006 census. Population counts for the race/ethnicity analysis were based on the Visible Minority and Aboriginal Identity information collected by the census⁽⁵⁾.

Key trends noted⁽⁵⁾:

- Rates were much higher for males than females in both time periods. The proportion of female cases increased slightly in the 2002–2011 period.
- MSM account for the majority of HIV cases in both periods. While nearly all reported cases were among MSM in the early years of the epidemic, between 2002 and 2011, MSM accounted for a significantly lower percentage. This is followed by higher rates of cases attributed to injection drug use and to heterosexual contact across all three subcategories between 2002 and 2011.

- While the absolute numbers of reported cases in non-white groups remained relatively constant (average of three per year), the proportion of white cases declined, with an increase among non-white cases.
- Not included in Table 1 but important to note in the 2002-2011 period:
 - Forty per cent of the black cases were female, which is significantly higher than the 17.5 per cent for Nova Scotia female cases overall. Also, 70 per cent of the black cases were born outside of Canada, and the exposure category for 60 per cent was origin from an HIV-endemic country. It is likely that some of the black cases acquired HIV outside of Nova Scotia.
 - For mixed race and/or other ethnicities, all were female cases, with more than half between 20 and 29 years of age. The same proportion was born outside of Canada in a non-endemic country.

Non-white populations, therefore, appear overrepresented when compared to the race/ethnicity distribution of the Nova Scotia population. (See note #2 in Table 1 regarding estimates of population counts.) Comparing ethno-racial categories, however, is difficult because identification by race and/or ethnicity may differ between what is used by Statistics Canada and what is used for HIV case follow-up⁽⁵⁾. Another challenge is that the statistics for people who were tested for HIV are not reported—only statistics related to the positive cases are reported. This makes it more difficult to understand changes in incidence and prevalence, uptake and testing behaviours, and the services and supports needed for diverse communities throughout the province. Comparisons between ethno-racial categories are also challenged by the large difference in the absolute numbers of HIV-positive cases (572 versus 194) and the difference in the number of incomplete or missing ethno-racial data (26.4 per cent versus 2.6 per cent) between the two time periods. The smaller percentage of missing ethno-racial data for the 2002-2011 time period allows for more meaningful comparison and interpretation of data.

It is important to bear in mind that HIV infection for all populations in Nova Scotia may be higher than reported, given that HIV can only be reported when someone tests positive for the virus. The intersection of HIV/AIDS-related stigma with racism, sexism, and heterosexism in Nova Scotia as well as other factors creating inequality may discourage HIV testing, particularly within non-white populations and/or marginalized populations.

“There are different levels of stigma within each of these groups—e.g. it’s a triple whammy if you are a gay man with HIV who is black. There is a history of racism and segregation in Nova Scotia.” (Key stakeholder)

While it is difficult to draw definitive conclusions from this data, it is important to enhance and continue to collect data relative to race and ethnicity to monitor trends in infection rates and support planning and advocacy for services. Moreover, as approximately 18 per cent of cases in Nova Scotia between 2002 and 2011 were among non-white populations, with more than half being black and/or born outside of Canada, there is a need to increase and support population-specific interventions to address and make visible HIV/AIDS within diverse communities^(51,52).

Finally, it was suggested by some individuals that current surveillance of HIV and STBBIs and the capacity to understand trends is limited by reporting incidence data separately for each infection. Some participants identified a need to enhance HIV/STBBI surveillance data by pulling together and reporting on HIV/STBBI co-infection, risk factors and behaviours, and information related to the social determinants of health (as is done by the PHAC through enhanced surveillance of priority populations).

3.4 Coordination, Planning, and Reporting

3.4.1 INVOLVEMENT WITH THE STRATEGY

Fifty per cent of the service providers and key stakeholders and 37 per cent of the PHAs surveyed were involved in the development of the Strategy. About a third of the survey respondents were satisfied with their involvement, a third were not satisfied, and a third would like it to change (generally toward more or a different form of involvement).

With the Commission as the coordinating agency, accountability for the Strategy was to be shared among many stakeholders identified as leads and partners for each of the recommended actions⁽¹⁾. This was to be facilitated primarily through the four original working groups established as a mechanism for collaboration and coordination. Participation on the working groups gradually diminished, seemingly because (particularly for members with a non-HIV-specific mandate) of workload challenges and/or some members working on the Strategy “off the side of their desk.” The result was that the working groups eventually disbanded.

PHAs who would like to see change cite the desire for more direct involvement in the work of the Strategy, such as outreach to prisons, reviewing Strategy documents, and a possible re-establishment of a PHA advisory committee or the former learning club⁶. Service providers and key stakeholders for the most part lament a lack of time to become familiar with and contribute to the Strategy. A number stated their interest in being involved in the updating of the Strategy.

3.4.2 INTEGRATION OF A GENDER AND SOCIAL INCLUSION APPROACH

There have been several initiatives to integrate a gender and social inclusion approach into the implementation of the Strategy, including the following:

- A gender-based analysis (GBA) of the Strategy was conducted by the Nova Scotia Advisory Council on the Status of Women⁽¹⁷⁾ in consultation with the Commission and other partners. There were significant challenges to doing a GBA *after* implementation, given how the Strategy cuts across many sectors and areas of expertise. The GBA was generally seen as an add-on to the Strategy.
- In 2006, a Gender and Social Inclusion Reference Group was established to help build capacity for incorporating gender and broader social inclusion issues at the policy and service-delivery levels, with the Commission as secretariat. Between 2006 and 2008, the reference group conducted several capacity-building workshops on incorporating GBA into HIV/AIDS-related work. The group has not met since 2009.
- Recognizing that GBA was incomplete without an analysis of other intersecting aspects of diversity and inclusion, in 2009, the Commission began work on a gender and social inclusion framework—based on an analysis of existing policy lenses and tools—that could be applied to the various recommended actions. Soon after, the Commission became aware that the provincial government

⁶ In 2006, a group of PHAs identified, proposed, and organized a PHA Learning Club that would assist in the knowledge transfer among PHAs and to health and social services and the general public. The PHA Learning Club was available as a resource for service- and care-provider training. PHAs have participated in Strategy activities through speakers' bureaus in Nova Scotia. Learning Club activities decreased following the retirement of the facilitator.

would be developing a social equity lens (SEL) as part of a new structure for the government's diversity and social equity work. Therefore, the Commission suspended work on a framework to contribute to the development of a provincial SEL and worked with the Atlantic Centre of Excellence for Women's Health to produce the document *HIV/AIDS and Vulnerable and/or Marginalized Populations in Nova Scotia: Making the Case for Gender and Social Inclusion in Public Policies*⁽⁵³⁾. With HIV used as a case example, composite stories were created to show the various intersections or complexities of what people are dealing with in their lives, such as housing, addictions, mental health, and incarceration. The Commission is represented on the government working group for the SEL and has provided this document as a reference.

- In 2010, the Commission became an active partner with the Halifax hub of CHABAC and co-hosted the capacity-building workshops⁽³²⁾ conducted in 2012 (as described earlier in this report).

Also, a population health approach and attention to the social determinants of health were the foundation for the Strategy, but interviewees commented that there appears to be no consistency across different health districts with respect to strategies to respond to the determinants of health. Some key informants suggested that the Public Health System Renewal^(54,55) process is addressing the social determinants of health, as the process is focused on epidemiological and transmission issues.

3.4.3 FUNDING FOR ASOS

For over 30 years, community-based ASOs have been the heart and driving force of the HIV/AIDS response across Canada, including in Nova Scotia. Currently, Nova Scotia has four ASOs: One is provincial and located in Halifax, two are local/regional and located in Truro and Sydney, and one serves aboriginal communities across Atlantic Canada and is located in Dartmouth. All rely on the federal government for core or operational funding, with two receiving some provincial funding (from the DHW) for PHA services/support. Some additional funding is provided on a short-term-project basis from the PHAC and other organizations, including the provincial government.

As indicated earlier in this report, many respondents feel that ASOs play a crucial role in the system and are relied upon by other service providers to provide essential support and coordination services but their funding is insufficient, unstable, and short-term. This creates uncertainty and diverts energy to finding resources. While the allocation of “sufficient and stable funding sources” was the intent of recommended action 1.2 in the Strategy, funding

levels have not increased meaningfully since the implementation of the Strategy. Given the lack of resources, there are some who feel that provincial funding allocated to the Commission should be redirected to ASOs and/or other community-based organizations for health promotion, education, and services and supports.

In 2013, the PHAC initiated a process to integrate its funding programs for community-based HIV/AIDS and hepatitis C organizations, with full implementation of the funding model by April 2017. PHAs and other key stakeholders are wondering what impact funding integration will have on services and supports.

3.4.4 MONITORING AND EVALUATION

Six annual reports⁽⁸⁾ reflecting the activities and outputs of the Strategy were prepared by the Commission between 2005 and 2010. These reports were released to stakeholders across the province, including Ministers of Health and Wellness (formerly the Department of Health and/or Health Promotion and Protection).

As described in section 1.0, a comprehensive evaluation framework⁽²⁾ was developed, with the intent to collect data on and evaluate specific components on a cyclical basis beginning in 2008. Due to limited resources and competing priorities, planning for this review of the Strategy was not initiated until late in 2011. The review was officially implemented in late 2012, focusing on a cross-section of priorities in each of the four components.

3.5 Strategy Successes, Challenges, and Priorities

3.5.1 SUCCESSES OF THE STRATEGY

In order of perceived importance, through the aggregation of survey and interview results as well as focus groups, the following have been identified as the successes of the Strategy:

- **Some visible increase in access to care, treatment, and support services based on a harm-reduction approach:** The Strategy has championed harm-reduction activities. Issues that the Commission and other organizations have actively addressed and/or are pursuing are access to MMT, needle exchange, and HIV testing. An overall increase in care and treatment options has been achieved.
- **Some visible increase in initiatives to increase public awareness and reduce stigma:** Strategy-related initiatives may have increased overall public awareness about HIV/AIDS (e.g., HIV/AIDS Awareness Week, World AIDS Day, Aboriginal HIV/AIDS Awareness Week, AIDS Walk, media manual). Some respondents see a reduction of stigma both inside and outside of the health care system (although stigma still exists).
- **Community/stakeholder engagement:** Work around the Strategy has built relationships, and connections have been established with a variety of communities. The approach has been inclusive, and those involved with the Strategy are working collaboratively with associations and research networks, as evidenced by the joint awareness-raising and research activities described earlier.

“Considering their [the Commission’s] tiny budget and the systemic challenges in this kind of work they have achieved a lot through their relationships. Shepherding the strategy through influencing other stakeholders.”

(Key stakeholder)

“NSACA are good connectors between all of the key stakeholders.”

(Focus-group participant)

- **Collaboration within government:** Some respondents see movement in the area of policy development (e.g., the development of blood-borne pathogens prevention services standards for Nova Scotia⁽⁵⁶⁾, an increased focus on gender and intersectionality research and analysis⁽⁹⁾, and the creation of resources and information useful for informing helpful policy changes that are beneficial for PHAs).

- **Provincial focus:** According to some respondents, the existence of the Strategy is a success as Nova Scotia is the only Atlantic province with this kind of provincial initiative.

“Many smaller provinces don’t have a strategy and I hear them say this absence hinders them. There is no strategy for Hep C and there are so many more supports for people living with HIV/AIDS that people with Hep C don’t have.”

(Focus-group participant)

Successes of the Strategy, according to PHAs, include the following:

- For those who feel supported, the Strategy exists as a watchdog for PHAs and is a crucial part of their advocacy network. As one PHA survey respondent wrote: *“It’s great to have a ‘Watch Dog’ to make sure we are all safe and treated fairly.”*
- Other PHAs identified the early PHA advisory group as a success as well as World AIDS Day (in helping to reduce stigma).
- One PHA appreciates that the Strategy “demands government accountability.”

3.5.2 CHALLENGES OF THE STRATEGY

In order of perceived importance, through the aggregation of survey and interview results, the following have been identified as the challenges of the Strategy:

- **Lack of resources:** This is the biggest challenge, identified by an overwhelming proportion of respondents. The Strategy is regarded as underfunded, with inadequate resources and supports for implementation. Resources are needed to further build integrative or collaborative care models. At the same time, ASOs and other community-based organizations are struggling for resources, and many are experiencing burnout.
- **Accountability:** For a number of respondents, it’s unclear who “owns” the Strategy and is responsible for its implementation. The Strategy was intended to have shared ownership and accountability across the province, with the Commission as the coordinating agency. However, HIV/AIDS seems to be a low priority in the health care system and in correctional services. Some are concerned that the arm’s-length and advisory nature of the Commission means it doesn’t have the necessary authority and influence to ensure accountability within the provincial government.

- **Public education and awareness:** Some respondents feel that there are new and important campaigns that could be happening around stigma and awareness (e.g., youth at risk, the issues of aging and HIV/AIDS).
- **Relationship with community organizations:** While some respondents see community engagement as a strength of the Strategy, others feel that the lines have begun to blur, especially around the Commission, and that competition for provincial funds may be occurring. Again, some individuals feel that provincial funding allocated to the Commission should be redirected to ASOs and other community organizations and/or that there is some overlap and, thus, confusion around the role of the ASOs and of the Commission in the Strategy. One service provider stated: *“I do not feel the Advisory Commission should be conducting work in the community such as World AIDS Day campaign or conducting research ... this money should be set aside for the ASOs to do this work.”*

It was difficult to maintain the inter-sectoral working groups; however, since they ended, some respondents believe community engagement has been lacking around priority setting and decision making. As one respondent remarked: *“There is no true mechanism to connect people other than projects already underway.”*

- **Rural versus urban access to services:** Services beyond Halifax and Sydney are difficult to access or non-existent. Examples include access to (or assistance with transportation costs for) the more extensive and better integrated specialist services provided by the clinic in Halifax and to harm-reduction services such as anonymous testing, needle exchange, and MMT. Although some services have been extended outside of Halifax, they still do not reach all communities.
- **Scope of the Strategy:** According to some, the scope of the Strategy poses challenges. Either it is too streamlined and therefore missing some of the richness encompassed in the original 92 recommendations identified in the 2000 Framework^{7 (57)} or it is viewed as still being too broad and therefore is an unwieldy attempt to do everything. Another concern is that the Strategy should not remain focused on HIV/AIDS but be nested within other STBBIs.

⁷ In September 2000, the Steering Committee produced Nova Scotia’s Framework for Action on HIV/AIDS(57). It synthesized the findings of the consultation process into 92 recommendations. In 2002, a strategic-planning process was conducted and resulted in the consolidation of the 92 recommendations into 19 recommended actions to make them clearer, action oriented, and directed to a particular organization. These 19 recommended actions formed the basis of the 2003 Strategy. Great care was taken to ensure that the recommended actions reflected the needs identified in the consultations.

3.5.3 PRIORITIES FOR THE FUTURE

In order of importance, the following have been identified as priorities for the future:

- Address the issue of integration: Given the federal direction toward funding integration for HIV/AIDS and hepatitis C, service providers, ASOs, and key stakeholders are wondering what's next. Respondents reflected on the need to address how HIV/AIDS is nested within these other issues while also noting the importance and necessity of HIV/AIDS-specific needs, especially around the issues of testing, treatment, and stigma. There are mixed views around whether treating HIV/AIDS as “exceptional” increases or decreases stigma and isolation. Some respondents suggest that prevention work could move toward integration while testing and treatment could still be approached through an HIV/AIDS lens.

“You can't include all the STBBIs in the strategy—that would dilute and mix it up too much. But regarding what's in the strategy, the strategic directions—there has to be more integration with the other STIs.”

(Research focus group)

Lewellen⁽¹⁵⁾ also notes:

“Potential shifts towards a reclassification of HIV as a manageable chronic illness will aim to remove the exceptionality of the condition ... What may be lost in this transformation are awareness and understanding of the exceptional and complex circumstances under which persons with HIV live. Neither diabetes nor arthritis, for example, come prepackaged with the social stigma that pervades the HIV experience ...”

- **Reflect on and reimagine the role of the Strategy:** Given the changing context in which HIV/AIDS work will be happening, many respondents are asking
 - What is the role of the Strategy?
 - How is the context of HIV/AIDS work changing? What could the Strategy be to reflect this?
 - What is the role of the Commission in relation to the Strategy?
 - What is the role of the DHW and provincial government?
 - How can a move toward greater accountability across departments and better-integrated policy be achieved and the Strategy given “teeth”?
 - What is the best way to re-establish and/or strengthen links to ASOs, PHAs, and other stakeholders—through working groups or other ways of convening?

There is a need for more financial resources to be put toward supporting the implementation of the Strategy, additional financial support for PHAs (to meet their basic needs and to better address the episodic nature of HIV), and more resources for ASOs and other service providers (e.g., needle exchange) to assist those most vulnerable.

- **Expand access to prevention, testing, and treatment:** Continue to increase the accessibility of testing, needle-exchange services, and treatment in ways that are proactive and culturally competent across the province, especially for rural areas.
- **Increase education and address stigma:** More resources could be invested in promoting sexual health and prevention (e.g., for seniors and youth), harm reduction, the education of medical doctors and other health care professionals, public awareness around stigma, and the topic of HIV and aging.
- **Improve social inclusion and cultural competency:** Continue to ask, Who is missing? and How can we best serve diverse and marginalized and/or vulnerable populations? This could be facilitated by increasing the use of tools such as intersectionality research and analysis⁽⁹⁾; expanding diversity and cross-cultural training opportunities to enhance inclusion and cultural competency; increasing outreach to diverse groups such as women at higher risk, transgender PHAs, immigrant and refugee populations, aboriginal people, and communities of African descent; and enhancing the collection and reporting of ethno-racial data in HIV/AIDS surveillance.

4.0 Discussion and Summary of Outcomes

This review of *Nova Scotia's Strategy on HIV/AIDS* assesses outputs and outcomes; identifies areas and key elements of success; and identifies gaps and unmet needs, including those within the implementation process. The review is rigorous and extensive, covering a cross-section of key priorities related to many of the recommended actions.

While progress has been made, the review reveals significant resource and systemic challenges to addressing the recommended actions in the Strategy. These challenges, coupled with the changing context of HIV/AIDS work (e.g., movement toward an integrated HIV/STBBI framework), raise fundamental questions about how to best position and address HIV/AIDS issues to meet the needs of the Nova Scotians most affected. A summary of outcomes related to the priorities assessed in the review is provided below for each of the four components relative to the original goals and strategic directions of the Strategy. For the benefit of the reader, Table 2 presents the Strategy's original goals and strategic directions.

Table 2: Goals and strategic directions of Nova Scotia's Strategy on HIV/AIDS (2003)

ORIGINAL GOALS	ORIGINAL STRATEGIC DIRECTION
1. Integrate HIV/AIDS policy development and service delivery.	1. Mobilize integrated action on HIV/AIDS.
2. Improve knowledge and understanding of HIV/AIDS and related issues that affect the risk of infection.	2. Build a broad research and information-sharing strategy.
3. Reduce the spread of HIV.	3. Build a coordinated approach to prevention and harm reduction.
4. Provide Nova Scotians living with and vulnerable to HIV and AIDS with the best possible care, treatment, and support.	4. Build a coordinated approach to care, treatment, and support.

4.1 Summary of Outcomes: Care, Treatment, and Support

4.1.1 HOW WELL HAS THE STRATEGY BUILT A COORDINATED APPROACH TO AND PROVIDED NOVA SCOTIANS LIVING WITH AND VULNERABLE TO HIV AND AIDS WITH THE BEST POSSIBLE CARE, TREATMENT, AND SUPPORT?

Coordination of services and collaboration among providers

- Overall, collaboration and/or coordination of primary health care services have improved. This works well for the majority of PHAs, at least for those living in urban areas (particularly within the HRM, where services are easiest to access).
- While improvements have been made, a number of challenges remain, including the following. (These challenges also apply to anyone who is marginalized and/or has complex health needs.)
 - A lack of primary-care physicians who are knowledgeable about HIV/AIDS and/or willing to take PHAs as patients
 - A need for capacity building within non-HIV-specialist, rehabilitation, and other ancillary services, especially outside the HRM; the growing number of PHAs who are living into their senior years is an emerging challenge that will increase the treatment and support requirements from a greater variety of health professionals and services
 - A lack of timely access to mental-health and addiction services for PHAs, particularly outside the HRM
- While the HIV Clinic, Direction 180, Mainline Needle Exchange, MOSH, and the ASOs were cited as excellent models of collaborative practice, there appears to be little progress toward a more holistic approach to care and system coordination.

Cultural competency

- Things have improved in Nova Scotia over the past decade at the policy and service levels. Some informants report that services have improved somewhat for some priority populations, such as women, aboriginal people, gay men, and youth (through youth-health centres).

- However, culturally competent services are ad hoc and not available equally across the province. While there are significant challenges, expanding capacity building and cross-cultural training initiatives and increasing collaboration with mainstream service providers would help increase culturally competent HIV/STBBI services in Nova Scotia. Recent trends in HIV surveillance support the need for more population-specific interventions^(4,5,6).
- There is a need for continuing vigilance as issues related to a lack of cultural competency may continue to arise in unpredictable places, such as private-sector service provision or new policy development.

Income security and support

- By far, the greatest area of concern for PHAs is income security.
- PHAs in Nova Scotia without a drug plan have long been able to acquire ARVs through the Exception Drug Fund. This is greatly needed. Not all provinces cover ARVs for PHAs who need them, and Nova Scotia should be commended for doing so. Most other prescribed medications are covered through Pharmacare for prescription drugs listed in the Nova Scotia formulary^(35,36).
- However, there are significant problems with Pharmacare and income support programs for PHAs and others living on a low income, including the following:
 - Most PHAs report a monthly income of less than \$1,000. Copayments and deductible amounts, and a need for drugs not listed on the formulary, often present a hardship^(15,35).
 - Income and disability support programs are insufficient to cover many medical and other basic needs (e.g., OTC drugs, alternative therapies, dental services, special diets, rehabilitation, transportation to and from appointments, rent, food, heat) and are generally difficult to navigate.
 - ESIA is regarded universally as inadequate, even for those receiving a special-needs allowance based on medical need.
 - EI and disability coverage are patchy. Gaps include a lack of eligibility due to not having accumulated sufficient years of work and coverage not being designed for episodic chronic illnesses and repeated claims.

Workforce participation

- PHA participation in the paid workforce is a significant challenge. Existing disability benefit programs do not adequately meet the needs of people with episodic disabilities like HIV/AIDS. People with episodic illnesses are often unable to secure stable work or support services for leave with pay upon relapse.
- Fear of losing eligibility for other benefits (such as medical) when they may be needed in the future due to episodic illness often prevents PHAs from trying to return to work when they are feeling well. Some PHAs are not aware of positive changes to CPP/D that may help some PHAs stay or return to work.
- Some PHAs are not necessarily aware of their rights around disclosure in the workplace—those who responded to the survey believe they would have to disclose that they are HIV positive (when they do not).

Stigma and discrimination

- Although some feel that stigma has diminished over the past 10 years, opinions are mixed, and it remains a significant concern for PHAs and service providers. Stigma affects service providers' ability to provide services needed by PHAs—by making PHAs reluctant to seek services or to disclose their HIV status—and discourages people from getting tested for HIV.
- There can be community opposition to the expansion of preventative or harm-reduction services, illustrated by the experience of Direction 180 in late 2012 and early 2013.
- Two recent public-opinion surveys^(41,42) show an increase in positive attitudes toward PHAs, but this was not universal.
- The use of criminal law for cases of non-disclosure of HIV may be augmenting HIV-related stigma^(4,22,28).

Both the data collected by CWS and Lewellen⁽¹⁵⁾ demonstrate the range of complexity and potential difficulties for PHAs in Nova Scotia who lack sufficient economic resources and community or social support. Overall, the review suggests that health and social service systems do not respond well to chronic illness and that stigma continues to be a barrier to service. There is an overall need to build capacity for culturally competent and holistic approaches to care, increased system coordination/navigation, and advocacy, especially for marginalized populations.

4.2 Summary of Outcomes: Health Promotion, Prevention, and Harm Reduction

4.2.1 HOW WELL HAS THE STRATEGY BUILT A COORDINATED APPROACH TO HEALTH PROMOTION, PREVENTION, AND HARM REDUCTION AND REDUCED THE SPREAD OF HIV?

Access to harm-reduction services and priority populations

- Access to services based on a harm-reduction approach for MMT, needle exchange, anonymous testing, and barrier protection has improved. Continuing challenges include inadequate funding, geographic isolation in rural communities, fear of disclosure and/or confidentiality concerns, a lack of cultural competency, poverty, and stigma associated with HIV and related issues (e.g., drug use).
- The lack of access to anonymous testing for many people in the province was cited as a barrier to being tested.
- Many survey/interview respondents did not know the current situation in provincial correctional facilities, although some said access to MMT has improved. This is a gap in this review, and further inquiry of the current situation is needed.
- Most survey/interview respondents lacked knowledge of some priority populations (as defined by the PHAC and adopted in the Strategy). Little information was available about whether accessibility had improved for immigrants and African Nova Scotians. Increased study is needed on access to services for these and other priority population groups.
- The review reinforces that the categories used to define priority populations overlap and are not mutually exclusive. This speaks to the need for an intersectional approach to research and policy development and analysis.
- The number of youth-health centres has increased⁽⁴⁷⁾, improvements have been made to the sexual-health aspects of the public school curriculum⁽¹²⁾, and training was provided in 2013 for teachers responsible for teaching the sexual-health components of the curriculum⁽⁴⁸⁾. The review did not explore the quality of the revised outcomes framework and training. At the time of release of this report, it was not known if such training would be ongoing and available to teachers across the province. Further expansion of and support for youth-health centres, regular evaluation of the sexual-health aspects of the curriculum, and ongoing training and support for teachers who deliver the sexual-health components are of utmost importance.

- As per recent research (e.g., “Our Youth, Our Response”⁽⁴⁹⁾), existing policies and programs for diverse youth related to HIV/HCV across health, education, justice, and community sectors demonstrate a lack of awareness as to what services youth can use and where these services can be accessed, coordination of services, and stigma associated with HIV/HCV and youth sexuality.

Awareness campaigns

- Public awareness of the importance of HIV/AIDS may have increased through media coverage and/or attendance at HIV and AIDS Awareness Week and World AIDS Day campaigns and events, but it was beyond the scope of the review to determine if this was actually the case.
- While general awareness may have increased, stigma still exists.

Overall, the review demonstrates that more work is needed to increase the profile of HIV/AIDS as a health equity issue to reduce stigma and to increase access to education, testing, and prevention-related services in ways that connect with other related sexual-health and social determinants of health issues and sectors.

4.3 Summary of Outcomes: Knowledge Development and Exchange

4.3.1 HOW WELL HAS THE STRATEGY BUILT A BROAD RESEARCH AND INFORMATION-SHARING STRATEGY AND IMPROVED KNOWLEDGE AND UNDERSTANDING ABOUT HIV/AIDS?

Collaborative research initiatives

- Primarily through AIRN, there is increased information flow about current research and priorities. While capacity to collaborate has increased, the lack of sustained funding to support AIRN raises doubts about future collaboration and information flow.
- Capacity to participate and collaborate in research among the stakeholders is also limited by time and resources as it is generally an add-on to responsibilities.
- There is a need for an intersectional approach to research and mechanisms to translate results into culturally competent and sustainable policies and interventions to help populations disproportionately impacted by HIV/AIDS and other related STBBIs in Nova Scotia.

Surveillance of priority populations

- From the 2012 Nova Scotia surveillance report⁽⁵⁾, it appears that non-white populations are overrepresented in HIV incidence when compared to the ethno-racial distribution of Nova Scotia's population. Again, while it is difficult to draw definitive conclusions from this data, it is important to continue to monitor trends in infection relative to race/ethnicity and to increase resources and collaboration for population-specific interventions.
- Timely access to enhanced surveillance data is also needed to understand trends in HIV/STBBI testing uptake, co-infection, risk factors, and behaviours for planning culturally competent and safe services and supports, including counselling and testing.

4.4 Summary of Outcomes: Coordination, Planning, and Reporting

4.4.1 HOW WELL HAS THE STRATEGY MOBILIZED INTEGRATED ACTION ON HIV/AIDS AND INTEGRATED POLICY DEVELOPMENT AND SERVICE DELIVERY? HOW WAS THE STRATEGY'S IMPLEMENTATION PROCESS COORDINATED, MONITORED, AND EVALUATED?

Involvement with the Strategy, including funding

- With the Commission as the coordinating agency, accountability for the Strategy was to be shared among many stakeholders identified as leads and partners for each of the recommended actions primarily through the four original working groups as mechanisms for coordination and collaboration. Participation on the working groups gradually diminished, and eventually they were disbanded.
- The early days (the period of the working groups) of the Strategy were more collaborative, fuelled by a lot of energy and enthusiasm. But over the years, the assumption has developed—and strengthened—that the Commission alone is responsible for the Strategy. A good number of respondents conflate the Strategy with the Commission. It no longer feels collectively owned.
- Opinions were mixed on the issue of community stakeholder engagement: Some said it was enhanced through collaborative work on various initiatives, while others said it was diminished after disbandment of the working groups.
- About a third said they are not satisfied with their involvement and/or would like it to change in a way that can “fit” within current roles. Some PHAs are looking for greater and more meaningful involvement and influence.
- Critical success factors noted in the Strategy⁽¹⁾—such as adequate funding to implement and evaluate the recommended actions and support community-based service organizations and a commitment from and coordination across all sectors of government—were not realized. This may be partially attributable to the arm’s-length, advisory nature of the Commission; it does not have the resources and authority to compel departments and other agencies to work collaboratively on the recommended actions that cross the mandate of many organizations and sectors. Indeed, as indicated in the Strategy⁽¹⁾, “commitment at the most senior levels of government to both the Strategy and to partnership with community stakeholders is essential.” (p. 39)
- Some say the lines have blurred between the role of the ASOs and of the Commission, resulting in what some see as a competition for provincial funding, and that funding allocated to the Commission should be redirected to ASOs and/or other community-based organizations.

Monitoring and evaluation

- Annual reports of the Strategy’s activities and outputs were produced and disseminated. However, resources for systematic and comprehensive monitoring and evaluation—as prescribed in the evaluation framework⁽²⁾ in collaboration with stakeholders—were not forthcoming.
- Despite these issues, it is worth repeating that this review was extensive, covering key priorities related to many of the recommended actions.

As the HIV/AIDS policy landscape is shifting toward integration with other STBBIs and/or chronic diseases, a re-examination of the scope of the Strategy and which issues should be integrated and which should be addressed separately is needed. Serious consideration is needed for how to best position the Strategy to achieve greater shared accountability and ownership; multi-stakeholder engagement and partnership; better use and leveraging of existing resources; and increased resources for implementation, ASOs and other community-based service providers, and PHA needs.

5.0 Concluding Remarks and Recommendations

5.1 Concluding Remarks

This document provides direction for a revisioning and renewal of the provincial Strategy for HIV/AIDS within a changing policy, service, and funding context. Some of the challenges and issues identified are not specific to HIV/AIDS. More attention is needed to address the social determinants of health and the needs of those most affected or most at risk. Stigma and marginalization remain key drivers of the epidemic—creating barriers to services—and must be addressed.

The review makes nine recommendations to renew and improve Nova Scotia's approach and response to HIV/AIDS. The current fiscal environment and complexity of the issues will present significant challenges to implementing these recommendations. The Commission will address the fundamental questions within the first two recommendations—questions related to integration, accountability, stakeholder engagement, resources, and funding. This will pave the way to addressing the remaining seven recommendations. Moreover, addressing these questions will foster shared commitment and ownership that is necessary to address the root causes and reduce the impact of HIV/AIDS in this province.

5.2 Recommendations for Moving Forward

1. **By March 2015, the Commission and the DHW will convene a process to reimagine and renew the provincial response to HIV/AIDS in Nova Scotia. This process will include the following:**
 - a. *Address the issue of integration.* This includes what a renewed Strategy *should* be in order to reflect the movement toward integrated funding, policies, and services. Resource/capacity implications for ASOs and other service providers (including those who have not been significantly involved in HIV/AIDS work) and the impact on PHAs and those who are marginalized must be thoughtfully explored and analysed.

Given the prevailing stigma and discrimination and overlap in the populations affected, it is important to determine which issues and services would benefit from an integrated STBBI and/or chronic disease approach and which would benefit from an HIV/AIDS-specific focus. Further, this work should be linked to and informed by the research project “Exploring the Landscape of Communicable Diseases in Atlantic Canada,” which will be completed in April, 2014.⁸

- b. *Address the issue of accountability and ownership.* This includes determining the roles and responsibilities of various stakeholders and identifying mechanisms to enhance engagement and collaboration and give the Strategy “teeth.” Questions should include the following:
 - i. What should be the role of the Commission given the evolution of HIV/AIDS work?
 - ii. What should be the role of the DHW (e.g., public health, primary care) and other provincial government departments in relation to the Strategy?
 - iii. How can shared ownership across the health, social, justice, and education systems for better-integrated policy and service delivery be achieved?
 - iv. What is the best way to re-establish and/or strengthen linkages with and engagement of ASOs, PHAs, and other stakeholders?
 - v. Given the complexity of issues relative to the social determinants of health, what is the best way to monitor and evaluate the Strategy?
- c. *Address funding and resource requirements for supporting a renewed Strategy and increase accessibility to prevention, testing, care, treatment, and support.* This includes increases in funding and support to ASOs and other front-line service providers who assist PHAs and/or those most vulnerable (e.g., people who are street-involved and living with concurrent mental-health issues and addictions).

⁸ Led by AIRN and funded by the PHAC, this project is a collaborative investigation into the current state of communicable diseases, affected populations, and associated service-delivery needs in Atlantic Canada.

2. Concurrently with recommendation #1, **the DHW and the Commission will convene a review of provincial HIV testing policies (including prenatal screening guidelines) as part of the continuum of quality health care for Nova Scotians that is aligned with the new national guidelines for HIV screening and testing released by the PHAC⁽¹⁰⁾.** This needs to take into account strategies to make HIV/STBBI testing and counselling services accessible to Nova Scotians in all of their diversity, innovations in testing technology (e.g., POC testing), stigma and criminalization, and infrastructure to respond to potential increases in HIV screening and support needs for new diagnoses.

Once the fundamental issues have been resolved through acting on recommendations #1 and #2, the following additional seven recommendations should be addressed:

3. **The Commission, in partnership with the DHW, the four ASOs, and the Hepatitis Outreach Society, should develop innovative strategies for the coordination and navigation of services for PHAs and people with hepatitis C and/or co-infected, particularly those outside the HRM.** Collaboration with the district health authorities (DHAs) and a wide range of health professionals and relevant cultural and/or support organizations is required to ensure access across the province.
4. In keeping with the recommendations of the Episodic Disabilities Network⁽¹¹⁾, other relevant advocacy groups, and documents completed for the Strategy, **the Commission should work with the DCS and relevant advocacy groups to improve the structure, coordination, and benefit levels of federal and private-sector disability programs and the provincial ESIA program.** This includes the development of a common definition of “disability” that takes into account the episodic, reoccurring nature of conditions like HIV/AIDS and allows for part- to full-time work during periods of good health, with the option for partial income support.
5. **The Commission should work with the DHW to address specific concerns of diverse PHAs living on assistance or low incomes related to Pharmacare, including copayments, the cost of OTC medications, and coverage of prescribed drugs not on the formulary.**
6. **AIRN and the Commission should work with the DHW to identify mechanisms that can sustain and facilitate collaboration among academics, community/service providers, and policy-makers in the identification of important research questions and increase uptake of results at the service-delivery and policy levels.** There is a need for an intersectional approach to

research and policy analysis⁹) to understand the implication of policy decisions on different population groups. ⁹

7. **The DHW and other key stakeholders should invest in and develop education/training and awareness campaigns for key audiences to increase cultural competency and inclusion, reduce stigma, and build awareness of HIV/AIDS as a concern for all Nova Scotians.** This process will include the following:
 - a. The DHW, professional organizations, and universities should identify opportunities (e.g., Continuing Medical Education, professional conferences) to increase the training of medical doctors and other health professionals and front-line providers around stigma, cultural competency, harm reduction, and the basics of HIV and HIV and aging.
 - b. The DHW and the Department of Education and Early Childhood Development (DEECD) should increase the capacity and resources of youth-serving organizations (including youth-health centres), parents, and educators to address issues related to sexual health, mental health, and addictions.
 - c. The DEECD and school boards should work with the DHW and other relevant partners to monitor, evaluate, and revise as required the sexual-health components of the public school learning outcomes framework⁽¹²⁾ and ensure ongoing access to training and support for teachers responsible for delivering these components.
 - d. The DHW and the Commission, in partnership with ASOs, should develop a public-awareness campaign to increase knowledge of HIV/AIDS and related STBBIs and reduce stigma.

⁹ Research, policy and programming should also be informed by *The National Consensus Statement on Women, Trans People and Girls and HIV Research in Canada* by J. Gahagan and the *Gathering of Spirits Collaborative* (2013), Halifax, NS, Dalhousie University, Gender and Health Promotion Studies Unit

8. **The DHW, the PHAC, the Commission, and other key stakeholders should work together to strengthen and support (including providing funding and increased collaboration) networks and organizations such as CHABAC, the Health Association of African Canadians, Healing Our Nations, and others to address and make visible HIV/AIDS within their respective communities and increase collaboration with mainstream services and organizations.** Training and other skills-building initiatives need to be supported and expanded in order to increase the cultural competency of providers to more effectively work with and respond to the needs of diverse populations.

9. **The DHW and other key stakeholders should enhance the collection and reporting of HIV and other STBBI surveillance data.** This process will include the following:
 - a. The DHW, the Nova Scotia Public Health Laboratory, and the PHAC should work together to facilitate timely access to enhanced surveillance data to better understand trends in HIV/STBBI testing uptake, co-infection, risk factors, and behaviours within diverse population groups.
 - b. The DHW, the PHAC, and testing providers should improve the completeness of demographics data collected at the time of testing and during HIV-positive case follow-up, including information related to the social determinants of health.

Appendix A: Glossary

Acquired immune deficiency syndrome (AIDS)

AIDS is caused by a virus called human immunodeficiency virus (HIV). AIDS occurs when the body's immune system is heavily damaged by HIV. When this happens, diseases and infections such as cancers and pneumonia develop. These diseases and infections are called opportunistic because they occur when the body's defences (the immune system) are weak. Although there are medications to help treat HIV and AIDS, neither one can be cured.

AIDS exceptionalism

While definitions have changed over time, AIDS exceptionalism is generally referred to as a disease-specific response with dedicated resources for addressing HIV/AIDS⁽²⁹⁾. Because of the significant stigma and discrimination associated with HIV/AIDS, historically it has been treated differently from other diseases—including other sexually transmitted and blood-borne infections (STBBIs) and/or life-threatening diseases—in public health policy and service delivery (e.g., anonymous HIV testing)^(29,30).

Anonymous HIV testing

The testing of a person for HIV and reporting the results to public health departments without requiring identifying information such as the person's name⁽⁵⁸⁾.

Co-morbidity

The presence of one or more additional illnesses, disorders, or diseases co-occurring with a primary illness, disorder, or disease or the effect of such an additional illness, disorder, or disease.

Cultural competence

Culture refers to a group or community that share common experiences that shape the way its members understand the world. It is multi-layered and evolving and includes groups that are born into or become, such as (but not limited to) residence, place of origin, levels of ability, gender, gender identity, sexual orientation, race/ethnicity, language, socio-economic class, or religion. Keeping in mind that people have multiple cultures/identities that interact, cultural competence refers to the attitudes, knowledge, skills, behaviours, and policies required to better meet the needs of all of the people we serve⁽³³⁾.

Episodic disability

Refers to chronic or lifelong conditions where periods of good health may be interrupted by periods of illness or disability. Often it is difficult to predict when these “episodes” of disability will occur or how long they will last. Episodes of disability are not unique to HIV. Increasing numbers of Canadians are living with lifelong episodic disabilities. These include multiple sclerosis, lupus, arthritis, cancer, diabetes, and mental and mood disorders⁽²⁴⁾.

Harm reduction

Policies, programs, and practices that aim to reduce the negative health, social, and economic consequences (e.g., HIV, hepatitis B and C, overdoses) that may ensue from the use of legal and illegal psychoactive drugs without necessarily reducing or stopping drug use. Its cornerstones are public health, human rights, and social justice. It benefits people who use drugs, families, and communities. It ensures that people who use psychoactive substances are treated with respect and without stigma and that substance-related problems and issues are addressed systemically⁽⁵⁹⁾.

Hepatitis C

A disease that affects the liver and is caused by the hepatitis C virus. The virus causes hepatitis (inflammation in the liver), which can progress to cirrhosis (extensive scarring that prevents the liver from performing its normal functions)⁽⁶⁰⁾.

Highly Active Antiretroviral Therapy (HAART) and Antiretroviral Therapy (ARV or ART)

HAART refers to treatment regimens used to suppress HIV viral replication and the progression of HIV disease. A combination of anti-HIV drugs from different classes is sometimes called Antiretroviral Therapy (ARV or ART) or Combination Antiretroviral Therapy (CART). At present there are five different classes of drugs approved in most of the world, including Canada: nucleoside reverse transcriptase inhibitors, non-nucleoside reverse transcriptase inhibitors, protease inhibitors, entry and fusion inhibitors, and integrase inhibitors. Each of these classes inhibits the HIV life cycle differently⁽⁶¹⁾.

HIV-endemic countries

An epidemiologic term that refers to countries or populations where there is a high prevalence (generally greater than 1 per cent) of HIV infection in the general population and the predominant mode of transmission is heterosexual contact. Currently, most countries in the Caribbean and sub-Saharan Africa have been classified as HIV endemic. The Joint United Nations Programme on HIV/AIDS (UNAIDS) refers to “HIV endemic” as a “generalized epidemic” as opposed to an epidemic within distinct groups of the population⁽⁶²⁾.

HIV/AIDS integration (or integrated approach to HIV/AIDS)

Based on various definitions and usages, HIV/AIDS integration refers to

- treating prevention, detection, and treatment/care as non-discrete elements of an overall strategy for addressing HIV/AIDS
- tailoring HIV/AIDS services to reflect the “life context” of clients, including co-morbid conditions (e.g., STBBIs, mental illness)
- reshaping the ways in which initiatives intended to address HIV/AIDS and related STBBIs are funded, structured, and delivered by expanding the mandate of disease-specific engagement mechanisms⁽⁶³⁾

Human immunodeficiency virus (HIV)

A virus that attacks the immune system of the human body. When the immune system is weakened, it is hard for the body to fight off diseases and infections. HIV can lead to acquired immune deficiency syndrome (AIDS).

Intersectionality

Intersectionality was born out of the black feminist movement and has emerged in feminist theory as an approach that focuses on multiple, historically oppressed populations. It is a framework that posits that multiple social categories (e.g., race, ethnicity, gender, sexual orientation, socio-economic status) intersect at the micro-level of individual experience to reflect multiple interlocking systems of privilege and oppression at the macro, social-structural level (e.g., racism, sexism, heterosexism). Intersectionality also challenges prevailing research practices that prioritize any specific axis of inequality, such as race, class, or gender, and rejects the assumed additivity of those inequalities⁽⁶⁴⁾.

Men who have sex with men (MSM)

A term used to categorize males who engage in sexual activity with other males, regardless of how they identify themselves. The term was created in the 1990s by epidemiologists as a surveillance tool to better identify the route of HIV transmission and spread of the disease through male-to-male sexual activity. Prior to this, researchers were limited by the identity-based analyses—whereby men who identified as “gay,” “bisexual,” or “two-spirit” weren’t necessarily sexually active while those who identified as “straight” or “heterosexual” might be sexually active with other men⁽⁶⁵⁾.

Methadone maintenance treatment (MMT)

Methadone is a synthetic drug used as a substitute narcotic in the treatment of opiate addiction. Methadone maintenance treatment falls under a harm-reduction approach, although the tolerance level or threshold (to gain and remain in treatment) for using other non-prescription drugs varies depending on the goal of a particular program or service⁽¹⁾.

Needle exchange (also referred to as needle distribution or needle and syringe distribution)

A range of programs that provide needle distribution and discard services as well as other supportive services (e.g., food, counselling, prevention, and risk reduction) and referral to other relevant programs and services in the community. Needle-exchange services fall under a harm-reduction approach⁽¹⁾.

Persons/people living with HIV/AIDS (PHAs)

Individuals who are living with HIV at any stage of infection—from initial infection to development of symptoms and/or dealing with complications to progression to AIDS⁽¹⁾

Population health approach

An approach that aims to improve the health status of the entire population and to reduce health inequities among population groups. In order to reach these objectives, it looks at and acts upon the broad range of factors and conditions (the social determinants of health) that have a strong influence on health and places primacy on social-justice values such as equity, accessibility, affordability, and respect for human rights in the provision of health care and social services^(1,66).

Stigma

In reference to HIV, stigma refers to prejudice and discrimination directed at people living with HIV. Many groups vulnerable to HIV—such as gay men, transgendered people, people who use drugs, women, sex workers, prisoners, youth, aboriginal people, and members of other ethno-racial minorities—already experience marginalization and are subject to homophobia, misogyny, ageism, or racism⁽²⁷⁾.

Viral load

A measurement of the amount of a virus in blood or other body fluids. The HIV viral-load test is used primarily to monitor HIV infection over time. It is a quantitative measurement of HIV nucleic acid (RNA) that reports how many copies of the virus are present in the blood. Evidence shows that keeping the viral-load levels as low as possible for as long as possible decreases the complications of HIV disease, slows the progression from HIV infection to AIDS, and prolongs life and decreases the likelihood of someone transmitting HIV to another person⁽²⁶⁾.

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