Our Youth, Our Response: Building Capacity for Effective HIV/HCV Policy and Programming Responses Across the Atlantic Region

Final Report

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Executive Summary

Our Youth, Our Response: Building Capacity for Effective HIV/HCV Policy and Programming Responses Across the Atlantic Region **(OYOR)** was a three-year interprovincial research study funded by the Nova Scotia Health Research Foundation (NSHRF). *Our Youth, Our Response* sought to investigate the current state of primary (eg. preventing the initial infection) and secondary (eg. preventing transmission) prevention policies for youth aged 15 to 24 across Atlantic Canada using population health and determinants of health frameworks. The overarching goal of *Our Youth, Our Response was to* develop evidence-based recommendations for a variety of stakeholders within government, community and research sectors on strategic and innovative prevention policy and programming approaches needed to help mitigate the impact of these diseases.

Why Does This Matter?

Despite prevention efforts, youth in Canada remain at risk for HIV and Hepatitis C (HCV) infection. Social determinants of health serve to shape conditions associated with the higher prevalence of disease, including HIV and HCV. The Atlantic region experiences more social, economic, and health inequities and higher rates of chronic disease than the rest of Canada. Atlantic Canadian youth face risk of HIV and HCV infection due to stigma pertaining to youth sexuality, barriers to accessing services, a lack of knowledge pertaining to exposure risks, and a lack of youth-specific programming and policy responses.

Key Findings

1) Inter-Organizational and Intersectoral Collaboration

Why Does This Matter?

Our participants indicated that collaboration between organizations and sectors was critical to strengthen youth-related HIV and HCV prevention policies and programs. Collaboration between organizations with different mandates may serve as a means of connecting with a wider range of target populations and providing greater access to services. However, a lack of financial and human resources makes collaboration difficult within provinces and across the Atlantic region.

Recommendations

Collaboration: Strategic Partnerships and Cross-Disciplinary Approaches

The establishment of strategic partnerships between sectors, health regions and provinces could help to improve the current prevention efforts in Atlantic Canada. Provincial HIV and HCV prevention policies should be developed in a manner that helps support organizations' ability to collaborate, including providing funding to offset the costs associated with establishing and maintaining collaborative working relationships within a province, and across provincial borders. Collaborative models should be developed based on the success of existing strategic partnerships.

2) Youth Engagement

Why Does This Matter?

Increasing youth engagement in the development and implementation of HIV and HCV prevention policies and programs can increase their reach and lead to services that better reflect the needs and preferences of youth. However, this type of engagement remains critically low, with difficulties recruiting and retaining youth that are representative of diverse populations, such as LGBTQ youth, Indigenous youth, and homeless youth.

Recommendations

Meaningful and Age-Appropriate Engagement of Youth

Consultation and collaboration with youth to determine what HIV and HCV prevention approaches they need, how they wish to be engaged, and the kinds of messages and formats that will capture their interest must be a priority for all organizations providing youth services. A number of strategies may be employed to encourage youth to engage in HIV and HCV prevention policies and programs, including providing adequate resources, capacity building, and establishing a standing commitment to solicit youth input. Additionally, programmers should focus on providing age-appropriate and youth-friendly outlets for inclusion, such as arts-based projects or by encouraging youth to mentor their peers. Educational and promotional materials should depict diverse youth, and care should be taken to ensure that wording does not exclude specific populations such as LGBTQ youth, or youth who use injection drugs. Materials should be developed collaboratively with youth from diverse backgrounds to increase its resonance with respective sub-populations. Social media, phone-based, and internet-based programs could also be an effective means of engaging youth populations.

3) Testing: Accessibility and Confidentiality

Why Does This Matter?

Access to testing, particularly anonymous testing, is a significant barrier across the Atlantic Provinces. Many youth prefer to seek testing at dedicated sexual health centres rather than emergency rooms, walk-in clinics, or from family physicians. However these services are not available in the majority of rural communities. Personal relationships between families and local healthcare professionals can also act as barriers to testing due to concerns regarding privacy, confidentiality, stigma, and negative perceptions of risk.

Recommendations

Increasing Access to Testing and Prevention Services

Increasing the number of testing sites, the types of sites where testing is provided (eg. school-based clinics), and the types of HIV testing available (such as point of care and anonymous testing) could increase the uptake of HIV testing among youth. Although this would involve an initial investment of financial resources, the long-term cost-saving capacity of HIV and HCV prevention policies and programs outweigh the short term financial investment. Policy makers and health care practitioners must work together to update legislation and programs related to HIV and HCV

testing. Mobile testing sites should be explored as a means of reaching rural communities and populations who are reluctant or unable to come forward for clinic- or hospital-based testing. Continuing education among health care practitioners is also required in order to ensure appropriate pre- and post-test counselling and referrals following testing. This could take the form of professional development courses for practicing professionals, and integrating HIV and HCV-relevant prevention materials into post-secondary health professional curricula to ensure that the appropriate standards of care for youth are being met.

4) Harm Reduction: Providing Condoms and Clean Needles

Why Does This Matter?

Providing non-judgmental and confidential services such as needle distribution and free condoms allow youth to exert some control over their own HIV and HCV prevention needs. Harm reduction services may also provide youth an in-road to other forms of prevention, education, counseling, and treatment services for both HIV and HCV, and for problematic substance use. However, the provision of harm reduction services is often hampered by negative public opinions, a lack of political support, and prevalent misconceptions about HIV and HCV risk. Even when available, youth may be unaware of what services are present within their communities and how to access them.

Recommendations

Reduce Stigma Associated with Harm Reduction by Educating the Public, Teachers and Policy Makers

Beyond the physical availability of harm reduction services, barriers included unsupportive political environments, negative (and often inaccurate) public perceptions, and a lack of awareness among youth of the harm reduction services that are available in their communities. Changing the views of these individuals and communities may be needed in order to increase the availability of materials such as condoms and clean needles. Countering the dominant conceptualization of youth sexuality as being inherently risky, drug use as an individual problem, and/or harm reduction as promoting undesirable behaviour will require meaningful collaboration with youth, and a multi-pronged public outreach strategy. This strategy could include promoting the understanding of problematic substance use as a health problem rather than a legal or moral issue within school-based curricula, news media, and workplace policies. Changing the perceptions of policy makers will require the presentation of data (such as cost-benefit analysis) that speak to the short- and long-term benefits of harm reduction policies and programs.

5) Education and Information: Youth, Parents and Providers

Why Does This Matter?

Providing youth with information on HIV and HCV risk factors represents an important component of primary prevention. This information can correct misconceptions (such as HIV being only a “gay man’s disease”) held by youth, parents and some healthcare practitioners that may lead to potential risk of exposure or present barriers to healthcare services. However, there is considerable variability in the overall quality of sexual health education that youth receive. Much of the educational and prevention information delivered to youth remains largely heteronormative and

often fails to engage other populations of youth such as LGBTQ youth. Further, little information is provided to parents, teachers, and healthcare providers in an effort to correct misconceptions or address social stigma often associated with HIV and HCV.

Recommendations

Increasing Education and Prevention Messaging for Youth, Parents and Providers

Across Atlantic Canada, there is a need for development (or regulation and evaluation) of policies aimed at ensuring the quality of school-based sexual health curricula, and the consistency of their delivery. Further, increased support should be provided to teachers tasked with delivering these curricula. For example, the quality and accuracy of this material can be increased through collaborative development involving school boards, youth-serving HIV or HCV organizations, health professionals, youth representatives, and/or persons living with HIV or HCV. Having prevention experts, guest speakers, and/or peer educators deliver some content could increase the perceived relevance of this information to the lives of youth, and their receptivity to HIV and HCV prevention messages.

Parents should be included in sexual health conversations to dispel negative attitudes towards sexual health education and harm reduction in relation to HIV and HCV. Teachers and providers should be offered training updates and should demonstrate competency in delivering accurate information that more effectively responds to the HIV and HCV prevention needs of youth. This could contribute to addressing misconceptions and stigma associated with harm reduction services.

Introduction

***'Our Youth, Our Response*: Building Capacity for Effective HIV/Hepatitis C (HCV) Policy and Programming Responses Across the Atlantic Region' (OYOR)** was a three-year interprovincial research study funded by the Nova Scotia Health Research Foundation (NSHRF). *Our Youth, Our Response* investigated the current state of primary and secondary HIV and HCV prevention policies for youth aged 15 to 24 across Atlantic Canada using population health and determinants of health frameworks. Over the course of three years, the research team:

- conducted a comprehensive scoping review of existing prevention policies and programs;
- interviewed key informants and conducted focus groups to identify gaps and strengths in prevention policies and programs in relation to youth, and;
- analyzed both quantitative and qualitative data in order to determine novel approaches to effective policy and programming related to HIV and HCV prevention aimed at youth in Atlantic Canada.

The primary research team was composed of one researcher/mentor and one or two policy trainees in each of the four Atlantic Provinces. OYOR researchers worked collaboratively both as inter-and intra-provincial teams by communicating regularly and working cooperatively to produce comparable data via one overarching methodological approach. Community Advisory and Youth Advisory Committees were developed to provide additional guidance and feedback as well as to contribute to the dissemination and knowledge transfer and exchange (KTE) activities over the course of the three-year study.

Objectives

The objectives for this interdisciplinary, interprovincial study were to:

- Conduct a comprehensive review and analysis of the current HIV and HCV primary and secondary prevention polices and their implications for youth in each of the four Atlantic Provinces;
- Investigate the strategies used by different stakeholders within and across provincial and community levels to inform their HIV and HCV primary and secondary prevention policy approaches;
- Develop and implement knowledge translation and exchange (KTE) strategies to share best practices in intersectoral approaches to mitigating the impact of HIV and HCV on the lives of youth;
- Develop evidence-based recommendations for a variety of stakeholders within government, community and research sectors on strategic and innovative prevention policy approaches needed to help mitigate the impact of these diseases; and
- Build capacity among stakeholders in relation to HIV and HCV primary and secondary prevention policy analysis.

The first year of the OYOR study, which focused on conducting a scoping review of existing prevention policies and programs in each of the Atlantic provinces, has been previously analyzed

and reported in a 2013 summary of the findings and can be accessed through the Gender Health Promotion Studies Unit website: http://www.dal.ca/diff/gahps/resources/publications.html

This final OYOR report focuses on the key findings from data collected during years two and three, which included forty-eight in-depth key informant interviews and four focus group discussions (n=21). Identified gaps in existing primary and secondary prevention policies and programs are presented, alongside examples drawn from successful approaches to engaging youth in HIV and HCV prevention across the Atlantic region. Recommendations based on these lessons learned are offered to help inform the next generation of HIV and HCV prevention policies and programs, specifically in the Nova Scotia context, the most populous province in the Atlantic region.

Background

Atlantic Provinces

Atlantic Canada, composed of Nova Scotia (NS), New Brunswick (NB), Newfoundland and Labrador (NL), and Prince Edward Island (PEI), is a region that experiences higher rates of chronic disease per capita than the national average. This includes both communicable and non-communicable diseases. This has been attributed, in part, to socioeconomic and related health inequities within the Atlantic region as compared to the rest of the country (Hayward & Coleman, 2003; Spigelman Research Associates 2002). Youth are particularly vulnerable to these conditions (Viner et al., 2012), which include a lack of employment opportunities (for their parents and themselves), and limited educational and healthcare funding (Community Foundation of Nova Scotia, 2014). It is therefore imperative that the impact of the unique social, economic, and political environments of the Atlantic region on the health of youth be examined and addressed, particularly in relation to the prevention of HIV and HCV infections.

Social Determinants of Health

In order to frame health inequities within the complex web of factors that cause and exacerbate them, this study has used a social determinants of health lens (Raphael, 2009). The social determinants of health are defined in various ways but often include income, education, employment, social exclusion, Indigenous status, gender, race, and disability, among others (Mikkonen & Raphael, 2010). These determinants influence the ways in which individuals and groups interact with, access, and either benefit from or suffer as a result of the health of social systems and services in place in Canada. In particular, our analysis focused on sex, gender (including a number of ways in which inequity is structured around gender), diversity (including Indigenous status, language, racialized groups, etc.), urban versus rural habitation, and the concept of equity. This analysis also places a special focus on youth, as they have been identified as a group vulnerable to the impact of the social determinants of health in ways that differ from adult populations (Sawyer et al., 2012; Viner et al., 2012; Currie et al., 2012).

Sex- and Gender-Based Analysis

In the context of health research, sex and gender-based analysis (SGBA) is a research approach that examines how sex and gender influence health outcomes through biological, social, economic and/or political pathways (Clow, Pederson, Haworth-Brockman, & Bernier, 2009; Johnson, Greaves, & Repta, 2007) Though national and international guidelines encourage the application of sex- and gender-based analysis in health research (Canadian Institutes of Health Research, 2014a; CIHR, 2014b; CIHR, 2010) this approach has not yet been ”mainstreamed” in practice by many policy researchers (Greyson, Becu, & Morgan, 2010). However, sex- and gender-based analysis was identified as an essential approach to this study and was integrated through the creation of the coding scheme that was used to analyze focus group and in-depth interview data.

Much of the grey literature, as well as many academic papers, misuse or conflate the terms sex and gender (Gahagan, 2013). This can result in making incorrect assumptions about gender neutrality and/or bias in health research or policies, often based on reporting aggregated data which fail to accurately represent the realities and experiences of distinct groups of people (Women’s Health

Bureau, 2003). Sex and gender play key roles in determining the types of health services women and men, girls and boys may need as well as the ease with which they may be able to access and interact with different health service providers. By accounting for sex and gender, it is possible to reveal the underlying socio-structural, political, and economic determinants of health that influence access to and uptake of services (Greyson et al., 2010; Women's Health Bureau, 2003).

The OYOR research team drew, in part, from the analytic framework offered by Clow, Pederson, Haworth-Brockman, & Bernier (2009) in *Rising to the Challenge: Sex- and Gender-Based Analysis (SGBA) for Health Planning, Policy and Research in Canada* to help inform our approach to our data. Specifically, each OYOR team member undertook a series of online training modules on sex- and gender-based analysis which was later solidified through a series of team discussions. The foundation of our methodological framework relied on a strong understanding of a number of key concepts and determinants of health including sex, gender, gender identity, gender roles, gender relation, institutionalized gender, diversity, and equity (see Appendix A for a Glossary of Terms).

HIV and Hepatitis C (HCV)

HIV and Hepatitis C (HCV) are both considered preventable, communicable, chronic diseases (Hayward & Coleman, 2003). HCV is transmitted through contact with infected blood, which can occur through several types of contact, including sharing drug equipment, using unsterilized tattooing and piercing equipment, and some high-risk sexual activities. HIV is also transmitted through contact with infected blood, in addition to other infected bodily fluids. Modes of transmission include unprotected sexual contact with an HIV infected partner, sharing of used needles, and mother-to-child transmission during pregnancy. Although there is currently no cure for HIV, there are medications available to slow its progression and to manage symptoms. While an individual can be cleared of HCV infection, this takes time and regular access to treatment services. Further, liver damage may persist even after viral load has been brought to an undetectable level and reinfection is possible (CATIE, ND). However, preventing primary exposure to HIV and HCV is preferred, as it removes the possibility for negative health outcomes and the health care spending associated with treating these infections.

Vulnerability of Youth to HIV and Hepatitis C

Canadian youth are considered to be a 'vulnerable population' who are at risk for a number of communicable and non-communicable diseases and health conditions (Boislard, Poulina, Kiesnerb, & Dishionc, 2009; Uhlmann et al., 2014) including HIV and HCV. These risks are shaped by the environments within which we live, including numerous interconnected determinants of health and related structural factors (CPHA, 2014; Gupta, Parkhurst, Ogden, Aggleton, & Mahal, 2008; Marshall, Kerr, Shoveller, Montaner, & Wood, 2009; Rhodes, 2002; Strathdee et al., 2010).

However, many programs and services are either not accessible to youth or are not provided in a youth-relevant or youth-friendly manner (Goldenberg, Shoveller, Koehoorn, & Ostry, 2008; Shoveller et al., 2009; Shoveller, Knight, Johnson, Oliffe, & Goldenberg, 2010). For example, the findings from a Nova Scotia survey of youth showed that only 1-3% of youth who have engaged in sexual intercourse have been tested for STIs (Nova Scotia Roundtable on Youth Sexual Health, 2006). Core strategies to increase access for youth include the creation and implementation of

policies and programs addressing the specific needs of youth as well as the meaningful inclusion of youth in the development and provision of these initiatives.

Methodology

Overview

As a means of coordinating the analysis of interview and focus group data across all sites, the research team employed thematic analysis techniques described by Braun and Clark (2006). Inter-rater reliability was determined during team meetings whereby research team members worked together to compare salient (potential) themes identified during analysis at each site, across the interviews and focus groups. Research team members from each location shared their initial findings with the rest of the team. When a potential theme was determined in each province, the research team compared coded excerpts to determine how it related to the research questions. If consensus was reached as to how a potential theme connected to the research questions, it was added as a key theme. An overview of participant demographics can be found in Appendix B.

In-Depth Interviews

Interview participants were recruited through purposive and snowball sampling. Members of the advisory committee, policy trainees, youth-serving organizations, and HIV or HCV service organizations disseminated recruitment material through their respective networks. Potential participants contacted the Project Coordinator or Research Assistants (RAs) to arrange one-on-one interviews. Individuals were invited to participate in an interview if they were a government or healthcare policy decision maker, health service provider, educator, staff or volunteer for a youth-focused HIV or HCV service organization. Inclusion requirements also ensured that participants possess knowledge of HIV and HCV prevention policy or programming issues for youth, live and work within one of the four Atlantic provinces, and were sixteen years of age or older. The interviews were conducted by a research assistant (RA) either by phone or in person. All interviews were audio-recorded and transcribed verbatim and later analyzed using NVivo 10. A copy of the interview question guide can be found in Appendix C.

The interview codebook was developed collaboratively by the RAs and the principal investigator, and approved by members of the analysis team from each province. Each interview was coded by at least one member of the research team. Research team members from each province reviewed the coded transcripts from their respective provinces, and compared initial findings during a series of teleconferences for the purposes of inter-rater reliability. Research team members from Dalhousie reviewed select coded interviews from each other province as well. Each reviewer identified emergent themes within their set of transcripts, and shared these themes with the rest of the analysis team, including examples taken from the interviews.

Analysis of the interview transcripts focused on identifying gaps in youth-oriented HIV and HCV prevention throughout the Atlantic region. Emphasis was placed on exploring how gender as a social determinant of health and issues of equity pertaining to sexual orientation and gender identity were reflected in polices, programs, and the overall approach to HIV and HCV prevention experts. The data analysis was also intended to identify promising practices and lessons learned within each province, with the goal of adapting and employing them in Nova Scotia. In this manner, analysis of the interview data was focused on identifying “what is being done for youth?,” and “what could be done differently?”

Focus Group Discussions

The purpose of the focus group discussions was to identify potential solutions or strategies to address the challenges and barriers identified during the one-on-one interviews, and to solicit feedback from groups of HIV and HCV prevention specialists, service providers, and youth regarding key recommendations for promoting youth-oriented HIV and HCV prevention. In this way, the focus groups provided an opportunity to engage participants in solution-oriented discussions that responded to the challenges, concerns, and opportunities that were described during the one-on-one interviews. Focus group discussions were only held in Nova Scotia. A copy of the focus group interview guide can be found in Appendix D.

Focus group participants were recruited through purposive sampling. A balanced mix of representatives from community-based organizations, provincial and federal government health departments (including public health), service providers, and clients participated, provided that they possessed knowledge of HIV and HCV prevention policy or programming issues for youth, resided and worked within Nova Scotia, and were sixteen years of age or older. These individuals were provided information regarding the study and consent process, and a time and location was arranged for each focus group. All focus groups were audio-recorded with permission of the participants and transcribed, and then analyzed using NVivo 10.

The focus group codebook was derived from the interview codebook, and modified to reflect emergent themes identified during analysis of the interview transcripts, as well as the solution-oriented goals of the focus group analysis. Focus group transcripts were coded by one Dalhousie RA and reviewed with the principal investigator. Themes identified in the focus group transcripts were incorporated into the overall team analysis, with other members helping to integrate the two sets of data into a cohesive analysis.

Analysis of the focus group transcripts focused on identifying opportunities for applying the best practices and lessons learned identified in the interview analysis. The focus was to determine “what should be done?” rather than exploring gaps and barriers, emphasis was placed on identifying practical opportunities to connect organizations, make better use of existing resources, and capitalize on the knowledge, experience and success of previous and ongoing prevention initiatives throughout the region.

Findings

Inter-Organizational and Intersectoral Collaboration

Why does this matter?

Across all sites, numerous participants indicated that collaboration between organizations and sectors was a critical component of HIV and HCV prevention. Several participants pointed to a lack of human or financial resources or to an absence of in-house expertise as creating a need to collaborate with other organizations to maximize finite resources.

> *Participant 1: So it's really about… Because none of us have a lot of funding. And so it's really about trying to milk it [collaborations] for all it's worth to really make it work for those most vulnerable and the people that we serve.*
>
> *….*
>
> *Participant 2: You have to use all your connections. In this type of an organization, you have to use every connection you've made to see how much you can whittle out of them all to just get that little tiny bit of information out. [NS Focus Group 1]*
>
> *We've worked in collaboration with one university to evaluate one of our strategies that we've done, an online strategy with youth. And we worked with one university, a professor to evaluate the effectiveness of that strategy. [NB 2]*

Overarching Challenges and Barriers

The challenges participants described in many ways mirrored those identified in previous research both in the Atlantic Provinces and elsewhere in Canada. These include:

Policy: Existing policies and program standards can limit the types of services that are available (such as policies that prohibit the provision of anonymous testing in Newfoundland and Labrador) and limit the accessibility of existing services to certain populations (for example, sexual health clinics in New Brunswick have age restrictions). A lack of formal policies can lead to service fragmentation or improper service delivery, such as is the case with sexual health education across jurisdictions within each of the Atlantic Provinces.

Availability or accessibility of services: In many rural locations, sexual health services may not be available at all. In some cases, it was found that some programs may refuse youth on the basis of their age, therefore limiting access to sexual health promotion initiatives such as pregnancy prevention, treatment of sexually transmitted infection, and counselling.

Stigma: Youth may be reluctant to seek services or information from walk-in clinics or family doctors. This may be due to past difficulties discussing matters pertaining to sexuality, and/or the perception of stigma related to youth sexuality, HIV, HCV, drug use, or gender and sexuality.

Confidentiality: Youth may be reluctant to seek services in rural areas out of a fear of being identified by a health care practitioner known to them or their family. Youth may also be concerned about being identified/labelled when seeking service from AIDS service organizations {ASOs} or other specialized locations.

Awareness of the services offered by other organizations may allow them to shift or adapt their focus while ensuring continuity in the services available to clients in their community.

> *If you talk to [organization], they're going to tell you that they just got some funding to take over a piece that we [organization] are no longer focusing on. And they will be providing STBBI testing in the community or in partnership with the [clinics] to be able to access this group that we no longer service or see at the [organization]. So that means as long as we all know what we're doing for prevention of HIV and HCV that the client is the one who's going to access reasonable services in our community. [NB 4]*

Collaborations between different organizations were seen as necessary to increase service coverage to rural locations where access can be limited. In some instances, the 'small town nature' of rural communities was seen as advantageous in that it facilitated collaboration between organizations, which helped to mitigate the lack of resources and personnel.

> *And just being able to gather all that information, having opportunities to network, to collaborate, to share that information, get new ideas from other areas, I think that would be a great help. That's the key thing that I feel is important. Being able to address the geographic barriers so that community organizations, youth-serving organizations from across the province have the same opportunities to avail of programs and services that are available in [urban centre] is important... [NL 11]*

> *I think that speaks volumes to the resilience and the ability within small communities that are doing so much with so little compared to some of the bigger centres that we actually have to try to strike that balance [in collaborations] and say "how do we reach individuals?" [NS Focus Group 1]*

Partnerships offered a potential means of circumventing some of the existing programming challenges. In New Brunswick, partnerships between public health and after-hours clinics in some regions have been successful in responding to the changes in sexual health program delivery (i.e. change in target populations, along with change in sexual health promotion and STBBI prevention strategies or initiatives). This partnership allowed sexual health nurses and physicians to share up-to-date sexual health information on prevention strategies including counselling, treatment, and referral to important resources in the community. This partnership and transfer of sexual health-related services also allowed youth to visit a clinic with hours that did not conflict with school schedules.

Further, collaboration between organizations with different mandates may serve as a means of connecting diverse target populations with services that reflect their specific needs. This could be particularly useful for ensuring continuity of services for youth who face complex barriers to service access, such as stigma faced by LGBTQ youth. For example, a school-based health nurse may be able to refer an LGBTQ student to a sexual health centre for testing, and/or an LGBTQ youth-serving organization for ongoing social support. Accounting for services provided by different organizations could help to address gaps at one site (i.e. lack of testing at school-based clinics, lack of ongoing support at sexual health clinic) by ensuring transition from one site to another through direct referrals.

What are the challenges?

Many participants discussed the potential for collaboration as a means of bolstering HIV and HCV prevention, but it was also suggested that much of the ongoing work within the Atlantic Provinces was approached by individual sectors, rather than intersectoral partnerships. Although collaborations were undertaken by organizations as a means of expanding service coverage, few policy or programmatic supports exist to help foster these strategic partnerships, often making them unsustainable. Some organizations had difficulty initiating collaborative working relationships due to a lack of experience, funding, human resources, expertise and infrastructure to support ongoing partnerships.

> *I mean it ultimately comes down to having resources. And that's not just the money, but also the infrastructure that supports the development of these think tanks and projects, and can keep them going. So often you end up getting a group of individuals together that are really enthusiastic about something, but without actually having some support to keep that group going, it's challenging to effect change. And everyone is being expected from a community-based perspective now, all the organizations that get funding are expected to do more with less. And that's a challenge. [NL 10]*

An overall lack of formal policies can create challenges to developing and sustaining collaborations and can actively undermine collaboration. Shifts in the administration or changing mandates of organizations can further impede collaboration among organizations, as described in the findings below.

> *I think, and actually that will go back to, earlier you asked me the question about policies, because sometimes those policies, there are policies in place that make a collaboration very difficult to do. [NS 1]*

> *I very much in the last few years, we've been going out and talking to community members, being really active in the community, and that's starting to change, and they're starting to pull back our role and wanting us to have less communication with our stakeholders so that creates a challenge because if we're not able, I think how it could be expanded upon is to let us continue doing that but I think that if there's a risk that that's not going to happen because they're changing the way we're doing business. [NS 1]*

> *There has been some changes in [organization]. And while they are very receptive to me when I call looking for material and supplies if I need it from them, they're very good. But no, I haven't really been working closely with them since they've had the changeover in their administration. [PEI 2]*

Some organizations preferred to retain autonomy rather than partner with other services. In some instances, partnerships were seen as a potential threat to existing programming integrity and service focus.

> *And there were a couple of orientations in [province] that are… The [organization in another province] was like, oh, yeah, [collaboration] is a great idea. And ourselves and [province] and [province] are kind of like, you know, that's a bad decision, and we need to remain separate because we have… Of the organizations that they want to conglomerate together, we're the biggest and we're the most complex, so to speak. So it would affect our programming, it would affect our public engagement, I think. And there's a lot of people upset because we had a public session discussing this possibility, and people were just like, "No way." [NS 3]*

While many participants indicated a desire to increase meaningful collaboration with youth, few organizations had ongoing collaborations with youth-specific partners. Many indicated a desire for initiating youth collaboration or building on past or existing collaboration. Potential benefits of collaborating with youth-serving organizations primarily centred on increasing the resonance of programmatic responses with youth populations.

What can be done?

Participants outlined some strategies or resources that could be employed to support collaboration between organizations. These included developing a list of HIV and HCV prevention resources that health care practitioners and others could use to direct youth to appropriate services based on their needs and corresponding organizational mandates.

> *I think that there needs to be a collection of resources in one area. So I think there needs to be either listing. Which kind of do exist online a little bit. But they need to be more geared towards public health. And I think that it needs to be identified into what age groups resources are for ... And you know, even an outline in terms of your care A, B, C and D. Like nothing is concrete. Like when someone comes in my office and they're struggling with mental health and addictions, I don't have anything to say, you know, a) you start with counselling, b) you go to [addictions], c) then this is the next line … And it's different for everybody but there's no step by step approach. Which there's step by step with everything else. [NL 7]*

Intersectoral collaboration could also be supported through the provision of funding to offset the costs of establishing and maintaining collaborative working relationships. Funding was seen as necessary to ensure service coverage across provinces as a whole.

> *…So whether there is funding for organizations to travel across the province or whether it's funding to better collaborate amongst colleagues from across the province and develop programs together and implement those programs together that would help address some of the geographic barriers. [NL 11]*

> *…It would be really interesting to look at these programs [in other Atlantic Provinces] and see if they're adaptable to NB and see how we can put a spin on it. And looking at it from a perspective of youth and youth STI, Hepatitis C and HIV, and see if those two would jive. It would be really smart. [NB 10]*

Youth Engagement

Why does this matter?

Increasing the active participation of youth in the development and implementation of HIV and HCV prevention programs, and increasing youth participation in community-based organizations was a priority for many participants. Potential benefits for the organizations included increasing the reach of programs, bolstering their workforce or volunteer base and better reflecting the needs and preferences of the youth they serve. One strategy for increasing youth engagement was the suggestion of the establishment of youth secretariats.

> *Have a youth secretariat that advises, I do think we do need like a secretariat who really focuses on ensuring that a lot of these issues get to the table, that it's standard that if we're developing new policies and it's targeting a specific population, then we should have folks from that specific population in there. [PEI 3]*

> *When there's any planning being done around programs that are targeting youth, I think there should be youth on the committee to give their input as to their thoughts and their ideas on the issue. Because I think we should promote more peer counselling. Like have a train-the-trainer for peers [youth] to talk to their peers about these types of issues concerning sexual health and STIs… I think there's research showing that peer education works much better. [NB 14]*

Participants also expressed a desire to build capacity among the youth themselves. Participation in HIV and HCV prevention activities was described as a means of developing employable skills, bolstering self-confidence, and initiating career trajectories within community-based organizations or the field of health promotion.

> *I know that for starters, [organization], who does a lot of the education for the Atlantic region, are over the last few years ramping up peer education. And so they have training that they usually do once or twice a year, and put out a call to youth who want to be involved with peer education. So when [organization] goes to the communities, the peer educator is involved in actually doing education on blood borne pathogens or STIs in a comfort zone that's comfortable for them. And as they progress, then they make connections with [National organization], which is the [National organization], or they have a youth council there. So there's little carrots that they are able to provide for youth. [NS Focus Group 2]*

What are the challenges?

Participants indicated that a program or organization must be perceived as relevant to the lives of youth before they would engage. Currently, most program campaigns depict heterosexual relationships and heteronormative youth, and therefore fail to engage LGBTQ youth. Organizations that only publish heteronormative material would not be seen as creating a welcoming space for LGBTQ youth.

> *So it is mostly targeted towards heterosexual gendered people. So just in thinking about some materials that have been created, they do depict heterosexual couples. The [program] committee is working to create materials that are sort of LGB neutral. So they will depict same sex relationships. But in terms of gender non-conforming people, gender diverse people, there's no real programs that target that group …[NL 11]*

Participants also indicated that some youth were prevented from accessing HIV and HCV youth-serving organizations, and/or harm reduction or sexual health services (such as HIV and HCV testing, needle exchanges, and condom distribution) due to a fear of being identified, 'labelled' or 'outed' based on interacting with these organizations. This was particularly relevant in small communities, where concerns pertaining to confidentiality were seen as particularly pressing.

> *Because I feel like sometimes people won't come to you because of that stigma. You know, "Oh well, I don't want to go that support group on HIV because then people might know that, you know, I have HIV or somebody close to me has HIV". We're finding stigma is a huge barrier. [NB 3]*

> *If someone comes in here, they're often afraid that they may run into their best buddy who's actually using injection drugs, and they haven't told each other yet. But they meet each other coming up and down the stairs with a bag of new needles and then all of a sudden the cat's out of the bag more or less. So they're really, really nervous about where they actually go so that they won't be labelled. [NS Focus Group 1]*

When engaging youth in program or policy development, it is important to ensure their contributions are meaningfully incorporated.

> *I think part of it is listening to what youth have to say and using what they have to say to inform your programs. Because sometimes people will have focus groups and listen to youth, and then they'll just go off and do whatever they originally intended. And whatever youth gave feedback on was never included in the priority or the program. And that affects youth because they're like, well, you know, I said my piece, and you know, this is valid but no one acted on it... [NL 16]*

What can be done?

Educational and promotional materials should depict diverse youth, and care should be taken to ensure that wording does not exclude specific populations such as LGBTQ youth or youth who use injection drugs. Where possible, developing such materials collaboratively with youth from diverse backgrounds may serve to increase its resonance with these sub-populations of youth. Simply put, youth can provide an insider perspective into what will appeal to their peers, and the kinds of information they would benefit from the most, while striving to acknowledge issues of diversity.

> *…usually our youth come, you know, to our organization and they have no knowledge really about how HIV or even HCV information applies to them because it's presented in a way that's so heterosexist that even if the information was relevant to them, they don't*

necessarily pick up on that or it's not made obvious to them. In this kind of transmission of education or information, it's presented in a way that doesn't seem accessible to them, I think on the whole. So they come in and ask, 'What about me? How does this apply to me? How can I keep myself protected and safe? And is it different if I'm queer or trans?'. [NS 6]

… And our workshops are actually gender neutral, as is our information pamphlets. We're in the process of revamping that information just to make sure that it is trans-inclusive… [NL 11]

Such efforts necessitate consultation and collaboration with youth to determine what they need to learn, how they wish to be engaged, and the kinds of messages and formats that will capture their interest.

I think we'd need to make sure that the testing programs were in place and that they're easily accessible, that youth can drop in, and that they're friendly and inviting, and that some of the services and stuff are actually designed by youth. I think sometimes we think that failure of people to access a program means that we didn't need the program. When it might mean in fact that we just didn't design the program in consultation with the people we were hoping to serve. [NB 1]

… And I probably should have mentioned this earlier but we are engaging gender non-conforming youth from our various groups. They are the ones that are assisting us in ensuring that our materials are trans-inclusive. [NL 11]

Games and creative or arts-based activities may also be effective means of engaging youth. These activities may make youth more comfortable, and more responsive to HIV and HCV prevention messages.

…in [PEI], they've developed a game that they play with the youth on being able to talk about what's safe and what's at risk around HIV and HCV. And so they engage youth in a manner that essentially just makes learning fun. And the questions that we see that get opened up in that presentation versus when we have a [health practitioner] come in, it's not matchable. It's a significant difference in just how comfortable the youth are in opening up and talking." [PEI 4]

… And [they] carried out a project where [they] went into the community and had the youth do artwork around AIDS and prevention and things. And then they took it and had t-shirts made from their artwork. And it was drawings and sayings. I remember one saying in particular that really caught people's attention… [NL 9]

They developed a program where the public health nurses would deliver education to the classroom about chlamydia. Then each student was given a paper bag with a bottle, and each student had an appointment privately with the nurse. Nobody knew and they had to return the bag whether they had peed or not. Everything [HIV/HCV testing] was done non-nominally and it was a great way to get to youth. I think that's very important because a lot

> *of youth view sexual activity as something that their parents would not approve of, so they want to keep it hidden. And I thought what a great way for youth to access the service. It was definitely youth-friendly. So a program similar to that, I can see that working with youth. But once again, you would have to work in collaboration with the school so that these could be implemented. But I thought that was an ingenious idea. [NB 13]*

Organizations wishing to solicit youth input on policy or program development for HIV and HCV prevention should consider ways of doing so through creative activities such as poster or video contests, particularly where there is an incentive for participation. Incorporating educational or outreach activities with fun activities such as bingo or yoga may also prove successful at capturing the attention of youth audiences.

Peer-led programs may also provide an excellent means of reaching and engaging youth, and in ensuring that messages are perceived as relevant to their lived experiences. This can be achieved by inviting youth guest speakers to talk about their personal narratives. Youth may perceive information delivered by their peers as being more credible and more relevant to their own lives.

> *...a lot of youth find themselves invincible. And to kind of put a face to someone with HIV and to know that this could happen to them. That it's not just this distant disease that was only heard of in the 90s. I guess it is a reality and it could happen to them. [NS 5]*

> *I find when the older guys get on, they're great guys, it's just the youth don't listen to, you know, it's quite interesting actually. I mean they do listen but I mean they're still not as engaged as when a younger person gets up. [NS 3]*

> *Those that have the necessary [sexual health] education have a good self-esteem, and that's mental health, right. We see that in youth-led school program initiatives and they're not embarrassed to say they've never had sex, and they're in grade 12. This is very empowering because, you know, these are the leaders of the school. [NB 13]*

> *Young people, you need to… Youth need to talk to youth. No one is going to talk to some old man that's… You know what I mean? [NS Focus Group 3]*

Materials and presentations should also be presented in a language that youth understand, and that resonates with them. Colloquial terms, even slang or swearing, can be more effective than using medical terminology that is unfamiliar to (some) youth.

> *… I remember there was a [health practitioner] who put together these presentations on STIs for youth, and it was so like textbook, medical. I'm like people don't call it sexual intercourse. It's sex. You know, things like that. Or even saying, like you know, if you're fucking. Like [staff] uses terminology that grabs youth and that grabs people. And when you're talking with youth, like they are going to swear, they're going to use slang. And any time you can talk to them on the level, they get it. [NL 16]*

Using social media, including phone and internet-based approaches, could also be effective means of engaging youth populations. Further, as many youth are proficient with social media platforms, this also represents an ideal opportunity for youth to contribute to HIV and HCV prevention programming. For example, youth may be able to provide insight and help with establishing a social media presence or the design of a social media campaign. Furthermore, social media may help reduce barriers in access to HIV and HCV prevention information, particularly among youth living in rural areas. Social media may also prove effective at disseminating information (such as the location of testing services) and helping youth connect with necessary services while preserving confidentiality.

Testing: Accessibility and Confidentiality

Why does this matter?

When speaking with participants who were involved in providing or promoting HIV and HCV testing services, it was suggested that access to testing, particularly anonymous testing, was a significant barrier across the Atlantic provinces. While many youth preferred to seek testing at dedicated sexual health centres rather than emergency rooms or walk-in clinics, these services are not available in the majority of rural communities. Further, anonymous testing is not available in Newfoundland and Labrador or New Brunswick. While it is available in Nova Scotia, it is currently only available at two locations.

What are the challenges?

Participants indicated that many youth were hesitant to seek out testing at non-dedicated service locations such as emergency rooms or walk-in clinics, or from family physicians who also provided care to their parents or other family members. This was also a potential barrier for youth accessing HIV and HCV specific services, especially in small communities and rural areas where "everyone knows everyone else".

> *And many times the nurses, you know, some of them have worked in the same clinic for many years, and know the families and know the people in the community. So those type of testings would definitely, you know, probably cause someone stress to go get the testing done. [NL 9]*

> *I've heard from youth, where we live… You know, in [PEI], everyone knows everybody. So if a youth wants to get medical help, get medical treatment, get medical advice, anything like that, it's very, very difficult. [PEI 3]*

> *They may feel uncomfortable with concern [about] maintaining confidentiality in a small population. We do find sometimes that youth, because they… You know, if they have a family doctor in their family, they don't want to go to that physician. So they might go to a sexual health clinic in [another province], you know, of their own volition. [PEI 5]*

When these locations were available, the concern was that youth would be labelled or stigmatized if they were seen at a known HIV service location. The stigma experienced by LGBTQ youth was seen

as compounding the stigma associated with being perceived as HIV positive. Individuals already lacking in social support were reluctant to seek testing due to a fear of being further marginalized.

> *… So you know, there's the stigma around HIV but then, you know, you hear from folks like within the gay community. It's hard enough to be gay in [Newfoundland and Labrador]. To be gay and have HIV is extremely prejudicial and there's a lack of support here for those individuals. [NL 10]*

> *… Stigma is so strong and discrimination. If we would address issues of stigma and discrimination from a program perspective it would make it easier to work with youth. I mean stigma is just... You know, why don't people get involved with AIDS organizations? Stigma, stigma, and discrimination it's just overwhelming. So I think that until we can sort of normalize somewhat access to testing and make it easier, we're just going to continue making it harder to access. Saying, no, you need to go to your family doc or to one of those walk-in clinics however, nobody really wants you at those clinics. Not for that sort of thing because there's no follow-up. [NB 1]*

An additional barrier to testing was related to fear that youth may have about experiencing stigma enacted by health care providers. Concerns regarding the perceptions and attitudes of health care providers can create barriers to both primary and secondary HIV and HCV prevention efforts.

> *… When you're talking about secondary prevention, you know, there are a lot of issues with people having privacy concerns and the concern with the confidentiality of their information and of their status even in their community. There are individuals who don't even want all their healthcare providers to know that they're positive…. [NL 10]*

> *And also the other issue that we have is that the province is trying to make HIV kind of part of regular testing become inclusive. In other words, trying to teach the physicians or the family doctors that if a patient asks for HIV testing, they might not tell you the reason why. Actually someone went to a family doctor and with her normal routine blood work, she asked to get tested for HIV. And the answer was, "You don't need HIV. I know you and your husband," like as though I'm going to tell you I got an affair, you know. So it was the perception that, this is an at risk person, this one isn't. So there's a lot of prejudice and stigma still surrounding HIV testing. [NB 13]*

Personal knowledge and relationships between families and local healthcare providers were perceived to sometimes negatively impact an individual's ability to obtain HIV or HCV testing. Health care providers familiar with an individual might assume that they are not at risk of exposure to HIV or HCV and therefore discourage testing. Families with shared health care providers were also perceived as negatively impacting testing uptake due to concerns that confidentiality could be impacted, particularly among younger aged youth.

What can be done?

Many participants indicated the need for additional education and information among service providers about HIV and HCV in general, as well as the need to recognize the potential benefits of normalizing HIV and HCV testing. Significant provincial awareness efforts on HIV normalization are presently being carried out by public health targeting health professionals such as family physicians and nurse practitioners in New Brunswick. The purpose of this initiative is to make HIV testing a part of routine checkups, which will decrease the stigma surrounding testing or discomfort in asking for testing.

> *…Again, I try to encourage youth to understand that if you are at risk for one STI, you certainly could be at risk for others. And we really try, this year especially, to take that as somewhat of a normalizing. That it's not just this person that gets tested for HIV but there may be... You know, it may be good to know your status regardless if you're sexually active. [NB 7]*

> *We were in the process of developing a provincial program for trying to get physicians and front-line staff to be trained so that they could be friendlier towards that particular population [LGBTQ], especially the high-risk population. Unfortunately there was not enough time to do this program so it never got started. So we're still hoping that it will be delivered, but I am not sure… [NB 13]*

Increasing the availability of different types of testing, such as point of care testing and anonymous testing, may also promote increased testing uptake, particularly in instances where concerns surrounding confidentiality and the fear of stigmatization act as barriers to testing uptake rates.

> *And that's a huge barrier. I mean as long as we have stigma around HIV, people are not going to want to get tested. We've got to normalize it somehow. And by offering point of care testing, it's one way to help normalize it. [NL 10]*

> *I think just people wanting to protect their own privacy and not wanting to be a part of… You know, they have to give these codes that identify themselves or MCP or their SIN or whatever. They don't want this HIV thing to go into the part of that big system that they don't understand. So if they can just do it without having to hand over their wallet or whatever, it's a bit more impersonal. So I think in a way, youth might fall into that … They don't want their parents to go to the doctor and open up their file. Or whatever belief they might have, it might be subsided a bit by making it accessible by not having to give all that personal information at the beginning. [NL 12]*

Anonymous and point of care testing were seen as more effectively meeting the needs of at-risk populations such as street-involved youth and youth who use injection drugs.

> *I found that the belief was that anonymous testing would benefit at-risk groups. So those in the minority, of diversity category, I guess, would benefit the most from anonymous testing. And also one of my [contacts] referred to her repeat [service users] and talked about people*

> *who come in always looking for testing, and it's the people who are low on the education, income scale, injection drug users, you know, taking risks with drug paraphernalia and sexual activity. [NL 12]*

Increasing the number of testing sites, rather than focusing solely on anonymous testing, was also identified as a potential solution in addressing this gap.

> *There's lots of people who come forward and say, well, you know, you really ought to have anonymous testing because you'd get more people. But I don't know that that is necessarily the barrier. I think that the barriers we have are more structural in terms of the number of clinics we can run or the number of places we can run a certain kind of clinic, the number of staff we might have available to do testing or engage youth in discussions and things like that. So the discussion around anonymous testing I think tends to be a bit of a distraction. [NL 14]*

Both of these goals could potentially be met by instituting additional locations, and/or by changing policies to allow for the provision of testing in a wider variety of settings. Rather than limiting testing to sexual health clinics, walk-in clinics and hospitals, broadening testing locations and types of testing could help youth avoid being stigmatized for seeking testing in these settings. For example, providing testing along with other general health services at school health clinics or youth health centres could allow youth to discreetly seek testing. Some nurse practitioners in New Brunswick have employed this strategy, moving from public health offices to health clinics in high schools. While at present nurse practitioners cannot draw blood in New Brunswick schools, they are partnering with school districts to expand the range of HIV and HCV prevention interventions that can take place. Mobile testing and sexual health programs were also suggested as strategies to increase the availability and uptake of testing. For example, mobile needle distribution programs have proven highly successful and provide a potential venue for administering testing. The support of policy makers would be required in an effort to implement changes in existing policies that prevent organizations from offering anonymous testing.

Harm Reduction: Providing Condoms and Clean Needles

Why does this matter?

Harm reduction was seen as an important part of HIV and HCV prevention by our participants. Providing non-judgmental and/or confidential services such as needle distribution and free condoms were particularly important as they provided options to youth that helped them lower their risk of infection.

> *... So by taking a harm reduction approach, you're providing people with options, and they're able to decide what the best approach, the best program or policy is for them for their own personal selves …. It helps them feel like they're not being judged … So like the [harm reduction] program is a good example. It acknowledges the fact that there are going to be people that are going to be using IV drugs no matter what policies, laws are put in place. So it just does allow people to access those programs. And because they feel less*

judged, it is easier to provide them with other information that they might need. In terms of the school system with their condom policy, by providing that information and by providing… Well, just in general, just by providing condoms, you're offering a harm reduction policy. So it does acknowledge the fact that there may be certain risks with certain sexual activities, and that condoms can help lower that risk. So you know, that's one way that harm reduction is being put into place. By having the curriculum in place, it's expanding on it by providing people with information that they need to reduce the harm, possible harms. [NL 11]

What are the challenges?

In some locations, harm reduction services were not available at all.

And like I don't know, also there's like coming from [Central Canada] where there are like condoms in every bar. You go to a bathroom in a bar, and there's a bucket of free condoms. And like especially in the village. Like the village area is full of condoms. And in the [social venue] here, nothing. [NL 3]

When harm reduction services were available, youth often faced barriers to accessing condoms or needles resulting from stigma related to youth sexuality, confidentiality, and/or a lack of knowledge about existing services.

It's still like a lot of stigma around sexual health. You know, people don't talk about it openly in our communities. And I mean the young, 14 or 15 or 16 or whatever, I mean we know that the age of youth having sex are much earlier. They're not going to go to the clinic. They're not going to go to the clinic looking for condoms. [NL 9]

Well, right across the province, access to condoms is a bit of a barrier as well. As I mentioned, some people do find it difficult to go to stores to buy condoms. [Organization] does get requests from people outside of the [urban centre] region that aren't able, due to the distance, aren't able to come to [organization] to pick up free condoms. So they request that [the organization] send them condoms. They're not able to go to the stores and pick them up just because they may know someone that works at the pharmacy. And I am speaking mostly about youth that contact [the organization] this way. You know, they know people that work at the pharmacy. So accessing condoms at a pharmacy is a barrier for youth. There's also the financial barrier piece because some youth don't have the funding. So I guess just offering…having those opportunities where free condoms are available to the youth is needed. [NL 11]

Just because a youth health centre nurse keeps a thing of condoms right on her desk doesn't mean she's increased access 100% because there are some kids who just won't even…[NS Focus Group 2]

Participants suggested the most pressing challenge to harm reduction initiatives was the current political environment, which was seen as actively opposing harm reduction-based initiatives.

And I think also to think about the whole term harm reduction or risk reduction… I like to call it risk reduction because I'm always trying to get around the federal government because now they won't fund harm reduction … If you put harm reduction… If we put harm reduction in our proposal, we probably won't get funding. If we put advocacy, we probably won't get funding. But if we put public engagement instead of advocacy, it fools the [Federal Government] and [Federal Government official] and all them because they don't want what public engagement is, I don't think. But anyway, that's the way it is. [NS Focus Group 1]

So when you look at that, when you look at the harm reduction terminology, and they think, well, harm reduction is providing condoms so they can have sex, or providing new needles so they can shoot up the drugs, or whatever. But when you look at sort of from a risk reduction or minimizing the level of risk. [NS Focus Group 1]

We don't have that resource right now. So the thing is that as far as I'm concerned times are tough and I don't think this government and this [department] has any money to spare, and I don't think it [prevention] is high on their priority. I also don't think hepatitis C and HIV is very high on their priority. Because for one thing, the government don't have the resources, they don't have the money… Like in the provincial and federal prisons, you need doctors and nurses to be in regularly to follow these inmates because they are usually there for 2 years or less. But again they do not have the resources… [NB 10]

Federal and provincial law, institutional policies and public opinion were also seen as barriers, particularly in relation to youth-oriented harm reduction initiatives.

Because again, because I can't… Because [Federal Corrections department] says you're not allowed to do drugs, right. So if you do drugs then I have to do something about it, right. Be that give you treatment or send you back to jail. … we're always saying, go use a clean needle, don't use dirty needles, don't share needles…. But unfortunately we have to act. And I can't say, "Hey, there's a clean injection site, and I'll keep you on the street". [NS Focus Group 1]

Yes. And like I say, it's very conservative here on the east coast. Other provinces have, you know, harm reduction specialists who work with Public Health. We don't have that here. [NS Focus Group 2]

I must say I think that one of the big areas that I stumble with … is not being free to … give youth … condoms … And I'm just not allowed to do that. And I find that that's a shame. And I that that's a big barrier. I can give them all kinds of information, I can give them directions on where to go get what they may need, but I can't give it to them. [PEI 2]

…Clean needle than use a dirty needle and possibly contract HIV or Hep C. With harm reduction, not everybody I find understands that philosophy and they're not as open to it. So then they feel that, you know, you're just encouraging it. When we're not. ... We know you're going to do it. So if you're going to do it, please do it safely. [NB 3]

And a lot of people misunderstand the term harm reduction. If you don't understand it and then you really get bent out of shape because a particular group is actually providing services around harm reduction, you can really get into a lot of trouble when it comes to your funder or your neighborhoods or wherever your office is because if your neighbors find out that you're actually giving needles out or giving out free condoms out, with the mentality, they basically say, oh, we're just encouraging that kind of activity. [NS Focus Group 1]

What can be done?

While some participants indicated that condoms could be distributed in an informal or unofficial capacity regardless of institutional policy, most agreed this made distribution difficult. Legitimizing and supporting the distribution of condoms in schools would help ensure the promotion of accessible harm reduction services. Helping youth locate and connect with harm reduction services could be done during interactions with health professionals, or during community or school-based education programs.

…I will inform them [youth who use injection drugs] where, if they have to have new needles, where they can go to get them. And so I don't see that as a barrier either. You know, I don't know that it's as publicly advertised where these needle exchange sites are. And that might be a bit of a barrier. [PEI 2]

Participants also suggested that educating parents, and the public more generally, to change existing perceptions could be an effective way to promote the availability of HIV and HCV harm reduction services. In this regard, participants described instances where the sharing of personal experiences, particularly of those working in related fields, helped to shift perspectives. This type of approach may be useful on a larger scale.

And then I asked my father who grew up in [Ontario town] and he was on the drug squad there. So he was undercover [police officer] dealing specifically with hard drug use and stopping it. And I'm like, "Well, how do you feel about the fact that we give clean needles to intravenous drug users?" And he said, you know, "They're going to do it. They're going to do it anyway. Nothing is going to stop them. So what you're doing is a good thing because…" And it totally switched my mentality from it because I went from being uncomfortable with it, I'm like are we encouraging this behaviour, to having somebody who has gone through hell and high water to try and stop the problem. I'm going, well, no, they're going to do it anyway. You're stopping other things. [NS Focus Group 1]

Research, including cost-benefit analysis, could be particularly effective at changing the opinions of public health decision makers regarding HIV and HCV harm reduction initiatives.

Participant 1: There's gaps in funding to provide any services.

Interviewer: To provide which kinds of services?

Participant 1: Well, harm reduction.

Participant 2: Yeah, someone needs to do a cost benefit ratio in terms of Hep C rates.

Participant 3: Yes, what it costs the province. And that way they would understand it. [NS Focus Group 2]

Education and Information: Youth, Parents and Providers

Why does this matter?

Providing youth with information on HIV and HCV risk factors represents an important component of primary prevention. This information can help correct misconceptions (for example, that HIV is only a "gay man's disease") held by many youth, parents and some healthcare practitioners regarding HIV and HCV that lead to risky behaviours.

So I think especially addressing these issues younger, if we can do with more health promotion education among youth about sexual health and how diseases are transmitted, and give them the tools to empower them to make educated decisions, I think we'll see a lot less… If we're hitting them early, we're going to see a lot less complications. If they know how to prevent getting HIV and hepatitis then they hopefully will be at a lesser chance of contracting it. [NS 4]

They should be offering education. I think education is a huge piece. First of all, many youth are unaware of their rights and unaware of HIV policy, and unaware of testing. [NS 5]

Our culture here is very conservative, I believe. So the more information we can disseminate to our students, the more we can increase the students' awareness and how comfortable they are with the subject area. Giving them current information and allowing them to critically think about best decisions is part of the role. And to allow teachers to feel comfortable with the material as well. [PEI 3]

Information pertaining to the types of services available and the locations of these services represents an important component of secondary prevention, as youth who are living with HIV or HCV require specialized information, services and support to remain healthy and prevent secondary transmission.

What are the challenges?

Participants indicated that there was considerable variability in the quality of sexual health education delivered in classrooms across the Atlantic region. While guidelines may exist regarding the material that should be taught and offered in schools, the actual content available for youth varied from school to school and from class to class, based on the comfort level of the teacher in question and sometimes on the comfort level of the school principal.

And it used to be luck of the draw, from what I can tell from students it seems to be luck of the draw at the high schools, who teaches the health class right...Right so I'm not sure how

people are selected to teach the class but there seems to be pretty big variability in terms of how that programming is delivered. [NL 1]

But I know one of the problems we've had is there's education within the school system has often been kind of sporadic and it hasn't really been consistent, and there's nothing… There's no guarantee that the education within the curriculum, within the actual school curriculum, if there's anything HIV-specific in there. [NL 13]

Because when you start to look at curriculum-based programming, and you look at a lot of the issues that we're talking around risk reduction or harm reduction, whether it is around sexual health or injection drug use or addictions or any of those kinds of things, we know that the present system in the school, most of those issues are taught by [Personal Development and Relationships, Career and Life Management, Physically Active Lifestyle] teachers who are really French, English, math, science teachers who have a free period … You're probably going to get stuck with teaching grade 8 PDR, which is talking about relationship building, unsafe sex, masturbation, whatever. And then you're not going to feel comfortable … And we know that HIV in particular is supposed to be talked about in grade 3 up, but is it being done? No, it isn't because a lot of those teachers don't feel comfortable. So then by the first of June, they start to say, "Oh, I have to do this. I better call in the troops." [NS Focus Group 1]

… I think that it [sexual health promotion initiatives] depends… it depends on the principal. There's really not a policy, you know. If a principal is comfortable with having condoms or different types of sexual health education in the classroom then you seem to be able to make some headway. If you have someone that culturally wasn't comfortable with the topic then it really wasn't happening. Condom machines are certainly not in the middle schools, even though kids are having sex in middle schools... it's at the discretion of the principal. It's a cultural kind of thing… I find if they've got a Francophone descent, they're a little more attuned to kind of addressing sexual health stuff [earlier]. … but it may also be a religious thing. [NB 12]

Further, in some instances the objections of parents limited the ability of schools to provide education on some important health promotion topics, including HIV and HCV prevention.

I'm not going to say a number because right now it's being discussed a lot because not everybody is happy about all the services that are being provided in high schools. You know, sexual health is very sensitive. So if you go in a school and you do counselling regarding abortion, for example, when a parent knows about that and the parent doesn't want to hear about that. So you see, that's a problem we had in high schools. [NB 2]

Educational and prevention information delivered from a heteronormative perspective was indicated as failing to engage LGBTQ youth, as this messaging did not reflect their needs, their identities, or their experience of stigma and discrimination.

… Again, though, sex is [not] really talked about in the schools at all. Or if it is, it's more like I guess your traditional, you know, vaginal intercourse, not anything beyond that. [NL 16]

Actually now that I think about it, LGBT youth have spoken to us about the fact that the curriculum does focus mostly on heterosexual gendered people. And I have heard from LGBT youth that have spoken to me about how when that information is provided to them, they aren't necessarily able to assimilate it into their own lives… [NL 11]

I think because LGBTQ youth are traditionally under-served in a lot of healthcare areas, including things around prevention around HIV and hepatitis and all of these, everything really, our education piece kind of comes in giving youth resources that are relevant to them and relevant to being LGBTQ. Because I think a lot of times youth don't get the accurate kind of health information sometimes based on their identity. So our education piece comes in giving youth the right information when it comes to meeting their health needs. [NS 6]

But they should provide more information about HIV... They could do more for the LGBTQ population but they don't because it's such a taboo topic... Because people think that it's something not... there's a lot of prejudice attached to HIV and gay men... and we don't have any education about it. I mean … and I have never seen a booth or a session or an education about HIV [at the university]. The same thing when I was at school, nobody talked about HIV. The only thing when they said about HIV, it was when I was in grade 10. So 7 years ago, the teacher said that gay men get HIV. So that's also going up with prejudice about gay men. [NB 11]

These gaps in HIV and HCV prevention messaging were perceived to contribute to youth engaging in risky sexual practices due to a lack of understanding regarding risk factors and harm reduction strategies, such as condom use or safe tattooing.

… I've heard of youth that were not aware…that they knew that condoms should be used for vaginal penile penetration but they didn't realize that condoms should also be used for penile anal penetration. And it was just because of the way the information was presented to them. Where with so heteronormative that only penile vaginal sex was being discussed. [NL 11]

And I know this from working with the community youth network, anal sex is quite common. Well, there's issues around anal sex, and people don't know that. Or even talking about LGBT sex, I mean I really don't think that's necessarily happening in the curriculum. Or access to condoms. [NL 16]

Youth may not perceive information provided by adults as being relevant to their own experience. For example, street-involved youth and/or youth who use drugs may be particularly hesitant to trust older individuals on the basis of negative experiences in the past.

But like I'm sure if you brought in just some random guy off the street, you know, all scruffy and everything, he goes in and says, "I have hepatitis C from shooting up," like kids aren't

> *going to give a shit. But if you bring in someone like me who's like 4 years like out of high school or whatever, and like you know, doesn't look like a bad, you know, out of whatever. And I went in and said I have hepatitis C because I took these…you know, I did whatever wrong or whatever. And that's what's going to make kids realize. They're not going to listen to some old scruffy old man who they don't relate to anyway. [NS Focus Group 3]*

Participants indicated that the majority of sexual health education, including HIV and HCV prevention, took place in school settings. In school settings, youth may be reluctant to open up to teachers, school staff, or administrators to seek information where gaps in sexual health education exist. Further, the perception of teachers as authority figures may make them less appealing as confidants.

> *And when the teen health centre nurse was there, those girls… They gave information but you could tell they were holding back. She probably about halfway through told us that she wouldn't be there the next 2 weeks, that she would let the principal know that it was all right for us when we got there to go up. The room would be open. If not, somebody could open the room up and let us in. And those 2 weeks, the information that came out of those girls, it's just like they vomited. It's just everything came out. We were finding out about abuse, we were finding out about how they were involved in sex. We got lots of information. So they felt safe enough to tell us but they didn't feel safe enough to tell us when there was somebody from the actual school there. So we've learned now that if we do go into those places, we have to try to figure out how to get the school authority out of the room. [NS Focus Group 1]*

Participants reported that HCV was either not discussed at all in youth-oriented education, or if it was discussed, the full range of risk factors and prevention strategies were not delineated.

> *Interviewer: Do you talk about harm reduction in that sense at all? So for example, with needle use?*
>
> *Participant: Not specifically. No, we really don't. And I know we do have like needle exchange programs here in [PEI], and such. But how broadly and how deep that conversation happens, it probably doesn't in our health curriculum. [PEI 3]*
>
> *… in terms of like sharing toothbrushes or like nail clippers, things like that even. You know, people aren't learning about any of this, you know, the hygiene piece… [NL 16]*

In addition to these challenges, adult participants indicated that information regarding testing, secondary prevention, and treatment services was often completely lacking, making it difficult for youth to connect with secondary and tertiary health care services.

> *I feel as though we do need to get better with our education, especially around HIV screening and education and prevention. [NB 3]*

…the sexual health education that people get in high school is so much more about primary prevention that that seems to be more out there and easily accessible but, well you know this sort of stigma about talking about secondary prevention, when you're talking to teenagers like oh my god you can't possibly assume that…. I would say that access to information on prevention, that's fairly clear, but that's fairly easy to find. But what programs there might be, that's harder to find out about. [NL 1]

And obviously in the school system, they're going to focus on abstinence. And then the next level down, condoms. And that's great. And then you're encompassing everything. But they're also not talking about, you know, who is affected now, how that changes your life, all these things that can happen once you get diagnosed with HIV. So yeah, I think there's a big gap for that in the school system right now. [NL 8]

Youth participants, on the other hand, felt that education focused on secondary prevention rather than primary, particularly once youth became infected with HCV.

Female Participant 1: They don't really teach you anything about prevention. But once you've got it, you know everything about it. That's when they educate you.

Female Participant 2: Yeah, once you have it.

Female Participant 1: After you have it. [NS Focus Group 3]

What can be done?

When providing HIV and HCV prevention education to youth, it may be useful to employ peer educators. According to our participants, youth may feel more comfortable confiding in other youth who are similar to them in age, who have had similar experiences, and who can embed prevention messages in the lived experience of youth.

…that seems to be from also what I hear from the organizations we support their biggest challenge, they still need to be doing education in the schools, although apparently I've been told, that education in the schools doesn't really work. I know that sounds awful, education, I'm making a very broad statement there, that that type of, HIV and Hepatitis-C doesn't, isn't necessarily the most effective way to get the information to youth. How it is, is a good question to me. I think all peer-based learning is a good idea and also, I have for what does seem to be successful is people going in and talking about their personal experiences so that they can actually see oh there's this person who has, living with this disease, yes they are still alive and fine but if they explain their experiences and some of what they've been through it might make it a little bit more real for them. [NS 1]

There's been implementation where grade 12 students would do presentations in schools with the younger population, and became more or less mentors. I know the program existed when I was there, but I don't know if they're still doing it every year... there was discussion on healthy sexuality given to grade 9 students with a purpose of talking about STIs and

birth control. The program was led by grade 12 students. So that when there was a discussion, they would have the grade 9 students speak with the grade 12 students as their peer mentors. They could also keep going to see them if needed. This program worked quite well actually and there was emphasis from the teachers… It was a big deal that teachers really wanted to make sure that the grade 12 students never talked about their own sexual experience but more on a general perspective. They didn't want it to be, well, you know, like I started having sex in grade 9. You know, that kind of stuff... They just wanted them to be there as a peer mentor. So if somebody, for example, got pregnant, you know, the peer mentor might do the leg work that was needed, like where can she go? So that worked quite well. [NB 13]

Involving youth as peer educators also represents a means of helping youth develop employable skills and develop connections with other organizations, and to build organizational capacity by fostering the interest and expertise of youth colleagues.

Participants recommended that sexual health education be outsourced to organizations specializing in HIV, HCV and sexual health. Guest speakers were regarded as able to command needed attention from students, making prevention information more impactful.

… And you remember it because it's not just your teacher who you talk to everyday, it's somebody new. You know, you're being really polite because it's somebody new. You're actually like this isn't going to be on a test. Like I can listen and actually learn for my own enjoyment. So I think it's really important to learn from people who are not your teacher… [NL 8]

But my main point is that every time I spoke to any class, they were always quite enthused with it and always…and afterwards would always come up and thank me for the talk and everything. So I think still school visits are…you know. Especially people who are either HIV-positive or Hep C-positive, going in and talk, I think that really hits home a lot. [NS Focus Group 4]

However, youth participants suggested that guest speakers might be perceived as less credible or relevant if they were older, as opposed to of a similar age as the audience in question. Ensuring that both the messages and the speaker delivering them resonate with a youth audience could be difficult given that different sub-populations of youth require different kinds of information, and might respond better to different speakers. Presenting a variety of speakers might be most effective.

Participant 1: I think having a range of different people, of different races and genders.

Participant 2: That's a good idea. Having a panel. [NS Focus Group 3]

Participant 3 Yeah, I think, you know, you need to get it in different ways because you're kind of targeting different groups of youth, you know. I mean the youth that I'm sort of familiar with would be the youth that are on the streets and things like that, you know. And

> *a lot of them, they are getting more of an opportunity to get some education. But you know, youth that are in schools, this is not stuff that their parents are probably talking to them about. And the teachers don't want to talk to them about it. And it's kind of just everybody is in denial, you know. Saying like, "Oh, my children aren't at risk." You know what I'm saying? But the reality is they are. [NS Focus Group 4]*

Participants indicated that the social stigma associated with youth sexuality, a reluctance to discuss sex and sexuality, and an adherence to the belief that youth did not engage in risky sexual or drug use behaviours were barriers to effective HIV and HCV prevention. These beliefs, when held by parents, school administrators, teachers, and policy makers, limited the extent to which educational materials could be delivered in school settings, or explicitly target youth. As such, participants suggested that HIV and HCV education programs targeting youth should also work with parents, policy makers, and the public to address social stigma and change negative perceptions.

> *Well, keeping the education and awareness there is major. Like I think… Like everything is focused on youth as well. And I think that we need to broaden that. Where do the youth learn from? Right? They learn from the adults. And if adults who go around and engage in activity, and these are their parents, these are the uncles, these are the aunts, these are the mothers, then you know, the youth… Like we might say anything we want to these kids but they're still going to engage in the activity because they've seen it, and they think it's okay. You know? [NL 4]*

> *Participant: And educate teachers and doctors, you know, for them to have a positive impact on people when talking about it. You know, instead of saying, "Oh, yeah, you have Hep C," or you have HIV, "and I'm going to send you here." You know, being empathetic and stuff. Because a lot of older old-school physicians and teachers and stuff like that, they just…you know. [NS Focus Group 4]*

> *Interviewer: So training for the providers, training for the educators, but also for…*

> *Participant 1: For the general public … [and] Senior leadership and management. [NS Focus Group 2]*

> *Yeah, that's right. And the teachers, you know, we don't do a lot of training around even the sexual health pieces of our curriculum. There's not a whole lot of training to be found. And it's a difficult topic, and they have to be so careful in what they can say. And all these… I mean kids ask quirky questions too, right. [NS Focus Group 2]*

Broadening youth education and prevention messaging to also reach adult populations, such as parents, teachers, health care practitioners, and the general public, has the greatest potential to ensure that HIV and HCV prevention messages are understood, supported and integrated into practice.

Recommendations for HIV/HCV Prevention Programs and Policies in Nova Scotia

A number of key recommendations emerged from the data analysis performed by the *Our Youth, Our Response* research team. These recommendations may be helpful in guiding the development of future HIV and HCV prevention policies aimed at youth in the Atlantic Region, and in particular, Nova Scotia, the most populous province in the region.

Collaboration: Strategic Partnerships and Cross-Disciplinary Approaches

The establishment of strategic partnerships between sectors, health regions and provinces could help to improve the current prevention efforts in Atlantic Canada. These partnerships exist in some locations, but not in all. Organizations wishing to increase active and meaningful collaboration should seek guidance from organizations with established networks. Provincial policies should be developed that help support organizations' abilities to collaborate, including providing funding to offset the costs associated with establishing and maintaining collaborative working relationships within a province, and across provincial borders. Increased collaboration has the potential to stretch limited financial and human resources and ensure service coverage to more remote locations and harder-to-reach populations. The development of an information bank of youth-related HIV and HCV prevention resources may also prove useful for health care providers.

Meaningful and Age-Appropriate Engagement of Youth

The meaningful inclusion of youth in the development of policies and programs aimed at preventing HIV and HCV among youth in Atlantic Canada is presently lacking. A number of barriers exist to the engagement of youth, including difficulty with recruitment, retention of youth, and inclusion of youth from diverse populations. However, a number of strategies may be employed to help encourage youth to participate, including providing adequate resources, compensation, capacity building, establishing an ongoing, formalized commitment to soliciting youth input**,** and providing age-appropriate and youth-friendly outlets for inclusion, such as arts-based projects or by encouraging youth to mentor their peers.

Increasing Access to Testing and Prevention Services

Access to rapid and anonymous HIV testing services is still unavailable in many parts of the Atlantic region. Increasing the number and types of testing opportunities, as well as the types of HIV testing available would have major impacts on increasing the rates of youth testing for HIV. Policy makers and health care providers must work together to update legislation and programs related to both HIV and HCV testing. Mobile testing sites should be explored as a means of reaching more rural and hidden populations. Education among health care providers is also required in order to ensure appropriate pre- and post-test counselling and referral following testing.

Harm Reduction

Participants indicated that it is becoming increasingly difficult to secure funding for programs labelled explicitly as harm reduction. However, a harm reduction approach offers a means of providing primary and secondary prevention education and services for HIV and HCV. Harm

reduction strategies can bridge sectors as well as provide new inroads for innovative HIV and HCV prevention knowledge and prevention tools. For example, offering free condoms in schools can facilitate student access to prevention strategies that they may not feel comfortable accessing through the formal health sector or in pharmacies. Harm reduction programs can be enacted at a community or grassroots level and can take creative approaches to reaching and meeting the needs of particularly vulnerable populations, such as street-involved youth.

Increasing Education and Prevention Messaging for Youth, Parents and Providers

According to our participants, youth and parents are not receiving the types of HIV and HCV prevention information that they need. Based on the data provided by our participants, the primary responsibility for providing sexual health education is seen as resting within the school system. However, participants indicated that policies were either not in place, or not enforced to ensure that all required content was delivered. Further, populations such as LGBTQ youth are not always reflected in the content that is provided in some jurisdictions.

While an updated sexual health curriculum is needed in some regions, policy changes are also required to provide guidelines for youth-focused approaches to the prevention of HIV and HCV. Increasing the coverage of topics such as HIV and HCV prevention, the location of sexual health and harm reduction services, and the needs of LGBTQ youth would be useful, but there must also be a means of ensuring that this content is delivered consistently. Further, teachers should be provided with appropriate training and support to deliver HIV and HCV prevention content.

In order to address these gaps, school boards should partner with youth-serving sexual health and HIV and HCV prevention organizations to develop and deliver sexual health education curricula. Involving youth-serving and/or HIV and HCV prevention organizations, and health care providers could help to ensure the educational materials are accurate and up to date. Involving youth representatives and those living with HIV or HCV could also help to increase the perceived relevance of the content for student audiences. Involving representatives from HIV and HCV prevention groups, sexual health organizations, and peer educators in the delivery of educational materials may help to gain students' interest, and ease concerns regarding disclosure of risk behaviors and related questions to teachers.

Conclusions

No individual organization or sector possesses sufficient resources, expertise, or personnel to comprehensively address the challenges facing youth-oriented primary and secondary HIV and HCV prevention. Therefore, the recommendations in this document focus on enhancing existing capacity, primarily through increasing communication and collaboration. Promoting youth-oriented HIV and HCV prevention in the Atlantic region requires the strengthening of relationships between government, community, public health and academic sectors, and on the meaningful engagement of youth. This holds true whether the goal is adapting existing policies or programs to meet the needs of youth in school, or initiating new responses to address ongoing gaps and challenges among street-involved youth.

While the availability of funding was identified as an ongoing gap by almost all participants, national policy changes such as the Public Health Agency of Canada's Integrated Approach to HIV prevention will further reshape the future funding landscape (PHAC, 2012a). With these changes, collaborations will become critical to sustain effective prevention responses. For example, AIDS service organizations and youth-serving health organizations will need to coordinate when competing for new pools of funding and share information and expertise in order to adapt HIV-specific mandates to these new realities. Organizations who currently function under an integrated model, or who work with partners to undertake work that is effectively 'integrated', will likely become leaders within the region in shaping the next generation of integrated HIV and HCV prevention policies and programs. Their knowledge and experience will serve as a guide for other organizations. The partnerships that emerge in the coming years should be able to use existing national and international guidelines as leverage to obtain funding from new and restructured sources.

Similar changes will be required at the policy level, as new HIV and HCV partnerships and programmatic responses will need to function across sectors, provincial borders, and communities. For these responses to be sustainable, they will require high level support from government officials and policy makers. Government and policy makers will need to remain aware of and responsive to the needs of community organizations, public health, health care providers, health researchers and youth. To this end, further opportunities exist for using national guidelines such as the PHAC HIV Screening and Testing Guide (PHAC 2012b) as leverage to promote effective evidence-informed policy and programmatic responses in meeting the HIV and HIV prevention needs of youth.

Appendix A: Glossary of Terms, Sex- and Gender- Based Analysis (SGBA)

Sex is commonly used to refer to "the biological characteristics that distinguish males and females in any species" (Clow, Pederson, Haworth-Brockman, & Bernier, 2009, p. 9). While sex is often conceptualized as a binary, consisting as male and female being the two options, there is in fact a continuum (Johnson, Greaves, & Repta, 2007).

"**Gender** consists of the socially constructed roles and relationships, personality traits, attitudes and behaviours, values, relative power and influence that society ascribes to the two sexes. In other words gender both describes and prescribes what it means to be female or male at a given time, in a given society. … Like sex, the binary division of maleness (masculinity) or femaleness (femininity) does not adequately capture the range of human experience or the expressions of self and identity that gender encompasses" (Clow et al., 2009, p. 11-12).

There are also four additional dimensions to consider:

Gender identity refers to the way in which we see ourselves as being male, female, transgender, or two-spirited. It is important that an individual's gender identity can change over time, and that it is a separate trait from sexual orientation **(**Johnson et al., 2007; Clow et al., 2009).

Gender roles reflect the types of behaviours commonly associated with being male or female. Gender roles can also refer to how we perform or display our gender identity in social settings (Clow et al., 2009).

Gender relations refer to "how we interact with or are treated by the people in the world around us, based on our ascribed gender" (Johnson et al., 2007, p. 7).

Institutionalized gender "reflects the distribution of power between the genders in the political, educational, religious, media, medical, and social institutions in any society. These powerful institutions shape the social norms that define, reproduce, and often justify different expectations and opportunities for women and men and girls and boys, such as social and family roles, job segregation, job limitations, dress codes, health practices, and differential access to resources such as money, food, or political power. These institutions often impose social controls through the ways that they organize, regulate, and uphold differential values for sexes and genders and women and men. These restrictions reinforce each other, creating cultural practices and traditions that are difficult to change and often come to be taken for granted" (Johnson et al., 2007, p. 7).

"Diversity refers to variations or dissimilarities between and among people. It is often used to denote observable differences, such as visible ethnic variations in a population and distinctions in age or location of residence. But diversity also includes differences that are not always evident, such as sexual orientation, education and religious or spiritual persuasion" (Clow et al., 2009, p. 14).

Equity "is the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically. **Health inequities** therefore involve more than inequality with respect to health determinants, access to the resources needed to improve and maintain health or health outcomes. They also entail a failure to avoid or overcome inequalities that infringe on fairness and human rights norms" (World Health Organization, n.d., para. 1).

Appendix B: Participant Demographics

Number of Interview Participants, by Sector	
Sector	**# Participants**
Education	12
Corrections	2
Health	19
Community	11
Unreported	3
Total	**47**

Number of Participants, by Home Province			
Province	**# Participants: Interviews**	**# Participants: Focus Groups**	**Total**
Nova Scotia	14	19	35
New Brunswick	15	NA	15
Newfoundland and Labrador	15	NA	15
Prince Edward Island	4	NA	4
Unreported	0	2	2
Total	**48**	**21**	**69**

Number of Participants, by Focus Group Topic	
Focus Group Number and Sector(s)	**# Participants: Focus Groups**
Focus group 1: Community and Corrections	5
Focus Group 2: Policy and Programming Developers	4
Focus Group 3: Youth and Healthcare Providers	6
Focus Group 4: Service Providers	6

Number of Participants, by Age Group			
Age	**# Participants: Interviews**	**# Participants: Focus Groups**	**Total**
16-25	6	5	11
26-30	6	2	8
31-35	5	1	6
36-40	7	2	9
41-45	2	2	4
46-50	5	3	8
51-55	4	2	6
56-60	7	3	10
61+	2	1	3
Unreported	4	0	4
Total	**48**	**21**	**69**

Number of Participants, by Gender			
Gender	**Interviews**	**Focus Groups**	**Total**
Male	23	9	32
Female	25	12	37
Trans	0	0	0
Undisclosed	0	0	0
Total	**48**	**21**	**69**

Number of Participants, Urban or Rural Setting			
Urban or Rural Setting	**Interviews**	**Focus Groups**	**Total**
Urban	34	14	48
Rural / Town	14	6	20
Undisclosed	0	1	1
Total	**48**	**21**	**69**

Appendix C: One-on-One Interview Guide

Interview Guide – Adult Participants

*If a participant is being interviewed over the telephone, the interviewer must first read the consent form to the participant. The interviewer must then turn on the recording device and establish verbally with the participant that the consent form has been read and understood, and that consent is given for each of the checkboxes on the form. The interviewer may then proceed with the following guide.

Introduction

The following questions are related to HIV and/or HCV prevention policies and programs aimed at youth (ages 16-25) in the Atlantic region. We are interested in knowing your ideas and perspectives in HIV/HCV prevention for youth. Please feel free to offer as much detail in your answers are you wish. Your answers will remain confidential and no names or other personal information will be reported.

***Key Terms to reference as needed**

Primary Prevention: Preventing disease, through methods such as protection, immunization (vaccine), etc; initial prevention of infection.

Secondary Prevention: Methods used to diagnose and treat in the early stages of disease to reduce the impact of the illness and/or preventing someone who has contracted the virus from passing it on to others.

Sex: Biological characteristics that distinguish males and females

Gender: Socially constructed roles and relationships, personality traits, attitudes, behaviors, values, relative power and influence that society ascribes to males and females

Diversity: Variation or dissimilarities between and among people. For example, Aboriginal, Caucasian, African Nova Scotian, new comers, French, or English.

Health Inequities: Differences in health outcomes that are deemed to be unfair, avoidable and changeable.

I would now like to ask you a few background questions which will give us a better sense of the types of people we have spoken to for this study. Please feel free to skip any questions you do not wish to answer. Your answers to the following questions will remain confidential.

Demographics

1. Where do you live? (i.e., Community, Province)
    a. City
    b. Town or rural setting

2. What is your age?
    a. 16-25 years
    b. 26-30 years
    c. 31-35 years
    d. 36-40 years
    e. 41-45 years
    f. 46-50 years
    g. 51-55 years
    h. 56-60 years
    i. 61 + years

3. What is your highest level of completed education?
    a. High school is not completed
    b. High school
    c. College Diploma
    d. University Undergraduate Degree
    e. Other (Please specify)

4. How would you describe your ethnic background? (i.e., Aboriginal, Caucasian, etc.)

5. What is your current occupational status? (i.e., Student, part-time/full-time employed)
    a. Student
    b. Unemployed
    c. Employed Part Time
    d. Employed Full Time
    e. Retired
    f. On employment insurance (EI)
    g. Unpaid work (Please specify)
    h. Other (Please specify)

If employed:

6. Can you tell me about your current line of work? [Probe: job title, description, responsibilities, and length of time there]
    a. Does your job fall into one or more of the following sectors?
        i. Education
        ii. Corrections
        iii. Health
        iv. Community
        v. Other (please specify)
    b. If your job does fall into one of these areas, what role do you see your area playing in primary and secondary prevention of HIV and HCV in youth [Probe: from a policy or programming perspective]
        i. How might this role be expanded or improved upon?

7. For how long have you worked in this profession? What are your responsibilities at work?

HIV/HCV Prevention Policy & Program Initiatives

8. Can you tell me about your current work and/or your interest in HIV/HCV prevention policies and/or programming aimed at youth?

9. Are you aware of any new or existing HIV and/or HCV prevention policies and/or programming initiatives in your community aimed at youth? In the province where you live and/or work?

If so: do you know

   a. Were youth consulted in the creation or implementation of these policies?

   b. What degree of collaboration was used in the creation or implementation of these policies or programs aimed at youth?

   c. What steps might be taken to increase the role and participation of youth in the creations and implementation of policies that are aimed at primary and secondary prevention of HIV and HCV in youth

10. Which of these policies and/or programming initiatives are directed at the ***primary*** **prevention of HIV and/or HCV among youth?**

11. Which of these policies and/or programming initiatives are directed at the ***secondary*** **prevention of HIV and/or HCV among youth?**

12. In Nova Scotia, how are **gender, sex, diversity, and equity** integrated into HIV and/or HCV prevention policies and/or programs aimed at youth

13. In Nova Scotia, how are HIV and/or HCV prevention policies and/or programs developed? (Who is involved in the development of such initiatives?)

14. What gaps, if any, do you see existing between ***primary*** and ***secondary*** prevention policies and/or programming initiatives for youth surrounding HIV/HCV in your city or community? In your province more broadly?

    a. How you see gender as influencing these gaps?

    b. Are these gaps more apparent for specific groups (e.g., aboriginal, women, those involved in the criminal system, homeless, those with addictions or mental health issues, etc.)?

    c. From your perspective, what barriers exist to the creation and implementation of primary and secondary prevention policies directed towards youth?

    d. We note that Nova Scotia may have examples of programs and initiatives that exist that play a role in HIV and HCV prevention among youth; however, these are not guided by formal policy. What are the costs and benefits to formal policy when it comes to HIV/HCV prevention among youth? Are such policies ever counterproductive?

15. What do you see as a possible solution(s) to enhance or improve existing HIV and/or HCV prevention policies and/or programming initiatives with respect to reducing the impact of these indicated gaps for youth?

    a. Would you see addressing sex, gender, diversity, and equity as part of the solution? If so, how?

16. What link do you see between the creation of HIV/HCV prevention evidence along with existing evidence and policymaking?

17. What kinds of new or novel approaches/policies and/or programming initiatives has your community developed with respect to preventing the spread of HIV/HCV among youth?

18. Do you have any recommendations/suggestions on how to reduce the spread of HIV/HCV among youth, specific to prevention policies and/or programs?

Sector Specific Questions

19. (Government, health, community): In Nova Scotia, access to programs and services is a key goal for the government as well as other sectors (e.g., health, community). How does/can policy facilitate access to programs/initiatives aimed at HIV/HCV prevention among youth?
    a. How do the issues of sex, gender, equity, and/or diversity play a role in such access?

20. (government, health, community, and school): We noted that in Newfoundland there are several wellness based policies aimed at facilitating health and wellness (the focus of these documents is on health/wellness versus disease/illness). What role do such policies/documents play in youth HIV/HCV prevention?

21. (schools): We noted that several school based policies in Newfoundland focused on harm reduction (e.g., condom machines). How effective are current policies aimed at HIV/HCV prevention in schools? How much do current policies actually impact practice in the schools around this topic?

22. (schools): We noted that several school based policies focus on differentiated instruction and developmentally appropriate instruction when it comes to teaching health curriculum (that would impact HIV/HCV prevention among youth) and even offering HIV/HCV prevention strategies. How effective are these policies and how much do these policies impact prevention practice for youth?

23. (health, school, community): We noted that several policies in Newfoundland emphasize multidisciplinary practices and in the school system cross disciplinary focus when it comes to health based curriculum (that has relevance for HIV/HCV prevention among youth). Are such policies sufficient for practice? How do such policies inform practice in your sector?

24. (community, health, school): How do existing HIV/HCV youth prevention policies work in relation to harm reduction strategies in your city/province? What are the strengths and barriers to such policies?

25. (community, health): We reviewed several documents from Newfoundland that focused on rural practices that had relevance for HIV/HCV prevention among youth (e.g., online, telephone, publications, retreats). How could such policies/programs/initiatives be improved in the province?

26. Do you have any further comments, suggestions, or questions about HIV and/or HCV prevention for youth?

27. Do you have any other recommendations of those who (individuals or organizations) would be good to be interviewed for this project?

If yes, give a paper version of the recruitment flyer to the participant.

If not, shut off recorder and thank participant for their help.

Appendix D: Focus Group Discussion Guide

Theme 1: Representation of youth in policy / program development: Youth are often not involved in the development of HIV/HCV prevention programs. However, there is a desire to increase youth involvement in this process, but a great deal of uncertainty as to how this can be accomplished.

[Preamble: We know that increasing youth participation in policy/program development is a means by which to improve youth-oriented HIV/HCV prevention. We also know that many organizations are supportive of inclusion of youth partners, however no one seems quite sure how to go about this process].

Questions:

1. Where can we go for guidance, or where can we find examples?
2. What existing work can we build upon, and where can we start to introduce youth partners?

Theme 2: A need to expand secondary prevention: [Preamble: Primary prevention is well represented among programmatic responses throughout the Atlantic Provinces. However, secondary prevention was not discussed to the same extent. Bolstering existing secondary prevention and initiating new secondary prevention-oriented policies/programs represents a means of improving HIV/HCV prevention].

Questions:

1. We would like to support the development of novel policies that will support secondary prevention programs. How can we promote the inclusion of youth partners in this process? What models of secondary prevention might be most amendable to co-creation with youth partners?

Theme 3: Communication and collaboration as key elements of successful program development and implementation: [Preamble: HIV/HCV prevention experts draw on the knowledge, skills and expertise of peers from other organizations. These communications represent a critical resource for HIV/HCV prevention, and in the coming years it will be necessary to increase utilization].

Questions:

1. What infrastructure supports effective communication/collaboration between parties from different levels/sectors/etc?
2. What could be done to facilitate increased youth participation in the development of HIV/HCV prevention programs/policies?

Theme 4: Harm reduction as opportunity and challenge: [Preamble: The initiation of harm reduction programs is indicative of considerable effort, and represents a success. However, these programs require effective monitoring, adaptation and expansion, nor can a single program address all prevention issues. There is a need to bolster harm reduction interventions with other forms of primary, secondary, and tertiary prevention].

Questions:

1. How can the successes of an individual harm reduction program be employed as a starting-point for future responses, particularly those oriented towards youth?
2. Are there synergies between harm reduction programs such as needle exchanges, and those that focus on providing condoms?
3. How might we go about supporting integrated harm reduction programs that support a wider range of behaviours, situations and youth populations?

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