

Rethinking ASOs?

Responding to the End of AIDS Exceptionalism through East-West Collaboration

Project Report

Prepared by San Patten, Andrea Langlois, Joanna Mendell, Sarah Peddle, & Janice Duddy
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Andrea Langlois
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Evin Jones
Janice Duddy
Joanna Mendell

Atlantic:

Sarah Peddle
San Patten
Julie Dingwell
Susan Kirkland
Jacquie Gahagan
Larry Baxter
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National:

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Background: AIDS Exceptionalism and Integration

Debates about AIDS exceptionalism are not new. There have been spirited discussions for decades about the importance of a privileging of funding to combat AIDS. Canadian Stephen Lewis, former UN Special Envoy to Africa on HIV/AIDS, recently defended the continuation of AIDS exceptionalism, arguing that: *“You just can’t permit an intellectual contrivance – an argument in favour of accepting the size of the pie and slicing it differently, rather than demanding a larger pie – you can’t allow that to be used to justify a terrible reversal in public policy. People infected with HIV or at risk of infection, are suddenly tossed onto the landscape of treatment ambiguity, and the gains we’ve made and the momentum we’ve achieved are put at risk.”*¹

What is AIDS Exceptionalism?

The word “exceptionalism” is not found in most dictionaries. It means “to treat or give something the status of being exceptional.” In the early days of the epidemic, HIV was considered so different from other communicable diseases that advocates and public health officials agreed that HIV policy should cater to this uniqueness rather than treating it like other infections or diseases.

AIDS exceptionalism grew out of the response to the pandemic in the late 1980s. It was intended to combat the discriminatory and often violent response to stigmatized populations most affected by HIV (i.e., gay men, people who use injection drugs, and immigrants from endemic countries)² and to “counter the pressure to fully re-absorb AIDS into regular administrative systems.” Although some people saw an HIV-specific response as an unjust “fragile, short-term solution,”³ AIDS activists advocated for both special resources and increased funding as a way to ensure the HIV/AIDS response was not subject to traditional top-down public health methods of disease control that could discourage people at risk from participating in HIV prevention, testing and treatment programs.⁴

For some, the stigma still associated with HIV and the populations affected warrants a continued exceptional response.⁵ However, HIV/AIDS is not the only disease in history that has been stigmatized (i.e., syphilis, tuberculosis, cholera) and treating HIV as exceptional could be seen as creating barriers and perpetuating stigma through separation and emphasizing difference from other STBBIs or chronic conditions.⁶ Others would say that criminalization alone makes AIDS exceptional: “Criminalization must come off the table before an exceptional response can move towards an equitable blood borne pathogen model of service and care delivery.”⁷

¹ Alcom, Keith. (2009, July 20). “AIDS exceptionalism a defensible concept, says Stephen Lewis.” [AIDSMap.com](http://www.aidsmap.com/print/AIDS-exceptionalism-a-defensible-concept-says-Stephen-Lewis/page/1435162/) <http://www.aidsmap.com/print/AIDS-exceptionalism-a-defensible-concept-says-Stephen-Lewis/page/1435162/>

² Steele, Derek G. (2000). “The evolution of the Canadian AIDS Society: a social movement organization as network, coalition and umbrella organization.” *Unpublished Doctoral Dissertation*. McGill University.

³ Rayside, David M.; Lindquist, Evert A. 1992. “AIDS activism and the state in Canada.” *Studies in Political Economy*. 39 (Autumn): 37-76.

⁴ Ibid.

⁵ Piot, P. (2008, May). AIDS Exceptionalism Revisited. *Speech presented at the London School of Economics and Political Science*, London, England.

⁶ Kerston, Paul, R. and Shelley Tognazzini. (2014, February). “Is This the End of AIDS Exceptionalism?” *PositiveLite.com*. <http://www.positivelite.com/component/zoo/item/is-this-the-end-of-hiv-exceptionalism>

⁷ Ibid.

Treating HIV/AIDS differently from other blood-borne infections was the basis of the public health response to HIV/AIDS in Canada since the first federal investments in HIV/AIDS in the 1980s. Yet, as of late, there are clear signs within policy and funding frameworks that this era of “AIDS exceptionalism” is coming to an end. For example, at a federal level, the Minister of Health has asked the Public Health Agency of Canada (PHAC) to align its role in the response to HIV and HCV within a broader communicable diseases perspective and to explore innovative partnerships and links to chronic diseases, mental health, aging, and other determinants of health. PHAC has indicated that this approach will be fully implemented by April 2017.⁸

This approach – referred to as “service integration” – is being promoted as a way to provide better continuity of care, create efficiencies in testing for communicable diseases, and promote collaboration across sectors. Within Canada, the term is being used to describe the integration of services around viral hepatitis, STIs and other health concerns into services that have been traditionally focused on HIV/AIDS prevention and care. On a global level, UNAIDS has begun to promote “integration” of HIV responses into wider health and development efforts as a way of taking AIDS “out of isolation” and is encouraging an integrated approach to HIV/AIDS in countries where the epidemic is generalized, as a way to “strengthen the impact of the AIDS response, leverage HIV-related gains to generate broader health and development advances and enhance the long-term sustainability of the AIDS response.”⁹ Although many AIDS service organizations in Canada are already implementing an integrated approach within their service delivery, there are concerns around these shifts, and many differing opinions around what directions policies and programs should take.

Exactly how HIV/AIDS policy’s shift to integration will impact people living with HIV/AIDS (PLHAs), people at risk of HIV, and on AIDS service organizations (ASOs) that are on the frontlines of the epidemic is difficult to predict. No doubt, one of the most important shifts underway on the policy front in recent years is the integration of HIV/AIDS services and funding with those for other sexually transmitted and blood borne infections (STBBIs). How can we make sense of this proposed shift? What does it mean for preserving the distinct characteristics of HIV/AIDS organizing, which has been marked by more than three decades of social movement activism in Canada and elsewhere? Does an integrated model of service delivery spell the end of HIV/AIDS exceptionalism as we know it? Can HIV/AIDS still be viewed as exceptional in such an integrated framework?

The community-based response to HIV/AIDS has evolved significantly over the past 30 years. From bake sales to AIDS walks, from kitchen table meetings to board rooms, from helplines to one-stop health centres, and, in some cases, from HIV-only to integrated services, the response to the epidemic itself has shifted. These shifts are due in part to the advent of new testing technologies and treatment options, as well as changes in policy, funding and service provision contexts.

In response to the myriad of questions arising from these shifts, teams of community-based organization representatives and academics from British Columbia and the Atlantic region (covering Nova Scotia, New Brunswick, Prince Edward Island, Newfoundland and Labrador) secured a CIHR HIV/AIDS Planning Grant in order to do some initial research and to work collectively to develop a

⁸ Canadian AIDS Society. (2013, May 27). “PHAC plans for integration of delivery of services.” CAS Member Update. <http://pacificaidnetwork.org/news/cas-note-member-update-phac-plans-for-integration-of-delivery-of-services/>

⁹ Joint United Nations Program on HIV/AIDS. (2012). UNAIDS Report on the Global AIDS Epidemic 2012. http://www.unaids.org/sites/default/files/media_asset/20121120_UNAIDS_Global_Report_2012_with_annexes_en_1.pdf

research agenda that will enable communities to best respond to these changes. These two regions share many common challenges in addressing HIV/AIDS, including: providing community-based services across a mix of urban and rural areas, heavy ASO reliance on federal funding, growing demand for services from people mono-infected with HCV or co-infected with HIV and HCV, shared concerns about pervasive HIV-related stigma and its impact, as well as the limitations organizations are facing when doing advocacy work.

Our goal for this project, called *Rethinking ASOs? Responding to the End of AIDS Exceptionalism through East-West Collaboration*, was to collaborate in sharing our understanding of the shifting roles of ASOs. The Deliberative Dialogues held in both regions on November 24, 2014, was an opportunity to share information and host conversations on what further research could be done to support communities to respond to these changes.

As our title suggests, our process was grounded in a question – do AIDS Service Organizations (ASOs) need rethinking within the current policy context? There’s so much we don’t yet know. Additional questions that informed this project were:

- If we were to start from scratch, what would HIV service provision look like in 2015? In 2020?
- How can we make sense of proposed policy shifts (i.e., the Public Health Agency of Canada’s shift towards a sexually transmitted and other blood borne infections model)?
- What do changes – to policies, programs, the epidemiology of HIV, and the experiences of living with HIV/AIDS in this era – mean for preserving the distinctive characteristics of HIV/AIDS organizing, which has been marked by more than three decades of social movement activism in Canada and elsewhere?
- Where do people living with HIV/AIDS find their voice in the end of AIDS exceptionalism and what does a move to integration mean for people living with HIV/AIDS? How is this experience by people with diverse lived experiences, for example, gay men, or aboriginal woman, or people struggling with poverty?
- Can and should HIV/AIDS still be viewed as an exceptional condition in such an integrated framework? Can the continuum of education, prevention, care and support remain HIV/AIDS-specific, and if it doesn’t what will that mean for the diversity of people who access services?

Objectives

There are multiple and sometimes diverging views on what the path forward should be for the delivery of AIDS services in both of these regions. Different individuals, groups, or networks have access to different sources of information.

The objectives of *Rethinking ASOs?* were process-based – to foster dialogue, to share knowledge, and to develop priorities for further research that can be acted upon together or separately, and ultimately benefit the HIV/AIDS sector. As outlined to the Canadian Institutes for Health Research (CIHR) in our application for funds, our objectives were to:

1. Bring together a multi-region and cross-sector team of leaders in HIV research, service delivery and policy in both the Atlantic and BC;

2. Foster multi-region and cross-sectoral collaboration and opportunities for knowledge sharing;
3. Facilitate a research agenda-setting process that will address both regional and demographic differences and ensure appropriate representation from both regions; and
4. Identify research priorities in light of the identified information needs relating to the current policy/funding and advocacy contexts.

To achieve these objectives, we held two simultaneous, one-day Deliberative Dialogue meetings on November 24, 2014 – one in the Atlantic region and one in BC – explored the future of HIV/AIDS service delivery in the context of the end of AIDS exceptionalism. In advance of these meetings, the team:

- Conducted an initial literature review examining how the mandates of ASOs have changed over the past 30 years, including professionalization, the relationship with advocacy, and service provision shifts away from exceptionalism to integrated service delivery;
- Conducted an initial policy mapping and developed a timeline of significant policy shifts over the past 30 years, relating to implications for advocacy, and shifts to integrated models, HIV as a chronic disease, and/or AIDS exceptionalism; and
- Recorded three videos and developed online resource pages featuring the findings from the above reviews, as well as from AIRN's PHAC-funded *Exploring the Landscape of Communicable Diseases in Atlantic Canada* report.

Rethinking ASOs? Deliberative Dialogues

We engaged a diverse group of stakeholders in each region, including people living with HIV/AIDS, representatives of community organizations, representatives from the policy sector, and university-based academics. (While these conversations may be of interest also to people living with hepatitis C or other STIs and the organizations that serve them, the resources available for this process didn't enable us to extend this invitation beyond the HIV sector.)

Balancing the different voices within a priority-setting process is a challenge, and we did our best to identify and invite stakeholders who would represent difference standpoints within the AIDS sector. While resource and process limitations meant that the events needed to stay small, we sought to bring as much diversity as possible into the room, and recognized this event as the first or second step in what is hoped to be a longer-term process where many more voices will be able to participate in the next steps. Thus, invitees were carefully identified by the organizing committee to include those who had strong historical perspectives on the HIV/AIDS sector, people living with HIV and current leaders in the HIV sector.

The discussions in each region took the form of a "deliberative dialogue." In this model, individuals with a stake in a given policy or other issue, come together to listen deeply to many points of view, to explore new ideas and perspectives, and to bring unexplained assumptions out into the open. It's a framework for creating mutual understanding and a common purpose that transcends mere ideas and opinions.

The result of a deliberative dialogue is not to make decisions, but to strengthen relationships, empower, and gain greater collective insight. Through dialogue, we aimed to broaden our understanding of these issues and their root causes, and used these insights to inform a collective and individual next steps or gaps in research or information.

The objectives for the *Rethinking ASOs?* deliberative dialogues were to provide the group with access to the same research and information, to create a space for dialogue on AIDS exceptionalism and integration as priority issues for the sector, to provide a space for multiple voices to be heard, and to identify next steps for the process. In addition to previewing the three videos (described below), the participants also were asked to complete a pre-event survey to provide input into the agenda. The questions for the pre-event survey were:

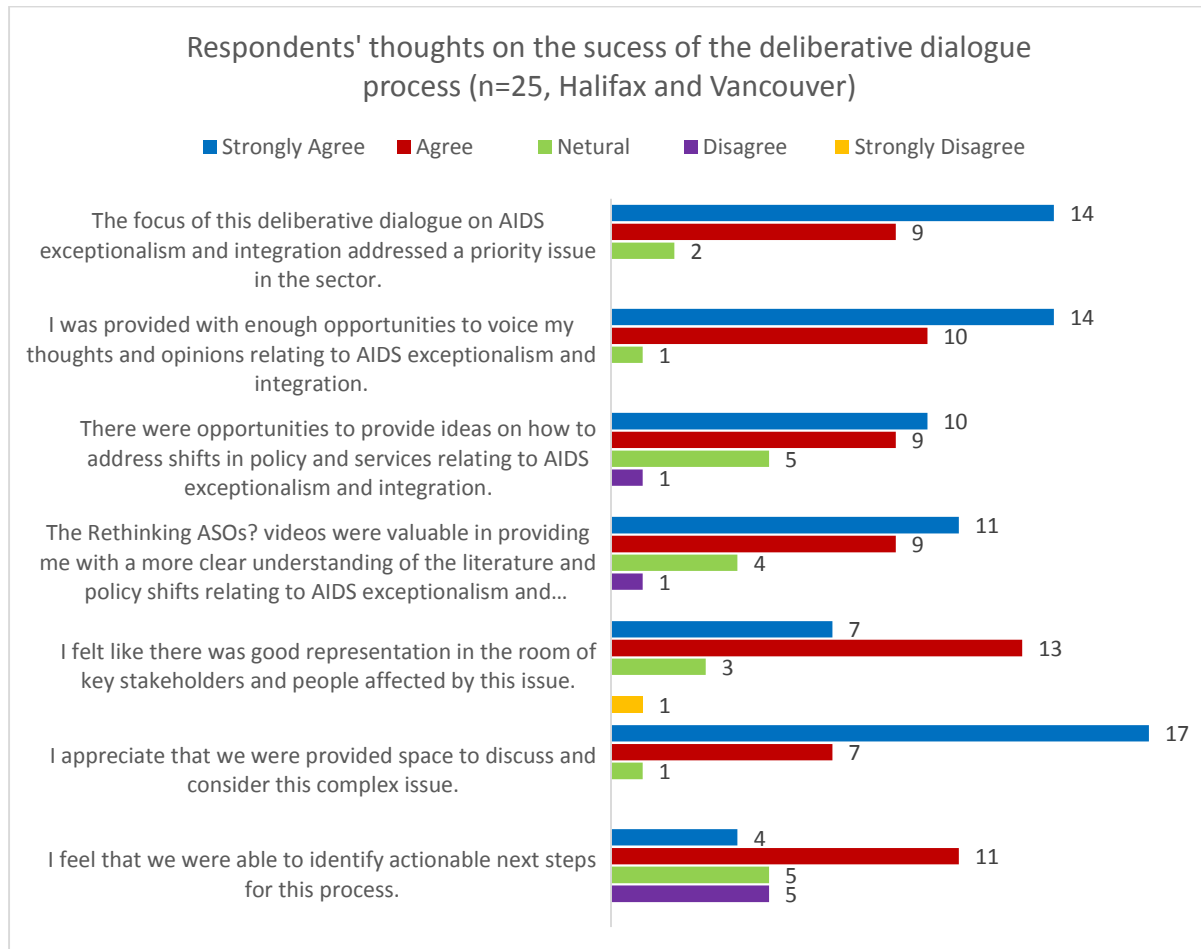
- What most interests you about participating in this process?
- What do you think are the most important "concerns of the day" in relation to policy and funding shifts around HIV/AIDS service delivery?

What is a deliberative dialogue?

- A "social technology" that provides opportunities for people to deliberate on key social issues.
- The objective is not so much to *talk* together, but **to think together**.
- Thinking together involves listening deeply to other points of view, exploring new ideas and perspectives, searching for points of agreement, and bringing unexamined assumptions into the open.
- Deliberative dialogue creates joint meaning and shared understanding.
- Not intended to solve problems, but rather to create open discussion on the nature of the problem itself, working to reveal its true complexity, or frame it within its wider, systemic framework.

- What do you think are the key elements of current AIDS service models? What needs to be preserved moving forward? What could be released or let go of?
- If we were to start from scratch, what would HIV service provision look like in 2015? In 2020?
- What would you like to get out of this process? What will success look like?

What Did Participants Say about the Deliberative Dialogue Process?



Video Presentations and Resources

Participants were asked to participate fully in the deliberative dialogue process by pre-viewing three recorded video presentations, reading some (brief) background documents, and joining an in-person full-day meeting in Vancouver or Halifax on November 24, 2014.

The video presentations were [posted on the PAN website](#)¹⁰ in the weeks leading up to our in-person meeting, and participants were encouraged to submit questions, comments and reflections through an online comments section. Presentations covered the following topics:

Video #1 – Where have we been? What are the roots of AIDS exceptionalism and what is integration?

In this video, we presented the findings from a literature review that was designed to inform our discussions and path forward. The question that drove the literature review was as follows: *“How have the mandates of AIDS service organizations changed over the last 30 years and what are the changes seen with regards to professionalization, the relationship with advocacy, and service provision shifts away from exceptionalism to integrated service delivery?”* Sources were drawn from searching multiple databases, gathering suggestions from experts, and reviewing relevant reference lists. Over 2000 sources were reviewed, and a total of 78 sources were included – all within or relevant to a Canadian context, and focused directly on public health.

The literature delved into different definitions of exceptionalism and integration, and, to some extent, how and where these were embedded in policies or programs. Historical context, especially with regards to exceptionalism and the changing roles of AIDS service organizations was also a prominent theme of this review. Finally debate within the literature was described with regards to whether or not AIDS still warrants an exceptional response, what the argued benefits and downfalls of integration were/are, and how these and other changes have affected AIDS service organizations. This background research acted as a jumping off point for this project, and along with the following two videos aimed to set the stage for the deliberative dialogue event.

The full text of the literature review is available as a separate document on the [resource page](#).¹¹

Video #2 – The Policy Landscape: Changes to HIV/AIDS policy federally and in the Atlantic and in BC

As part of the background research for the process, we conducted a policy mapping of HIV/AIDS policies –including HIV/AIDS strategies, funding changes, and testing and treatment guidelines – as a way to examine shifts in the response to HIV/AIDS over time. Timelines were developed to showcase key moments and important policy documents nationally, in British Columbia, and in Atlantic Canada. Additionally, the structure and key players for both BC and the Atlantic were outlined to show significant influencers of the policy landscape.

In developing this resource, we hoped to chart important moments in our history relating to specific HIV policies, as well as shifts in political climate that may have had an effect on principles of HIV exceptionalism, integration of services, and/or AIDS service organizations’ roles. One such example is the move towards more integrated blood borne pathogens strategies within health authorities in

¹⁰ <http://pacificaidnetwork.org/re-thinking-asos-project/>

¹¹ <http://pacificaidnetwork.org/rethinking-asos-literature-review-resource-page/>

British Columbia. The video presentation laid the ground work for discussions on where HIV/AIDS policy is headed and the impact of these shifts.

Video #3 – The Landscape: Reflecting on the Contexts in Atlantic Canada and BC

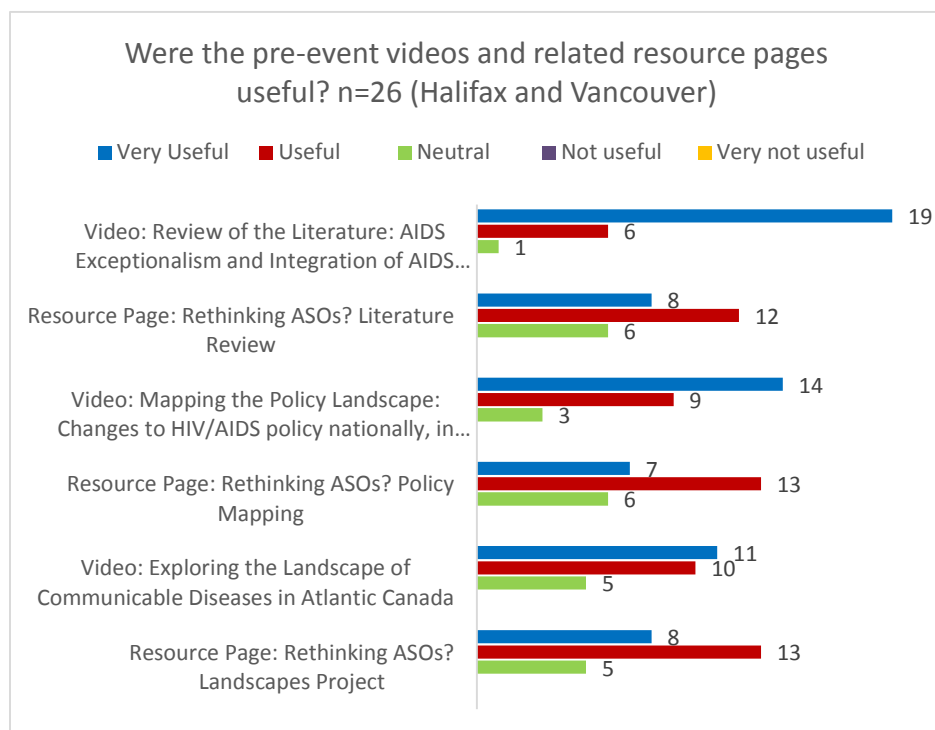
In this video, we presented findings from the *Exploring the Landscape of Communicable Diseases in Atlantic Canada*¹² in Atlantic Canada, conducted by AIRN, which maps out the current service delivery landscape as well as some of the challenges faced by organizations in that region. The *Landscapes Project* was a collaborative and consultative investigation into the current state of HIV/AIDS, HCV and other STBBIs, affected populations, and associated service delivery needs in Atlantic Canada from the perspective of community-based organizations and the people who access their programs, services and supports. The objectives of the project were:

1. To identify the current and emerging needs, key issues, and gaps in the area of services provided to populations living with communicable diseases – specifically, HIV/AIDS, Hepatitis C, and other sexually transmitted and blood borne infections (STBBIs) – in Atlantic Canada.
2. To generate evidence to guide decision-making concerning how organizations serving these populations might position themselves to provide effective and efficient services to those most affected in the region into the future.

The full report is [available online](#).¹³

Feedback on the Video Presentations and Resources

As indicated by the evaluation feedback (n=26) from participants in both regions, the pre-viewed videos and resources were overall useful or very useful to participants. The most useful video was the one summarizing the literature review on AIDS Exceptionalism.






¹² Kirkland, S., Patten, S., Krahn, T., Peddle, S., Gaspar, M. and the Landscapes Research Team (2014). *Exploring the Landscape of Communicable Diseases in Atlantic Canada*. Halifax, NS: Canada.




¹³ <http://www.med.mun.ca/Airn2012/Research/Publications.aspx>

The majority (73.1%) of evaluation respondents felt that the videos would be helpful beyond the context of the *Rethinking ASOs?* Project, and over half (53.8%) planned to share the video with their colleagues or peers.

Do you feel the videos would be a useful tool outside of the *Rethinking ASOs?* context?

Response	Chart	Percentage	Count
Yes		73.1%	19
No		0.0%	0
Don't know		26.9%	7
Total Responses			26

Are you planning to share the videos with your colleagues or peers?

Response	Chart	Percentage	Count
Yes		53.8%	14
No		7.7%	2
Don't know		38.5%	10
Total Responses			26

Respondents' Reflections

The deliberative dialogues began with a panel of respondents who were asked to reflect on what was presented in the literature review, policy mapping, and *Landscapes* report in order to spark discussions about the background research. In each region, the panel of respondents helped to bridge the information that participants consumed in advance on their own with the discussions to take place at the meeting.

Three local experts from each region were asked to carefully review the three videos and provide their reflections in responses, as guided by the following questions: *What struck you about the information presented? What was missing? What questions did it raise for you? How did the ideas that were presented fit with your experience in the HIV sector?* Below is a summary of each of the respondents' reflections.

Panel Remarks – Larry Baxter (Atlantic)

- What we are really missing is the names of the many people who led the way over the past three decades, many of whom are not with us today. So we must keep their memory with us always as we move forward and think about how they would have acted. The GIPA/MIPA lens is one which we must not forget. GIPA was the core of the early HIV movement and now it seems to be struggling to survive in some aspects of our work.

- While we tend to focus on the federal government (as the major funder), we must not forget the role that provincial and municipal governments have or could play in financial support, as well as non-government fundraising.
- We really should have a more specific geographical analysis of our work; for instance, where are the new infections being found, where are the PHAs now residing and what are the distances they need to travel for the various clinical, ASO or other health and social services. How much have personalities and local context shaped how ASOs have developed over time rather than by the various federal funding formulas. For instance in Nova Scotia, Sydney, Truro and Halifax seem to operate in very different ways, so what can we learn how these three have evolved over time?
- The evolving nature of the HIV epidemic has added layer upon layer of complexity of what we have to know about HIV and services we need to provide. So-called mission drift has really been unanalyzed and unplanned. As a somewhat privileged PHA, my own personal concerns are no longer my actual HIV infection but issues around the longer term effects of living with a chronic condition, issues around aging and my changing family responsibilities. Just as we now tell people not to make HIV the sole focus of their lives, we as the HIV community must also not think that we have to be the sole provider of the major services for PHAs. I don't feel the need for my ASO to accommodate my every need; I want the various community services to prepare themselves to accommodate the changing needs of my communities.
- While criminalization is somewhat unique to HIV, we should not fall into the trap of letting it define our movement or shadow all of our work. Just because there is criminalization does not make our movement exceptional; it just means we have consider it as part of program planning.
- The PHAC Integration model looks good on paper because it takes a holistic view of the person and the determinants of health. We have all been advocating for this approach for years. The danger is in the missing details. How much funding? Who is going to get the funding and will they understand PHAs? Is one of the intended but unsaid objectives to reduce the number of ASOs (which itself a by-product of earlier funding models). And are we prepared to reorganize ourselves or amalgamate our organizations?
- On the inside we may complain about how government funding has affected ASOs, but from the perspective of some other disease groups, we are seen with envy because we have so many separate funded organizations across our region, we have regular and ongoing government funding programs, even if underfunded, and we have had such great previous public support and success. These organizations have numbers and needs as great as or even greater than ours. While we have examined what has happened to the HIV movement over the years, we could learn from how other segments of society have adjusted and moved forward in these economic and political times.

So in conclusion, I hope we guide our discussion today through the lens of:

- a. What is best for the individual PHA? Let us remember that not all PHAs need ASOs, so let's focus on which groups of PHAs truly need the ASO and at which times in their own HIV journey.
- b. Where does stigma really play a major factor so we can design our programming to buffer it? And where are we actually reinforcing or failing to reduce stigma, and take opportunity to do things differently, or work with others, or even let others do it?
- c. Are we creating our own programming silos which make it harder for PHAs to receive services in the longer term? What are the times when ASO really need to provide the targeted services? What makes sense in larger cities with more concentrated epidemics does not make sense in

- smaller provinces and communities. We just don't have the numbers, so we have to find innovative ways to have the community provide them. We need to keep asking ourselves, "Are we programming because we think we can do it better or because no one else is going to do it"?"
- d. Finally, what are the ways we can rebuild the ASO model so that PHAs truly play meaningful roles within them? If we have strong PHA engagement in programming and Board decision making, many of these issues will eventually get worked out.

Panel Remarks – Julie Dingwell (Atlantic)

The videos provided a great analysis of our past and how we got here, setting the stage for people to understand why the time to move ahead is now. The end to AIDS exceptionalism was overdue. We have many reasons for moving ahead now – there are huge gaps that we haven't been good at filling and have left segments of our population out who could have used that leadership. If people with hepatitis C had the same leaders and ability to move forward earlier, we'd be in a very different state now. We need to look at what are the needs of other populations, and what will their involvement look like? There has been an absence of support to other groups due to our exceptional way of working. So, how will we make integration work? Everyone needs to feel included and see the importance of working together. We need to engage new people and host deliberative dialogues around what is the end of AIDS exceptionalism and where that places us in relation to other issues.

Panel Remarks – Maria Mac Intosh (Atlantic)

This policy shift to integration is an opportunity to create synergies. There are many cases where integration makes sense and we have already been doing it quite a bit. For example, the "Check me out" campaign in Halifax focused broadly on gay men's sexual health, including HIV, HCV, anal exams, etc. In delivering support programs, there may be a need to have exclusive programming depending upon what the needs are. We should not see our programming as all one or another, but adapt our programs based on needs. The policy landscape video was a good start, but there is so much more and it could be a whole separate project to map our policy history comprehensively. It is hard to pick out from the policy landscape video how the community-based AIDS movement has influenced the public policy, and we need to champion that we have had an influence and a strong voice.

Panel Remarks – Maxine Davis (BC)

"A different approach is needed" – or maybe a different approach is being thrust upon us. We cannot stop what is emerging, but we need to do our best to make it as positive as possible. How do we steward the gift that was given to our community, and country, by people that are not here today. We need to take charge of the conversation and lead it. Let's get it written down and articulated together as a group. In philosophy it makes sense, in practice it is going to take some work. This will be experienced very differently in different communities that have gotten to different places in the movement. Each government will hopefully urge moving at a pace that works with that setting. "Integration may be being looked at as a cost piece, and not as a human piece," is a quote that struck me from the *Landscapes* video. We want to make sure that these changes are being made from a service and human perspective, not solely from a financial perspective. Integration when possible, exceptionalism when necessary – as a continuum. It needs to be done with such care, and it should never be a blanket target for everybody.

Panel Remarks – Sandy Lambert (BC)

How safe will places feel as we open the doors to providing services related to other blood borne pathogens? How do we create culturally safe spaces? There are still places (such as up North) where we don't speak openly about HIV, so as we move things together, and more people are included in HIV work, there comes more concerns about confidentiality. Serious concerns about stigma remain as things change.

Panel Remarks – Cathy Worthington (BC)

We've been talking about professionalization of ASOs since the early 1990s, and so it's not like ASOs have ever been static, unchanging entities. Service integration has been evolving over the last 15 years, as ASOs have adapted their services for different clients and different contexts. People living with HIV are complex individuals with many things affecting their lives other than HIV: HIV is only part of a "bundle" of elements that make up and influence people's lives. ASOs have been supporting these other elements – from mental health to food security to other STIs or BBIs – in people's lives, so at an individual service level integration has been happening as agencies respond to people's needs. Maybe our thinking has not caught up to what we are actually doing. Perhaps if we are able to look at the programs we are delivering, we will be able to describe this "integrated exceptionalism" that Maxine has described.

What integration looks like for each ASO – and even each program or service within an ASO – is going to be very different based on who the service recipient is. What people will want and need from services will be very different for different people. And as the background materials described, there is often a benefit to some redundancy or duplication in services, so that people are able to find "the right door" into services for them. Given the efforts of community members and public health workers in the early days of the epidemic, we have been fortunate in the AIDS movement to have resources and space to develop and innovate within our sector. But now, we face a demand to be cost-effective within an era of the "new public administration" and the social shift towards neoliberalism. So, our way forward may be to take an organizational learning and organizational development perspective: if we take the time to reflect on what ASOs are doing, we may be able to create a common language and framework that articulates a model of integration that is flexible and community driven.

Vancouver: Rethinking ASOs? Deliberative Dialogue Summary

Participants:

Becu Annelies
Kindra Breau
Jessica St. Jean
Wayne Campbell
Brian Chittock
Moffatt Clarke
Maxine Davis
Dakota Descoteaux
Monique Desroches
Janice Duddy
Betsy Mackenzie

Katrina Jensen
Jennifer Evin Jones
Sandy Lambert
Stacy Leblanc
Joanna Mendell
Greg Oudman
Sheena Sargeant
Marcie Summers
Kath Webster
Vanessa West
Cathy Worthington

Facilitator: Andrea Langlois



Framing our Dialogue: Reflection and Discussion

Within this section, we have endeavored to summarize the key discussion points from our deliberative dialogue event in Vancouver on November 24, 2014, based on notes captured from the discussions.

Following the respondent panel described above, the deliberative dialogue began with the posing of a few questions to begin our discussion and reflect on the preliminary research: *What was missing from the background research? What did it bring up in your experience? What more do we need to know about exceptionalism, integration, or other pieces?* There were many thoughtful and insightful responses from the room, which can be summarized within four themes:

1. Definitions and clarity around “integration”

While the literature review conducted for *Rethinking ASO's?* outlined the history of AIDS exceptionalism, as documented within published and grey literature, and provided examples of how integration is described in various sectors, participants described feeling a lack of clarity with the definitions of integration, particularly within their jurisdiction and within exciting policy discussions. As one participant said, “We are all doing these things [i.e. offering integrated services] but we just may not be speaking about them in the same way.”

There was a strong desire to collectively define what exactly is meant when we talk about integrated services, and to define when integration makes sense and what it looks like on the ground. One example provided was that while it may make sense to integrate services for HIV with those for hepatitis C, because of common routes of transmission and populations affected, it may not make sense to integrate services for hepatitis A. It was also noted that how we talk about integration within the HIV/AIDS sector has shifted over time, and how in the 1990s, integration referred to moves towards integrating services for different populations, such as creating services for people who use drugs at organizations that had traditionally served primarily gay men. It was also noted that the literature on integration is not definitive with regards to how and whether integration or exceptionalism service perpetuate or combat stigma.

2. What is currently being seen on the ground?

There is little written about the integration of services around other sexually transmitted infections or blood borne pathogens (STBBIs) into HIV services in Canada. Participants were keen to understand the current landscape of services and expressed interest in seeing an inventory of where and how integrated services are being provided within British Columbia. It was noted that Vancouver Coastal Health did an inventory of what ASOs have been doing, but that it has not been shared widely, and participants were curious as to whether other such inventories exist.

The group expressed a strong desire to learn from what has been learned thus far from ASOs that have integrated hepatitis C, or taken a social determinants of health approach. It would be informative to learn from organizations with



experience integrating services, for example hepatitis C prevention and care to identify challenges, successes, and to better understand how these changes are operationalized. This was seen as a gap in the evidence as well as in community-based knowledge. It was also noted that ASOs outside of major cities are more likely to have integrated services, sometimes due to low incidence of HIV in their regions.

3. Strengths of a “no person is left behind” approach

Debates around exceptionalism, as noted in the literature review, are not new within the HIV/AIDS movement. While there were concerns voiced regarding the movement away from exceptionalism, there was a sense of solidarity and optimism within the group, particularly around the social justice roots of the movement and the desire that “no person be left behind” when it comes to opportunities for improving service delivery. Possible benefits of integrating were noted, including how in some regions services have been improved for people co-infected with HIV and hepatitis C, the prospect of a more holistic approach covering the social determinants of health, and that even though we may be working with people with HIV, at times HIV may not be their primary challenge – highlighting that for people with complex issues integrated services may provide better support.

An interesting point was how people may come in for certain services (e.g. harm reduction) before they are HIV positive, and that after an HIV diagnosis, service providers sometimes see their health improve as they start accessing additional services and receiving more support. It was discussed that service providers have been including elements of integration throughout the history of ASOs in Canada, trying to meet people’s needs. It was strongly noted that creating change will not happen in a silo, that “unless we solve issues for all populations, we are not going to solve any of them because they are so interconnected.”

4. Concerns with the impacts of trying to “be everything to everyone”

Some of the concerns discussed included the complexities of integrating low-barrier services, while considering differences for people coming from different walks of life. When changes were made to ASOs that mainly served gay men to also include other populations (such as people who use drugs), this may have led to some feeling isolated. It was expressed that it is not possible to integrate all populations and that HIV is often only a small piece of people’s needs, making it impossible to treat everyone as one population and assume they have the same needs (gay men, Aboriginal People, women, people who use drugs, etc.).

In addition to issues that may arise for those accessing services, the question was posed regarding how changes may affect those working within ASOs, and for executive directors, what might it mean to sit with executive directors from other sectors? Concerns were also voiced that integration is a bureaucratic exercise in expedience, and a response to decreases in resources and increases in apathy. It was also stressed that it is unclear how GIPA/MIPA can be attended to within a post-exceptionalism era and that the current climate of the criminalization of HIV/AIDS non-disclosure in Canada must be taken into account as a differentiating factor between HIV and other related illnesses.

Learning from Our Past to Inform our Future

When looking towards the future, it is often important to look first to the past.

Appreciative inquiry is a model that is used when confronting change by focusing on identifying what is working well, analyzing why it is working, and using this knowledge to define what may be helpful in moving forward. During the deliberative dialogue, the room was broken into small groups to use an appreciative inquiry lens to the topic being discussed. The following questions guided small group discussions, after which each group then shared their most salient points with the room, which are summarized below.



1. What are the successes we have had in the HIV sector in the last 30 years?

There was agreement among those in the room that over the last 30 years that the HIV sector has had many successes – almost too many to count – and the lists identified within each small group were extensive, and in many ways inspiring. Successes have come in the form of advances in treatment and services, but also in the way these outcomes were achieved. Activism and advocacy by those affected by HIV as well as partnerships with health care providers, volunteers, and governments were all identified as fundamental in bringing a social justice lens to health care and influencing public health practices and policies, health care ethics, and patient centered care.

It was clear that HIV/AIDS has changed the landscape of public health as a whole, in ways that perhaps no other illnesses or viruses have, such as by bringing forward issues of privacy and consent. One of the most recognized successes was the development and sustained commitment to GIPA and MIPA principles throughout the movement, and in the progression of both peer-driven service models and community-based research. Some of the other successes highlighted were obtaining dedicated funding streams for HIV, reduced infection rates and no cost treatment in BC, and having HIV recognized as a disability – drawing social benefits. Further, the sector has made progress, although in some cases baby steps, towards effectively serving those not traditionally well-served by the mainstream health systems, such as Aboriginal people, gay men, and people who use drugs. The continuity of leadership was also highlighted, noting how so many people have been working this sector for over 20 years.

2. How have these been achieved?

Participants acknowledged that the successes achieved in BC were possible because of a highly organized movement, which in the early days was propelled by a sense of urgency, given the number of people dying. Strengths of this movement included: people living with HIV and Aboriginal people living with HIV being involved in decision-making and leadership roles and the global implementation

of GIPA/MIPA; the creation of effective alliances and national networks; creativity in accessing and using available funds; and activism, advocacy and the use of a human rights framework.

Additional recognized catalysts for success were the strength of research, education and knowledge generation and the involvement of academics who worked to strengthen the evidence base. British Columbia has also had its share of high profile HIV/AIDS champions, including Dr. Peter Jenson-Young, Dr. Michael O'Shaughnessy, Dr. Julio Montaner and supportive political leaders, such as Gordon Campbell and Phillip Owen. Pressure from academics and allies in the government, media, and the medical community enforced the sense of urgency in mobilizing the effort. All these examples of leadership and advocacy were able to shape public policy (notably in the areas of HIV/AIDS and harm reduction) and to attract resources not only to health care, but also for the creation of diverse community-based services, some serving distinct populations, such as women or people who use drugs, and others focusing on prevention and harm reduction and/or addressing the social determinants of health (i.e., housing services).

3. How can we draw on these strengths as the sector evolves?

Our history and our leadership were seen as the key strengths from which to draw on moving forward – “we have an inspiring legacy, past and future.” Yet ensuring a strong future, it was noted, will require that we continue to nourish the HIV/AIDS movement and work to inspire the next generations of people connected to AIDS service and community-based organizations. It was mentioned that we should keep advocacy alive as we shift our focus to specific issues (e.g., criminalization of HIV non-disclosure).

As we celebrate the successes achieved by this resilient community we are able to draw from its strength and knowledge to keep our identities alive, and maintain our commitment to social justice, equity, sex positivity, the OCAP principles, and the meaningful engagement and leadership of people living with and affected by HIV. Strengths related specifically to ASOs were also highlighted: that ASOs should maintain their identities, peer-based models must be retained, and ASOs must continue to be safe spaces and lead the fight against HIV-related stigma and discrimination.

4. What are our most important strengths that can guide us moving forward?

The following is a list of the strengths respondents felt are the most important to hold on to as we navigate seas of change:

- Social justice, human rights, health equity
- Passing on knowledge and history
- Activism
- Continuity and collaboration
- GIPA/MIPA and the positive voice
- Leaders – the people
- Stories
- Professionalization and succession
- Resiliency
- Inspiring legacy with pride rather than burden
- Harm reduction – philosophy and innovation
- New leaders and listening to critics
- Creativity and humour
- Adaptation and evolution
- Inclusion

Deliberative Questions

At the heart of the dialogue we collectively explored the issue of the future of ASOs, weighed the strengths and weaknesses of various options, and searched for a common understanding. The process was defined by four key questions which were identified ahead of time as important points of deliberation. Each question was set up at a station in the room, and at each station, a master list was created with answers from every group. After discussing all the responses as a room, each person was given the opportunity to participate in the identification of top priorities for the group (through a dot-voting exercise), which are described below.

1. What are the most important elements of current AIDS service models? What is valuable to us?

The core element identified as the most important was that current AIDS service models be informed by people living with HIV, as well as by professionals. The element of priority that followed was the recognition that no one model fits everyone. Other essential elements identified included: having a holistic, social determinants of health approach; trying to reduce competition between organizations; speaking with “one unified voice” and that a network organization (the Pacific AIDS Network) exists to help with this; remaining adaptable, responsive, creative, and client-centered; including capacity building; and being cost effective. The core values identified as strengths of the movement above, were also listed as valued by ASOs, particularly with regards to advocacy, harm reduction, cultural sensitivity/safety, history of the movement, and empowerment.

2. What are the benefits, costs and consequences of the options ahead of us? (i.e., integration and evolving ASOs)

a) Benefits

Reducing stigma was seen as the most beneficial possible outcome of shifts towards more integrated approaches to service delivery, followed by the promise of “one-stop-shops” that are able to meet more needs, save money, and prevent more people from falling through the cracks. Other benefits were seen as stopping the duplication of services and breathing new life into those services that remain relevant, building new partnerships, and using a broader social determinants of health approach. Finally, a key benefit is that many organizations are already working within an integrated model.

b) Consequences/costs

The most concerning issue identified the possibility that some current HIV positive service users may stop accessing services because of decreasing comfort and safety within these spaces – the idea of no longer seeing “people like me” at ASOs. Concern of losing the HIV community’s identity and that medical models might overshadow the community approach were also seen as an issue of high priority. Other consequences included losing therapeutic space for self-identified groups, loss of confidentiality and/or sense of belonging or ownership, and the dilution of limited resources.

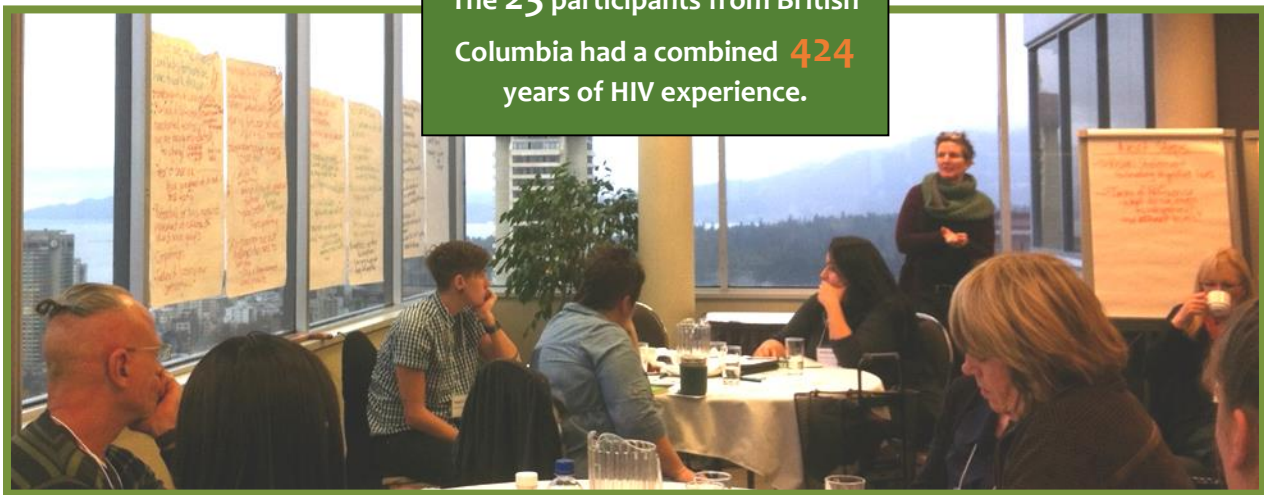
3. What are the inherent conflicts/tensions we have to work through?

The priority issue identified by the most participants was described as “the ambiguity of the whole exercise” (i.e., shift towards more integrated models of service delivery) and, as mentioned earlier, the absence of an agreed upon definition of what we mean when we say “integration.” Is it the

integration of HIV prevention and care? The integration of other related illnesses? The integration of services for multiple populations? A point of consensus also included that as a sector, there is a sense that we do not have a clear understanding of what other changes are up ahead, in terms of medical advances, the changing needs of people living with HIV, and, in particular, what the future of HIV holds as the population ages. Will we see decrease in new infections? Fewer people dying from AIDS? How do we trim our sails appropriately? What is our challenge epidemiologically? What will be peoples' needs for the next 20 years?

Concerns were raised that specific marginalized population groups may be left out as competition increases. In addition many concerns were raised regarding the inherent differences between HIV and other blood borne pathogens (e.g. hepatitis C can be cured), the history of each of movements formed around each of these illness' ability to organize and be effectual and how this impact future working relationships, and challenges in serving multiple populations, and a fear that change may also bring a loss of "our community."

The 23 participants from British Columbia had a combined 424 years of HIV experience.



Summary of the deliberative discussion:

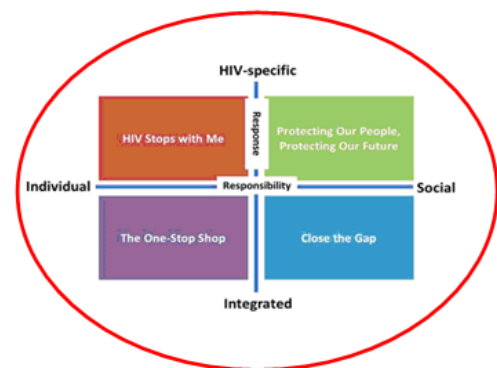
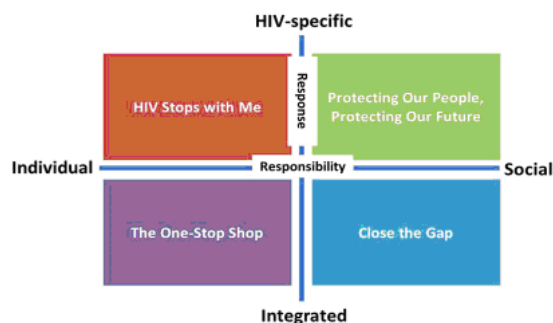
To summarize, the most pressing issues identified through this exercise are as follows and organized based on the how they were prioritized by participants:

- ASOs evolution being driven by people living with HIV as well as professionals
- Benefits: they can be "one stop shopping" for clients, reducing stigma
- Consequences/costs: the medical model can overshadow the community response and clients with HIV may no longer feel comfortable accessing services
- Inherent conflicts: ambiguity of the whole exercise, lack of a definition of "integration," fear that marginalized groups will be left out (women, people who use illicit drugs)
- Where does the future of HIV lie?
- Retaining volunteers if the population and mandate changes within an organization or sector
- How do we lead and cooperate with other sectors respectfully?

- Who and how many people will be accessing services in the next 5, 10, 20 years? How does an aging population of HIV positive people, some of whom have not been accessing services, impact service provision in the future?
- The need to maintain organizations serving unique populations and having unique mandates

Foresight Activity: Scenario Planning

The diagram below,¹⁴ illustrating four different scenarios of the HIV epidemic in Canada over the next 25 years, was shared with the room (see [Appendix B](#)), and participants were asked to reflect on what an ideal fifth scenario would look like. The discussion was brief as the group came quickly to consensus to draw a circle around all four scenarios, to create our ideal fifth scenario (reminiscent of a medicine wheel). There were also many questions that arose about regarding how these scenarios were initially developed and a desire to read the full report that went with it.

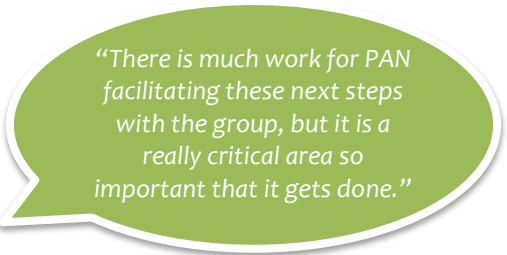


An ideal fifth scenario – encompassing all quadrants

¹⁴ San Patten and Associates (2011). *Foresight Document: Four Scenarios of the HIV Epidemic in Canada over the next 25 years: Uncertainties, Drivers and Forerunners*. Prepared for the Ministerial Advisory Council on HIV/AIDS.

BC: Next Steps

Ideas and recommendations for next steps came from both the discussion during the Deliberative Dialogue, as well as from the evaluation survey, in response to the question: “What would you prioritize as an important next step in this process?” In terms of the proceedings of the Deliberative Dialogue, several participants noted the importance of capturing next steps and developing a plan to ensure that all of the action items identified that day are captured and moved forward

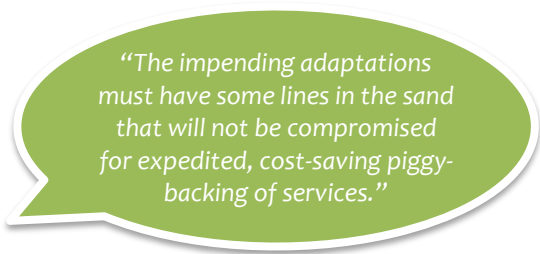


“There is much work for PAN facilitating these next steps with the group, but it is a really critical area so important that it gets done.”

Defining our present state

The first set of next steps aim to define where we are right now within the HIV movement to frame our future discussions. Many in the room felt that it is important to create a clear picture of what is currently being done, as well as specifically define what changes may lie ahead for ASOs. For example, by mapping out what is currently being done elsewhere, organizations may find examples of strategies in moving forward. The following are a list of suggested next steps to take an active role in mapping out the present state:

- Write a consensus document – What do **we** mean when we say integration?
- Document the core values and principles, and identify a list of non-negotiable components of the community-based service model moving forward
- Engage with organizations that are already doing integration work to chart successes, challenges, and failures
- Conduct a community-based gap analysis examining: How do we serve populations well? How do we reach and support vulnerable members of communities? How do different types of services (i.e., population-specific organizations/services or more general) serve different needs? What are we missing?
- Pose a question to the CHERT (Community HIV/HCV Evaluation and Reporting Tool) to learn about how community organizations are integrating services
- Consult PAN member organizations and PHAs about desire for integration



“The impending adaptations must have some lines in the sand that will not be compromised for expedited, cost-saving piggy-backing of services.”

Looking forward

These next set of steps are about looking forward, and gathering information that can allow us to continue strategic discussions of how we should move forward as a sector.

- Gather information on what will the HIV epidemic (and hepatitis C epidemic) look like in 5, 10, 20 years, and what will we need in terms of services and for in particular how service provision will look in relation to those aging with HIV?
- Educate broader the HIV community on integration so more can join the conversation
- Need more qualitative and quantitative research on older adults with HIV and their needs

- Further detail what it is we prioritize to maintain within current service and engagement models (prevention, GIPA/MIPA, etc.)
- Ask the Public Health Agency of Canada for further details on their rationale for integration and the evidence used to support it, which has been cited, but never shared, as well as for the full *Foresight* document
- Develop a process tool that ASOs can use to help think through if and how integration would be appropriate for their organization (no or yes, and if yes, how), provide recommendations for adaptability (how to approach integration and other changes constructively and/or create a framework to adapt to different organizations), and identify successful models of integration
- Have another *Rethinking ASOs?* discussion with a document outlining some of the above as a deliverable

Closing the Circle

As a conclusion to the dialogue, participants were asked: *In closing, what word best describes your experience today?* Below are their responses.



Halifax: Rethinking ASOs? Deliberative Dialogue Summary

Participants:

John Arenburg
Larry Baxter
Julie Dingwell
Sonia Gaudry
Nicole Greenspan
Susan Kirkland
Alana Leard

Maria MacIntosh
Jeannine McNeil
Priscilla Medioris
Sarah Peddle
Julie Thomas
Debby Warren
Gerard Yetman

Facilitator: San Patten



Framing our Dialogue: Reflection and Discussion

1. Definitions and clarity around proposed changes

Looming funding policy changes from the Public Health Agency of Canada (PHAC)

Despite the intention to orient the discussions on the evolving roles and structures of ASOs beyond PHAC's policy shift of STBBI integration, the participants were understandably preoccupied with their main (or in some cases, only) source of funding. Generally, the participants expressed apprehension about the future of the HIV sector in Atlantic Canada and what the restructuring will look like, come 2017. Many noted that there have been mixed messages from PHAC on the national webinars and regional teleconference calls.

The HIV epidemic has changed – and we have changed

The group acknowledged that the HIV epidemic and service needs have changed, and the time has come to face the reality of major changes coming. As one participant who is living with HIV noted, previously, the ASO office was a warm place of hugs and personal concern. Now walking into an ASO does not have that same feeling. A key question, from the perspective of PHAs, is whether the newly diagnosed or those who still need support are getting the support they need.

Need for concrete next steps

With the recently completed *Landscapes Project*,¹⁵ the Atlantic region has a lot of information to guide our thinking, but what is needed are coherent next steps. ASOs need to communicate to PHAC the Atlantic perspective on integration. Not all ASOs are going to be able to expand their mandates and

¹⁵ Kirkland, S., Patten, S., Krahn, T., Peddle, S., Gaspar, M. and the Landscapes Research Team (2014). *Exploring the Landscape of Communicable Diseases in Atlantic Canada*. Halifax, NS: Canada.
<http://www.med.mun.ca/Airn2012/Research/Publications.aspx>

become experts in STBBIs (nor is that the intention of the PHAC funding). ASOs also need to do more work with the provincial governments on STBBIs. The sector needs to have a better understanding of the needs that are being met, and those which are not under a broadened STBBI framework. A key question for the HIV sector is: *“What it is that we can do best with the amount of funding that will be available to us, and how do we focus on the new and real issues of HIV today?”* Overall, the participants agreed that they need to get ready for the policy changes so that they can be poised to be competitive when integration comes into effect.

2. Framing integration as an opportunity

Several of the participants see integration as a chance for agencies to do some “looking within” and to “do something fresh and new.” While recognizing that the HIV sector collectively, as a social movement, has invested a great deal of “blood, sweat and tears over the years” and want to be respectful of our history, the sector also needs to “move on with the times.” While people living with HIV still need support and be acknowledged, ASOs have clients living HCV who “get put on the back burner” despite their numbers being much higher. Other participants reminded that “we have survived open [funding] calls in the past” and that the policy shift is an opportunity to address gaps, yet “still be who we are and where we are.” Indeed, for some small communities, integration is a good opportunity to have services all in one location. Participants also see the current transition time as an opportunity to “think outside the box” and as a chance for renewal.

3. Key partnerships to support integration

The participants discussed key partnerships that will be essential to making integration successful. Priority was placed on better communication and collaboration with provincial governments in order to establish partnerships for financial and program support and also to avoid duplication. In the Atlantic region, AIRN will be an important regional support for the community-based organizations, whether through advocacy with PHAC, or acquiring funds to do community consultations or needs assessments. The staff from the PHAC Atlantic office have committed to ensure that the perspectives of the Atlantic region are represented at national meetings.

Learning from Our Past to Inform our Future

1. Issue at hand: What is the issue? What are we wrestling with?

Participants began the discussion by reminding one another that they need to try to think beyond their own organizations’ interests. The sector must establish the collective needs in the Atlantic region so that organizations can plan how to adequately address them. The sector needs to identify what work needs to happen regardless of how organizations are currently structured and distributed. Funding that was predominantly HIV-specific in the regions will change to include other STBBI issues that some have experience dealing with and others don’t. The old advice used to be “know your epidemic” but now it is know your HIV, HCV, syphilis, gonorrhea, and chlamydia epidemics.

Know your EPIDEMICS (syndemics)

Know your ORGANIZATIONS (allies/partners)

Know your POPULATIONS

Many organizations have already revised their strategic plans to incorporate expanding mandates. Many have also already branched out when it has made sense to do so (e.g., syphilis campaign for men who have sex with men). ASOs should see themselves as one small piece of the continuum of health services and determine how they fit with their partners. Participants noted that we need to recognize that “we can’t be all things to all people.”

2. What constraints are the provinces under? Us? PHAC?

A key action area is to sit down with provincial partners to look at what HIV issues the province is dealing with and what role the sector can play in the continuum of health services. What is the service that ASOs can provide that no one else is providing (e.g., crisis intervention and referral)? ASOs also need to understand what strengths their partners bring that are unique from their own.

It is important to remember that PHAC is not requiring individual organizations to do it all and be everything to everyone. It is about formalizing partnerships, reducing duplication, sharing resources and collaboration. If a gap and assets analysis is what is needed to determine what the proposed Community Alliance Model (CAM) would look like, then the ASOs could advocate as a region for resources to support further community planning processes.

Mental health and addictions and co-infection have been a part of the work of the HIV sector for decades. This is not new, as many ASOs have been doing this already. In fact, for the most part, ASOs have been addressing both HIV and HCV already. The new integration model will simply formalize this broad mandate. And, as before, ASOs don’t have to target all work to every population.

3. What are we good at and who are the partners we need to be working with?

One key strength of the AIDS service sector is that it puts the client first and focuses on their needs and perspectives as much as possible. One of the worries about the transition to integration is that the process has not yet included enough meaningful input from the perspective of PHAs. The support that a person living with HIV/AIDS needed 5 years ago isn’t the same as the supports s/he would need now. At the same time, individuals aren’t always aware of the supports available to them. In thinking through integration, ASOs also need to be mindful of how, for example, someone who is living with HCV would feel about accessing an ASO service. Will people assume s/he was HIV positive and make them feel stigmatized?

One of the challenges of the transition period is that PHAC hasn’t communicated clearly throughout the process. This lack of clarity has also resulted in substantial protectionism and positioning within the community. ASOs want to be able to control the transition from a bottom-up perspective, and focus on how best to meet the needs in our own region, even if that means reorganization. ASOs recognize the need to reduce administrative burden and increase coordination from a programmatic perspective to increase synergies in the region. In addition, ASOs need to put pressure on provincial governments (and potentially municipal governments) to do their fair share. Overall, participants recognize that change is difficult and acknowledge that PHAC has been listening to the results of consultations. Participants in the dialogue reminded each other that there have been open funding calls before, and the organizations have all survived. There is a fear that those who are more adept at grant writing will get the funding, and that small organizations will no longer exist.

There are additional challenges for those who rely on PHAC exclusively for their operational funding that were outlined. Those who have traditionally received project-based funding feel less concern,

since they are accustomed to working from this approach. The participants recognized that they bring many strengths and assets as a community. They bring expertise and strong partnerships. They are doing great work but there are still gaps and more coordination could be beneficial across the provinces. The participants identified that there is a need to map out who they know, who they work with, and who the key partners are. Conversations with partners who are doing sexual health work are already underway in some provinces. ASOs need to be transparent in the approach they are taking and ensure they aren't duplicating.



4. Key strengths of our sector:

- Capacity to create community mobilization around an issue
- Leadership from the PHA community
- Educating the public about STBBIs via social media (public engagement and education)
- Champions and allied professionals from outside the HIV sector (e.g., nurses, social workers or educators) who are passionate about HIV work
- Working with vulnerable populations: capacity to be understanding and compassionate to others; meeting people where they/we are at
- Advocacy: such as around treatment access and drug formularies
- Ability to make changes in human rights via public policy change
- Educate youth/empower youth to take responsibility
- Research and treatment
- Understanding diseases as political and social issues, not just medical
- Ability to use the media
- Involvement of people with lived experience
- Bringing forward taboo topics

Deliberative Questions

At the heart of the dialogue we collectively explored the issue of the future of ASOs, weighed the strengths and weaknesses of various options, and searched for a common understanding. The process was defined by four key questions which were identified ahead of time as important points of deliberation. Each question was set up at a station in the room, and at each station, a master list was created with answers from every group. After discussing all the responses as a room, each person was given the opportunity to participate in the identification of top priorities for the group (through a dot-voting exercise), which are described below.

1. What do you think are the most important elements of current AIDS service models? What is valuable to us?

Some of the key elements of ASO models include one-on-one support services, outreach to marginalized populations, harm reduction, and an overall mindfulness for ensuring accessibility for clients. Peer support is a key program model (both in person and online). Another common model is train the trainer initiatives to build capacity for program delivery and sustainability. Some ASOs operate under a one stop shop model, having comprehensive services in one place to reduce access barriers, reduce stigma, and increase ease of referrals.

Another key feature identified by participants is the deliberate and meaningful involvement/participation of those we serve (based on principles of empowerment and ownership), and PHA engagement in decision making at all levels (GIPA/MIPA/MEPA/MEWA principles). The HIV sector pays attention to the creation of culturally relevant and appropriate services (e.g., western as well as traditional options) and creating safe spaces (within the ASO and outside of the ASO). ASOs are also generally seen as supportive work environments that are diverse, fun and inclusive.

The HIV sector has also been adept in influencing public policy through active engagement in policy-making and analysis processes. This goes hand in hand with strong community-based principles, partnership and coalition building, as we can't do it all ourselves.

The HIV sector has made good use of community mapping as a means to recognize community expertise and partnerships, and to identify gaps. Generally, the sector is committed to using evidence-based research to inform programs and using evaluation to establish the efficacy of interventions. Increasingly, the sector is learning to use a program science lens so that programs and evaluation inform each other.



2. What are the benefits, costs, and consequences of the options ahead of us (i.e., integration and evolving ASOs)?



Participants identified several consequences or costs that may come from pending policy and structural changes. They recognized that some organizations may no longer exist or be amalgamated into larger entities. Another possible cost is that organizations may lose some capacity for individual engagement of clients, and lose person-to-person interactions between staff and clients/members. Some expressed fear about loss of connection to the history of the AIDS movement. Communities may feel grief at the transition and loss of the ASO sector as we know it, and we must make concerted efforts to “bring our communities with us through these changes.” There was also the fear that the work of ASOs may be diluted (e.g., clearing house/referral service only), and that a cost-effectiveness orientation will lead organizations to be service-based rather than user-based.

The potential benefits that may come with policy changes are that innovative program delivery models (e.g., the one stop shop model) may emerge, to the benefit of clients and service providers. New program delivery models and organizational structures will hopefully be more cost effective for community-based organizations and government, and bring improved coordination and collaboration across the non-governmental and governmental sectors. Service providers will learn new roles and responsibilities in community settings. Some participants noted that the integrated work that they are already doing will now be more formally recognized. Reports to funders, for example, may now more accurately reflect the populations that we serve but which did not fit into the previous reporting structures.

The participants recommended that we work together to identify in detail the contributions made by ASOs in our communities, offer and participate in education on cultural relevance and cultural safety (e.g., for Aboriginal communities, training from Healing Our Nations), and ensure that the most-affected populations are hired to offer services within the organizations.

3. What are the inherent conflicts/tensions we have to work through?

The participants identified several points of conflict/tension that will arise through the transition to an integrated model of service delivery. Limited funds innately brings more competition and the potential for conflict. In provinces where there are multiple organizations, there is anticipation of major structural changes such as amalgamation, satellite offices, shared services, etc. One outstanding question is whether there will be cooperation and shared planning at the level of the Atlantic region or by province. Questions remain about the role and responsibility of provincial governments, and how organizations will manage shared accountability under PHAC’s new funding model.

Beyond the financial implications, there will be challenges in working cross-culturally, potentially with several organizations trying to serve the same populations and different perceptions of the needs for various sub-populations (e.g., long-term survivors of HIV vs. those who are newly infected; people living with HIV vs. those living with hepatitis C). With many staff and clients having long histories in the HIV sector, there is bound to be personalization of the changes (e.g., organizations changing their names and mandates), and we need to find ways to not only honour the memory of the HIV movement's veterans, but also build and encourage an openness to change.



There are strong personalities within organizations' staff, board, clients, partners, funders, etc., and within any given jurisdiction, each of these groups likely have different expectations and views on the needed changes for the future. Some participants noted that their boards of directors need to “catch up” in these discussions and be more involved in the transition process. Another concern is that board members who are PHAs are sometimes basing their guidance on their own needs from decades ago.

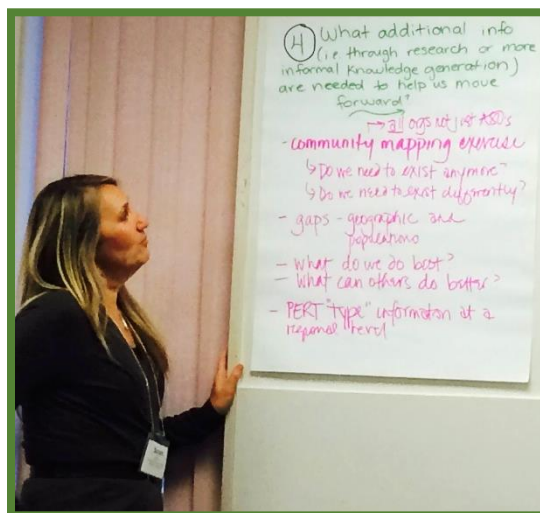
Finally, a key concern identified was that the strong grounding of the HIV sector in principles of GIPA/MIPA could be diluted by under an integrated model. At the minimum, organizations will have to change terminology to meaningful client/user involvement or engagement. Overall, there will need careful communication and fine-tuning to ensure that our terminology and language is inclusive.

4. What additional information (i.e., through research or more informal knowledge generation) is needed to help us move forward?

Community Mapping

A key information gathering step recommended by participants is a comprehensive community mapping exercise of all organizations (not just ASOs) working on STBBIs. The community mapping exercise would help us to answer some key questions:

- Do we need to exist anymore? Or do we need to exist differently?
- Where are the gaps – geographic and population-based?
- What do we do best?
- What can others do better?



Information held by PHAC

The participants identified several pieces of information, held by PHAC at national and regional levels, which are deemed important for the planning process. There is also information that could be gathered by PHAC to help guide organizations through the transition process. Specifically, participants required the following information:

- Funding allocation amounts for each region based on reworked ACAP and Hepatitis C programs
- Compilation of PERT information at a regional level
- Up-to-date statistics – epidemiology, surveillance data (particularly hepatitis C data)
- Case studies of what integration looks like when it is done well
- Literature reviews conducted by PHAC to inform their own decisions

Potential organizational and service delivery models

While the *Landscapes Project* provided a helpful starting point on service delivery models that currently work well for ASOs, participants expressed the need for a formal collection and analysis of service delivery models and organizational structures that are conducive to an integrated mandate. They emphasized that we need to consider other models in addition to the one stop shop.

Priority Action Areas

Based on the “Dotmocracy” voting process, the following were priority areas that the participants wanted to discuss in more depth.

Priority 1: Community mapping, network mapping and gap analysis

As discussed above, the participants expressed a strong need for a community mapping exercise that creates an annotated inventory of all organizations in the region that work on STBBI-related issues. This would also involve engaging in dialogue with existing organizations in each of the provinces and in our communities, working with them to identify partnerships or possible amalgamations, and generally to avoid duplication and identify the overlaps and gaps. Before this can be done, we need to identify a funding source (e.g., PHAC – Community Planning; [Nova Scotia Community Counts](http://www.novascotia.ca/finance/communitycounts/)¹⁶). Network mapping would help to identify where there are already linkages and connections between organizations.

One note of caution from some participants was that our proposed ideas for additional information gathering may be too ambitious since we need to have plans in place by January 2016. However, the *Landscapes Project* took less than a year from funding to completion and we accomplished a lot during that time.

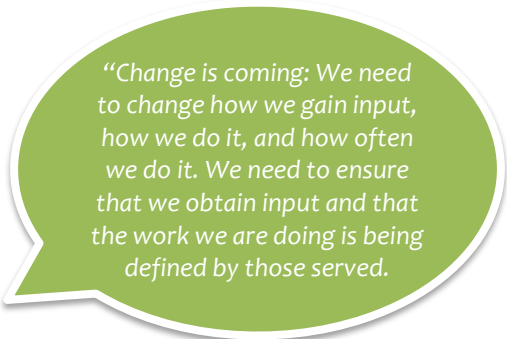


¹⁶ <http://www.novascotia.ca/finance/communitycounts/>

Overall, the participants encouraged one another to think about the bigger process. People are already aligning,¹⁷ without having specific information to provide concrete guidance on the formation of these alliances. With the proposed Community Alliance Model to be implemented by PHAC, organizations will be able to choose partners in any part of the country, and we may not necessarily want to focus only on alliances within Atlantic Canada. By focusing only on Atlantic alliances, we may be missing out on some of the benefits of the Community Alliance Model that would support collaboration across populations, or across social determinants of health.

Priority 2: Sustaining GIPA/MIPA principles

A key concern is preserving the spirit of GIPA/MIPA principles throughout the transition process, without the principles being diluted, improving user/client involvement, and broadening the principle to more inclusive terminology beyond just HIV or PHAs. There is an overall concern about how we move toward an integrated model with meaningful engagement of an expanding client base, and ensuring that the transition is respectful of our current clientele.



“Change is coming: We need to change how we gain input, how we do it, and how often we do it. We need to ensure that we obtain input and that the work we are doing is being defined by those served.”

Some key questions that arise in regards to client engagement:

- How do we provide an equal voice for all members of our client base with no extra resources?
- How do we create inclusive spaces where people feel safe and comfortable together?
- How do we ensure that the transition process stays focused on the individuals we serve and not the organization’s interests?

By-laws will have to be reviewed and rewritten, program policies will need to be reviewed and rewritten, and partnerships will need to be expanded.

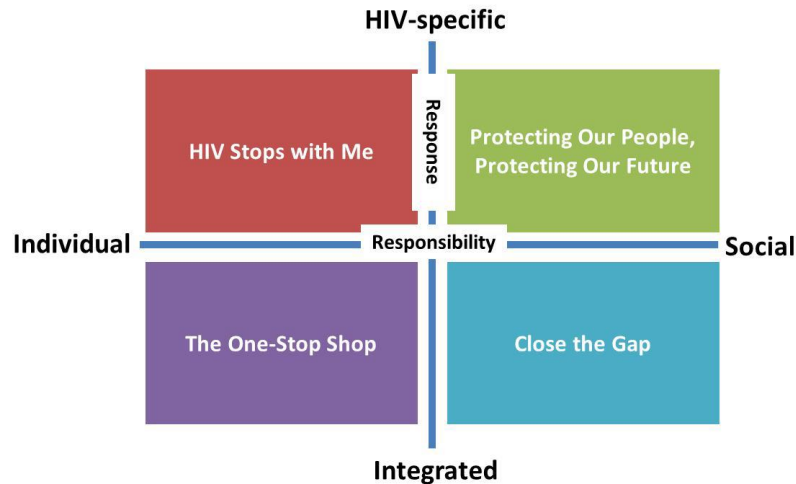
Communication with PHAC

A key information gap for ASOs is the dollar value of regional allocations that will be available under PHAC’s new funding model. It is likely that under current HIV-specific criteria, a recalculation with up-to-date epidemiological data, social determinants of health indicators, and balancing the principles of burden of disease, equity, vulnerability, the Atlantic region stands to lose (while Saskatchewan would see a significant increase, for example).

The participants expressed the challenges and fears around the funding policy shifts. The process towards integration should be considered as a phased process, with the first phase focusing on building alliances, eventually moving over 5 years to more formal coalitions. One source of anxiety is that PHAC is asking us to do two major paradigm shifts at the same time – integration and coalition building, leaving the ASOs to feel overwhelmed.

¹⁷ Nova Scotia and Prince Edward Island groups have been discussing how to work together under a Community Alliance Model. Newfoundland and Labrador have also been involved. New Brunswick ASOs are already exploring ways to partner with each other and also more broadly in the region (could work on project grants together, for example).

Foresight Activity: Scenario Planning



Using the four scenarios as a discussion tool (see [Appendix B](#)), the participants discussed the following three questions:

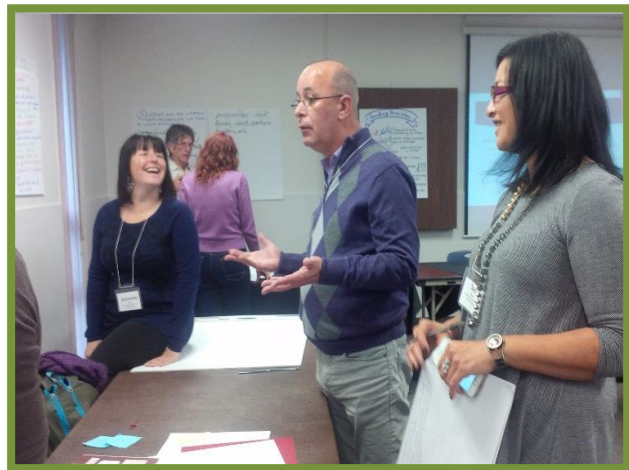
1. What are the focus areas of actions/services for your ideal fifth scenario
2. Would your ideal fifth scenario have priority populations? If so, which?
3. What would the name of your ideal fifth scenario of service arrangement be?

Ideal Fifth Scenario

According to the participants, an ideal 5th scenario would be one in which individuals have all the tools that they need for care, treatment and support of STBBIs. In discussing the One-Stop Shop scenario, the AIDS Coalition of Cape Breton (ACCB) was discussed as a good example. The model makes sense for the ACCB community context, and incorporates a holistic set of services along with navigation assistance and a focus on priority populations (e.g., youth, Aboriginal people, women, gay men, baby boomers). The participants conceptualized the one-stop shop as an optimum model for intake and referral.

Clients would be moved into different services or programs based on their needs identified at intake. Referrals to partners would focus on closing the gaps that any one organization cannot fill. It was also noted that the one stop shop does not necessarily have to be in one location, but rather, it could be reimaged as a network of organizations working in partnership as referral sources.

Another important feature of an ideal fifth scenario is being able to “come in any door and not be dropped.” This translates into seamless and connected referrals, navigation and advocacy services,



one-on-one services, and broad systemic change to support these features. The idea is not to “pass the buck.”


Important throughout the process is meaningful engagement of clients, bottom-up decision making and program design, and thinking about an ideal fifth scenario from the perspective of a PHA journeying through each scenario and the inherent benefits and challenges of each. A key concern voiced by participants is: Will other groups really understand HIV stigma? We need to ensure that there are still safe spaces for PHAs and work to get other service providers to understand the issues of stigma if HIV services are integrated into other organizations.

The participants saw an ideal fifth scenario as leaning towards the right side of the grid (social in focus), with an emphasis on connecting to peers (e.g., buddy systems), peer leadership and community capacity building. Some key organizations to work more closely with are on the right side of the grid – such as gay men’s health organizations or Aboriginal organizations.

The participants also felt that the vertical axis of the grid highlighted the question: *Are HIV-specific services still needed?* They noted that issues such as sexual health, poverty, housing, and other social determinants of health make a strong case for an integrated (non-HIV-specific) approach.

Atlantic: Next Steps

Ideas and recommendations for next steps came from both the discussion during the deliberative dialogue, as well as from the post-event evaluation survey, in response to the question: “What would you prioritize as an important next step in this process?” In terms of the proceedings of the event, several participants noted the importance of capturing next steps and developing a plan to ensure that all of the action items identified that day are captured and moved forward.



“We need a shareable report – for participants and PHAC – that is clear about our anxieties, strengths/ assets, and key features of ASO models that must be preserved.”

Clarifying our present state

The Atlantic region has already undergone an extensive community-based research project to create a comprehensive picture of its organizations and programs working on HIV and hepatitis C issues (*Landscapes Project*), but there are still some pieces of information missing that would give more clarity to the HIV sector in the planning process towards integration. The following are a list of suggested next steps to take an active role in mapping out the present state:

- Community mapping (not just of the HIV sector) to identify who we work with and who we need to work with
- Network mapping to identify where there are already linkages and connections between organizations in each of the provinces and in our communities, collaborate in identifying partnerships, overlaps and gaps.
- Needs assessment and/or gap analysis that comes from community – How do we serve populations well? How do we reach and support vulnerable members of communities?

Clarifying policy change implications

A key next step for the Atlantic region is developing clarity on “what we’re working with” in terms of integration policy shifts. Some key next steps for clarifying the implications of these changes are to:

- Seek clarity from PHAC on the funding allocation that will be available to each region
- Engage in dialogue with provincial governments to clarify how they will help to meet the community-based needs around STBBIs
- Investigate or brainstorm promising service delivery models and organizational structures that are conducive to an integrated mandate, and analysis of how best to transition to an integrated model

Looking forward

Many participants felt that it is important to proceed with the perspective of integration as an opportunity. These next set of steps are about looking forward, and gathering information that can allow us to continue strategic discussions of how we should move forward as a sector.

- Identify key partners that we need to work closely with in order to make integration effective and engage in discussions with stakeholders beyond *Rethinking ASOs?* participants
- Work with our client populations and boards to deliberately plan how to preserve principles of GIPA/MIPA (or more broadly, meaningful engagement of client populations) throughout the transition to integration
- Follow up with further dialogue as we move towards PHAC’s Letter of Intent phase (2016)

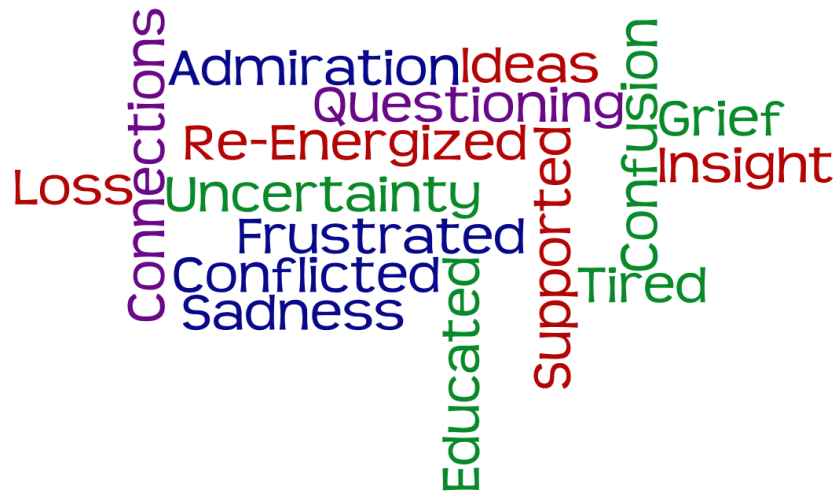


Closing the Circle

Participants spoke about feelings of uncertainty, sadness and loss for organizations who will be shut down and noted the diminished involvement of PHAC staff locally is problematic.

"I feel hopeful and re-energized that we are getting the pieces together and will work together to get it right."

On the flip side, participants felt more supported in the process after participating in the event and hearing about where others are in the process and where they fit on that trajectory.



Conclusion and Next Steps

Overall, the *Rethinking ASOs?* process was successful in bringing together a cross-sector team of leaders in HIV research, service delivery and policy in both the Atlantic and BC. The deliberative dialogues events provided the opportunity to have similar discussions across both regions in order to foster cross-sectoral collaboration and opportunities for knowledge sharing, set priorities for action as we move out of an era of AIDS exceptionalism and towards integration, and identify key research (or information gathering) priorities to help us navigate through the current policy/funding and advocacy contexts. Many participants felt that it is important to proceed with an assets-based orientation that takes stock of and appreciates the strengths brought by the sector, and proceeding with the perspective of integration as an opportunity to move forward as a sector.

The organizing committee members and facilitators were impressed with the honest, open conversations that took place during the deliberative dialogues. The background research, presented within the videos and resource pages, were well-used and participants actively reflected on them. They were useful resources to have as a precursor to the meeting as they imparted useful information and set the stage for fruitful discussions and the opportunity to think together.

It was advantageous to begin the meeting with a discussion of the HIV sector's strengths, as it set the tone for an assets-based discussion. There was broad representation from people with various numbers of years of experience living with HIV and/or working in the sector. The discussions were informed by veterans of the HIV movement who could reflect on what we've accomplished. At the same time, we were inspired by the next generation and learned how to create an HIV sector that new members would be excited to join.

The meetings resulted in valuable ideas for next steps that can provide clear direction for each region in the lead-up to PHAC's proposed funding policy changes. A clear message for PHAC is that many ASOs are feeling anxious and overwhelmed, particularly in the Atlantic region, and this is fueled by uncertainty about the funding constraints that each region will be facing. And finally, there is universal commitment to uphold the principles of GIPA/MIPA throughout the transition process.

Each region had its own specific next steps, but overall, some **key action areas** for both regions are:



- Needs assessment and/or gap analysis that comes from community – How do we serve populations well? How do we reach and support vulnerable members of communities?
- Consult organizations and people living with HIV about desire for changes and commit to preserving GIPA/MIPA principles through this evolution
- Developing clarity on “what we’re working with” in terms of integration policy shifts
- Investigate or brainstorm promising models from other jurisdictions, how best transition to an integrated model
- Develop a report with official recommendations for adaptability – how to approach changes in service delivery models constructively and/or create a framework to adapt to different organizations
- Have a second discussion with a subsequent report outlining some of the above as a deliverable
- Develop a cross-regional consensus statement (endorsed by both BC and Atlantic regions) about what our strengths are, what we mean by “integration” and what elements of the HIV sector must be preserve

Appendix A: What Did Participants Say about the Event?






Below are some general evaluation findings gathered through a post-event online survey (n=26). Additional evaluation findings are embedded within the report.

(Completion rate: 85.19%)




In which region did you participate in *Rethinking ASOs*?

Response	Chart	Percentage	Count
Atlantic		34.8%	8
British Columbia		65.2%	15
		Total Responses	23

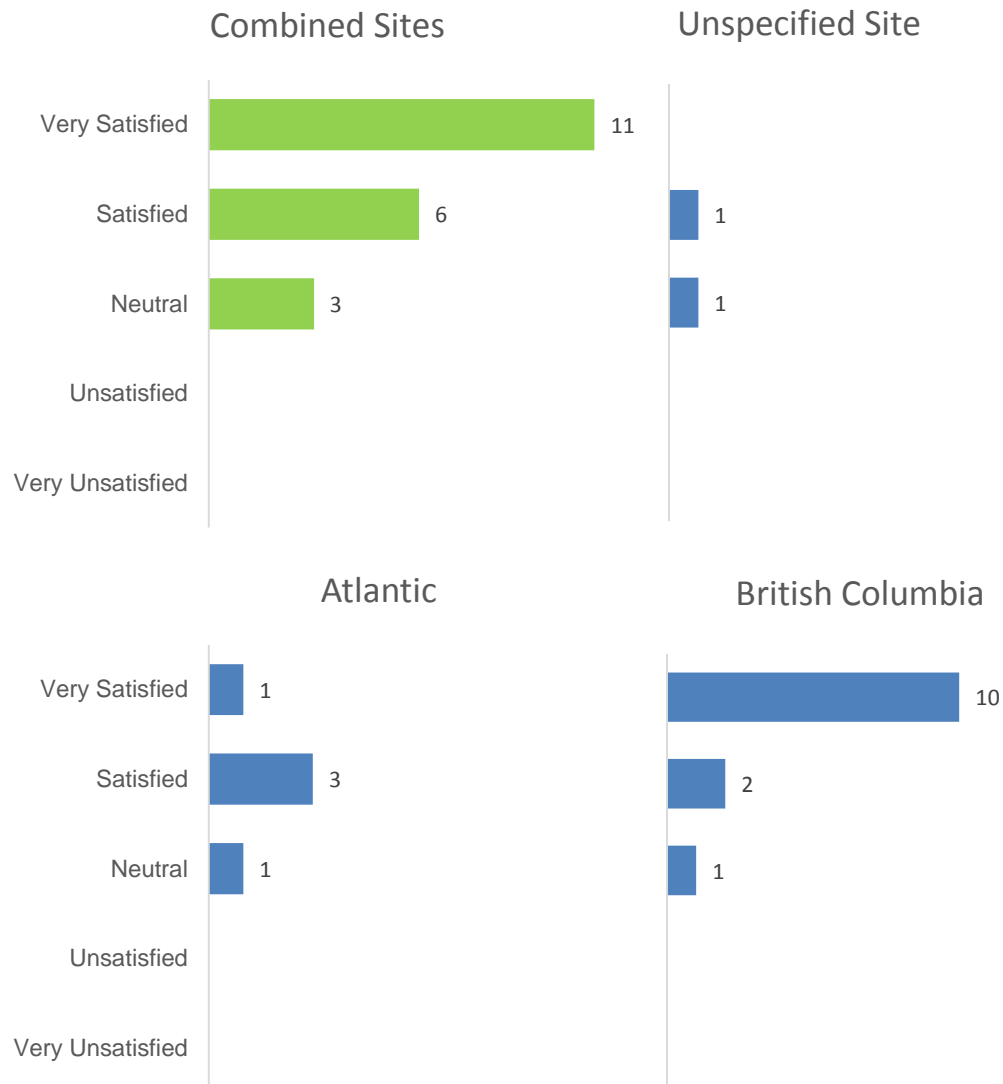
Which of the following best represents you?

Response	Chart	Percentage	Count
person with lived experience		21.7%	5
policy-maker or decision-maker (works for government or health authority)		4.3%	1
staff at a community-based organization		52.2%	12
academic		17.4%	4
other		4.3%	1
		Total Responses	23

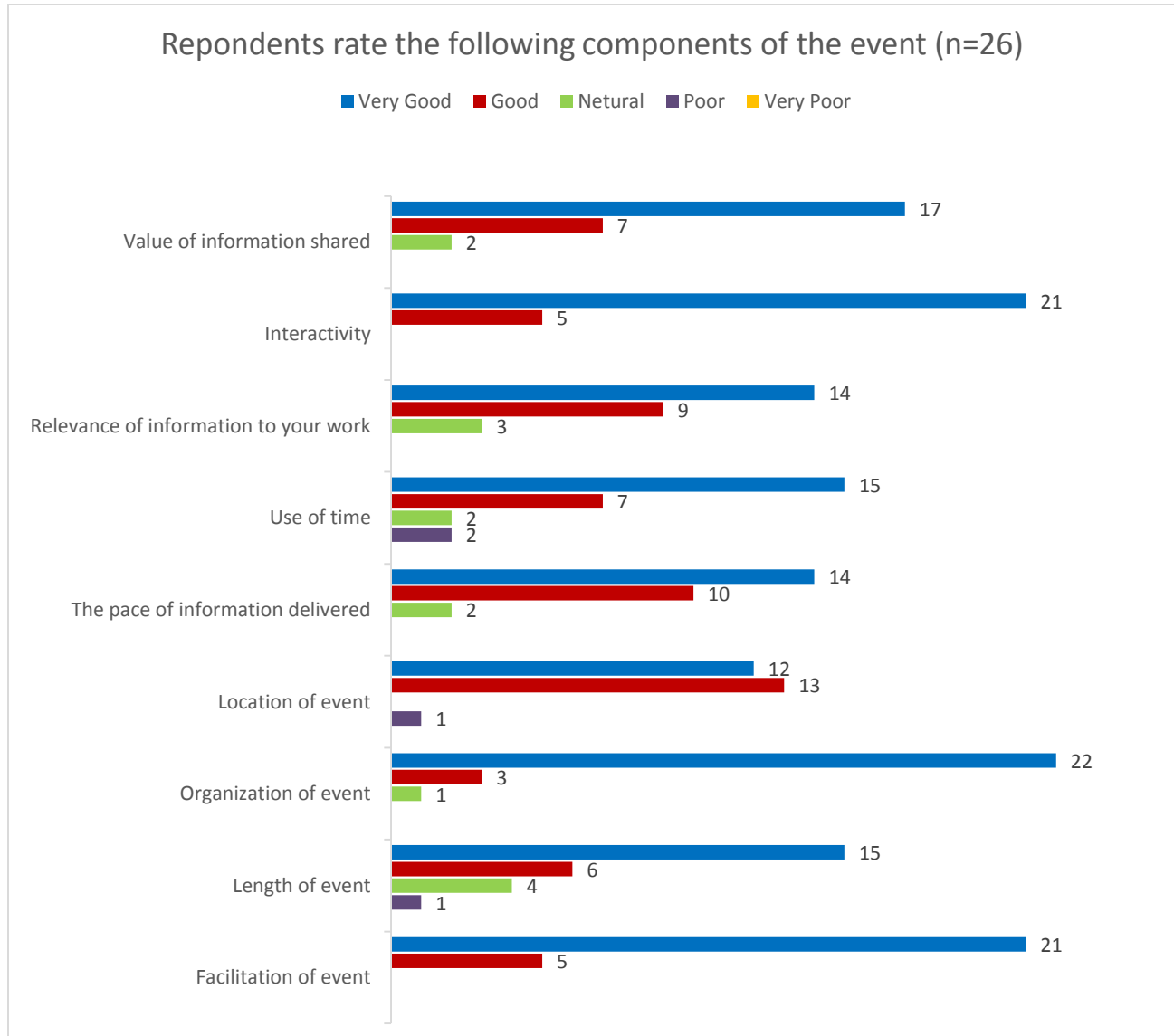
Overall, how would you rate your satisfaction with the *Rethinking ASOs*?

Response	Chart	Percentage	Count
Very Satisfied		55.0%	11
Satisfied		30.0%	6
Neutral		15.0%	3
Unsatisfied		0.0%	0
Very Unsatisfied		0.0%	0
		Total Responses	20

Overall, how would you rate your satisfaction with the *Rethinking ASOs?* deliberative dialogue event?





How would you rate the event on the following?







Considering what you have discussed and learned on this day we would like you to reflect on the questions asked in the pre-event survey: What do you think are the key elements of current AIDS service models that need to be preserved moving forward? What could be released or let go of? Are there any new insights or thoughts that you would like to share?

Atlantic Region		
Theme	Frequency (n=)	Related Quotes
Need to remain client-oriented and to include people we serve	3	Value of input and participation of people we serve
Not ready or unsure of what to release in terms of services	2	I'm not sure the process of releasing/letting go is something that I'm prepared for (personally), or the sector is prepared for. However, its hard to prepare for things when you're not exactly sure what will happen/what will be let go, and the consequences/implications of these losses.
Need to ensure we are working within a human rights framework	1	
Need to keep prevention, education and direct support	1	
Need to ensure that services are culturally appropriate	1	

British Columbia		
Theme	Frequency (n=)	Related Quotes
Need to ensure that GIPA is kept as a fundamental	2	It's not a new thought but I will repeat - GIPA
We need to do some future state planning and thinking about the epidemic and services needed	2	Key elements need to be reevaluated to integrate the needs of a diverse group of people. We have a first generation of HIV positive individuals aging with HIV and we also have a youth generation experiencing HIV in a very different way. More integration at ASOs would be a helpful conversation to have.
Let go of the fear of change – stop resisting and accept integration	2	Let go of the fear of change. Everything has already changed - it's time to stop resisting.
Appreciate the resilience of ASOs through history	2	My insight was into being reminded of the resilience of the current models of ASO's. They have continually adapted to the shifts and changes of serving a population with changing needs and changing demographics as the disease itself has evolved from a death sentence to a chronically managed condition.

Need to ensure safe spaces and culturally relevant information	1	
Feeling of “moving ahead without us”	1	 When I returned back to my agency and provided the information about the session to my staff, there continued to be a feeling of "moving ahead without us". Basically, that as the HIV/AIDS movement was so grassroots and inclusive of PHAs, this shift by the federal government seems to be exclusionary to PHAs.
This is just a first step in important ongoing dialogue	1	
Need to be proactive and collectively identify successful models of service integration	1	 We need to collectively identify successful models of HIV service integration (in the many ways that is happening) and present a more proactive model of integration for policy makers/funders.
Need to keep skills-building	1	
Need to keep wellness models	1	
Need to continue to address stigma	1	

What was the biggest learning you had from this process?

Atlantic Region		
Theme	Frequency (n=)	Related Quotes
Appreciate the openness and honesty in the room and meaningful conversation	2	 I really valued the time for meaningful conversations with different people who are responding to change. It helped me understand my own responses to uncertainty, and to get some insight in how some groups may go from here.
Learned about the opinions of organizations on the ground	2	 The opinions of organizations at the ground level on the changes to come.
Anxiety	1	 There are some who are much more anxious than others, overall openness and honesty of participants in expressing their fears and anxieties
This discussion came a little late as some people had preconceived ideas which dampened free thinking/discussion	1	 This was a little late as some people were already establishing their own scenarios which dampened the initial free thinking.

Need to move forward while retaining our roots as ASOs	1	That others share some of the same concerns about how we move forward yet retain our roots as ASOs.
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Challenges of seamless collaboration in Atlantic due to geography	1	
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British Columbia		
Theme	Frequency (n=)	Related Quotes
Feeling inspired, to know I am not alone in thinking about these issues	3	What creative, high level thinkers participated in a respectful, collegial manner.
Consensus among participants	2	... how much consensus there was in the room on various issues and excited by the willingness to continue to evolve this work in partnership and collaboration - for example a possible consensus statement on integration for BC.
Have a better understanding of exceptionalism and its complexity	2	the issue gets more complex as you start to breakdown subgroups... there are some areas where exceptionalism is a must and then there are other areas where exceptionalism can lead to further stigma and discrimination.
Integration is not a new phenomenon	1	I also learned that while the buzzword of integration may be relatively new, this is something that may be being done to varying degrees in this sector already.
About the costs and benefits of integration	1	I learned that while the move to further integration of services in the area of ASOs may be inevitable, there will always be benefits and costs to this process.
We need to encourage emerging leaders to have a voice in the change	1	That we need to encourage emerging leaders from the next generations to have a voice in the changing landscape of the 'movement' and we longer term players can start passing the torch...
These conversations need to keep taking place	1	These conversations need to keep taking place because we are experiencing a shift in what HIV looks like for positive people and new funding expectations.
Beneficial to focus on successes	1	I really appreciated starting the conversation focusing on our successes. It was an important and positive framing tool for the rest of the day and I learned a lot from this process.
No one model for every organization/ region	1	

How could this event been made better?

Atlantic Region		
Theme	Frequency (n=)	Related Quotes
More voices at the table from a wider audience, including PHAs	4	<p>Attendance by additional stakeholders that are partners with AIDS organizations such as needle exchanges or methadone clinics.</p> <p>More PHAs</p>
More answers from PHAC	1	<p>more answers from PHAC so that we know what we're working with in terms of regional allocation</p>
Needed more time to talk about how to develop LOI and determine our directions	1	<p>Given time restraints - it would be challenging to fit all needs within time frame. Seemed to want to steer towards more research to inform where we go yet we have very limited time frame to develop LOI and determine our directions.</p>
Longer event	1	

British Columbia		
Theme	Frequency (n=)	Related Quotes
Bigger room	2	<p>A little bigger room, with more space for moving around and putting up sheets of paper</p>
Switching around seating to increase interactions with different people	2	<p>Move the participants at each table around once a section of the agenda was completed. Working with the same people all day felt stale.</p>
Longer, more time for discussion	2	<p>could have been longer.... lots of discussion on a tight schedule</p>
Discussion could have benefited from having some epidemiological/surveillance data presented to provide context	1	<p>I wonder if the discussion might have benefited from having some epidemiological/surveillance data presented to contextualize and provide a common understanding of the populations we were talking about.</p>
More voices at the table from a wider audience, including youth and new Canadians	1	
More action steps coming out of the event	1	
Some exchange with the Atlantic group	1	

Is there anything else you would like to tell us?

- Thank you for a stimulating and open discussion. San as a facilitator was great, kept us on track, interesting exercises and lots of variety.
- One of the best HIV events of this year; maybe of the last several years: the opportunity to bring a thoughtful group of people together to address an issue highlights our strengths and enables collective action as a community (of practice).
- thank you
- The event was excellent - a day very well spent! Thank you to PAN for the valuable work you do so well.
- Great initiative but I still think we are being backed into a corner by political players not telling the whole truth.
- How much I appreciated being a part of this dialogue. It was inspirational to be in a room with so many dedicated, passionate key players in the AIDS mosaic of organizations that have been providing compassionate programs and services to so many, for so many years. I loved it!
- Appreciative of the opportunity to come together with Atlantic ASOs to discuss the issue of integration.
- I somewhat found it difficult to speak with the PHAC funder in the room. In the future, for people to be able to speak more freely, meetings should not include any representative from any funders.
- Thanks so much for a fantastic opportunity. Very stimulating and so well prepared.

Appendix B: Foresight Scenarios



Foresight of HIV/AIDS in Canada in 25 Years

In 2011, the Chief Public Health Officer (CPHO) expressed interest in the thinking of the Ministerial Council on the *Federal Initiative to Address HIV/AIDS in Canada* (Council) on the future of HIV/AIDS. The Council commissioned [San Patten and Associates Inc.](#) to develop a foresight document on the future of HIV/AIDS in Canada over the next 25 years. The report will be used as a basis for the Council to inform the CPHO and the *Federal Initiative to address HIV/AIDS in Canada* regarding the future of HIV/AIDS with particular emphasis on HIV/AIDS policy.

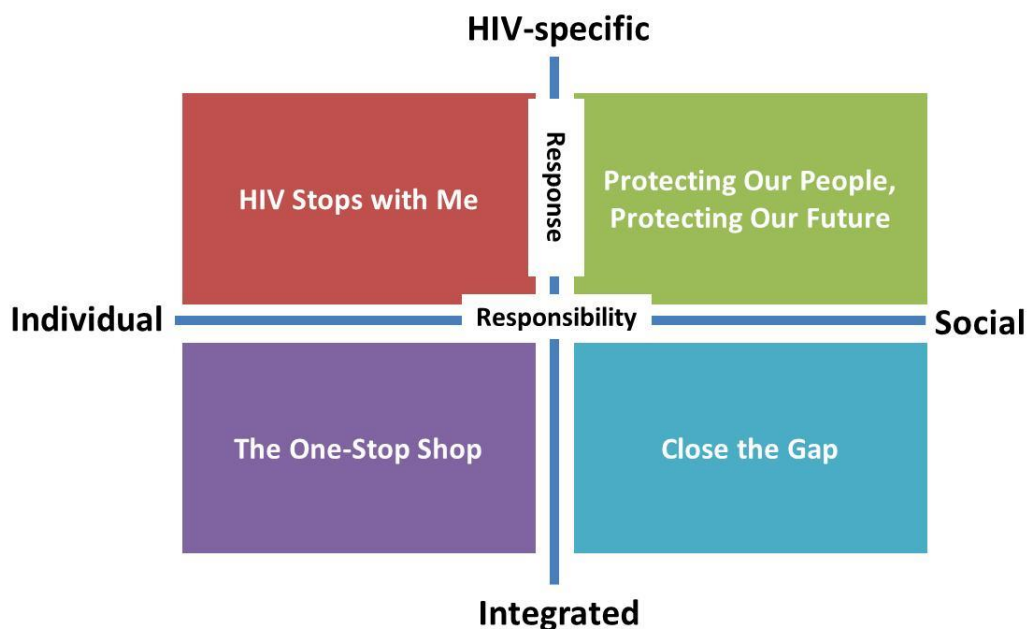
The Foresight Document provides a comprehensive analysis of possible futures for HIV/AIDS in Canada, which can guide the Government of Canada's evidence-based and strategic decision making, and support its capacity to act in response to new trends in the HIV/AIDS epidemic. The Foresight Document will assist in the planning, development and implementation of strategic policymaking.

Methodology

In order to develop a comprehensive and visionary account of possible future scenarios of HIV in Canada, the consultants conducted literature review, key expert interviews, and national stakeholder consultation meetings. The key experts were those who are domestically or internationally connected to HIV/AIDS issues, health care system analysis, and/or social, political or economic trend analysis.

The Scenarios

We have given each scenario a distinctive, memorable name to try to capture its key characteristics in an abbreviated way. We provide below a brief summary of some of the key characteristics for each scenario.



Scenario One: HIV STOPS WITH ME ¹⁸

Policies and services are focused on meeting individual HIV prevention, care, support and treatment needs. The emphasis is on giving people the tools they need to make healthy decisions or actions. There are few linkages between HIV-specific services/policies and other illnesses or social issues (e.g., little connection with social determinants of health). The community response is led by AIDS Service Organizations (ASOs) and the government response is predominantly through HIV-specific funding and programs. HIV/AIDS has its own dedicated siloed funding from the health sector. There are HIV specialists and special clinics set up for HIV and they are not well-equipped to meet other health needs. HIV prevention focuses on individual risk behaviours, health promotion and capacity building to help individuals reduce their risk. Awareness campaigns messages include: “know your risks,” “protect yourself,” “do you know your status?”. There is a focus is on individuals’ rights to access health and social support services. Services are not targeted to specific vulnerable populations, but rather to individuals on a case-by-case basis.

Scenario Two: PROTECTING OUR PEOPLE, PROTECTING OUR FUTURE ¹⁹

There is a focus on key populations most at risk for HIV, but at a social level. Interventions target communities most at risk, and are primarily community development approaches. Programs and interventions are tailored to meet the needs of communities most at risk. The most successful program models are driven and delivered by these communities themselves. Prevention programming and messages are tailored to specific communities, and prevention and support programs are strongly based on peer models. The organizations responding to HIV have a mandate to work directly within these communities (e.g., immigrant-serving organizations, gay men’s health organizations, ethno-cultural community organizations). The community-based organizations either have a primary HIV mandate with programming targeting specific populations, or they have a primary focus on a specific population group, and have HIV-specific programs. Programs focus on addressing HIV-specific stigma and discrimination, social isolation amongst key populations (MSM, IDU, people from endemic populations, Aboriginal). Government responds by providing financial supports to community organizations, and funding is not necessarily just from the health sector. Data collection and policy analysis is conducted at the level of populations (e.g., status reports for specific vulnerable populations). Funding programs are HIV-specific, using a population-based approach that prioritizes communities at highest risk.

¹⁸ “HIV Stops With **Me**” is the name of a U.S. social marketing campaign that began in 2000 as a prevention program for HIV-positive people in Los Angeles and San Francisco. The original goals were to “discover more effective ways of (voluntarily) finding people who are HIV+ but don’t know it yet, so that they can be offered the options of treatment, social services and connection to supportive community organizations.” and to “directly or indirectly support positive people in reducing their risk of infecting others while leading full, healthy lives”. (<http://www.aegis.com/pubs/bala/2000/BA001002.html>; Accessed 3 December 2010)

¹⁹ The scenario name, “Protecting Our People, Protecting Our Future,” is a combination of two social marketing campaigns: “Protect the People” was a tag line from a 1994 poster by Feather of Hope Aboriginal AIDS Prevention Society (Alberta), and “Protect Our Future” was an adapted tag line from 1992 from the Joint National Committee on Aboriginal AIDS Education and Prevention.

Scenario Three: CLOSE THE GAP

Canada's approach to HIV is to address the social determinants of health, without a focus on HIV specifically. This includes a health systems approach. The focus is on addressing housing, poverty, income security, gender inequities or homophobia—which is seen as necessary to reduce the conditions of vulnerability to HIV. Programs and policies seek to change the underlying causes of HIV for different populations—by targeting the social determinants of health that are most relevant to each population. This involves working in broad coalitions with many other stakeholders, in cross-cutting themes. The community response is organized around specific social determinants of health, with a great deal of collaboration and referrals amongst the organizations. The community response is not HIV-specific but addresses one or more social determinants which drive risk for HIV and other health and social issues. Services take the form of health promotion and prevention initiatives at a community level (e.g., vocational training, community kitchens, wellness programs), and are structured to be responsive to the needs of vulnerable populations. This approach is believed to have an indirect impact on the HIV epidemic, requiring long-term investment in creating systemic and structural changes. Government funding is channelled through programs which seek to reduce inequalities around social determinants of health for key populations (e.g., income support programs for new immigrants, entrepreneurship grants for Aboriginal people).

Scenario Four: THE ONE-STOP SHOP

The focus is on meeting individual needs from a holistic perspective, and assisting individuals with their needs across a range of determinants of health. There are strong partnerships and referrals between community-based organizations and other agencies. The goal is ideally for an individual to have access to “one-stop” services that meet all of their social and health needs, with a seamless referral process. The person is at the centre of the network of services that are set up to meet their broad range of individual needs. Funding programs are not HIV-specific, but focus on cross-cutting issues of poverty, income generation, housing, and how they can alleviate HIV-negative individuals' vulnerability to HIV and how they can help meet the support, care and treatment needs of people living with HIV. Community response is focused on individual needs, through mechanisms such as multi-disciplinary case management teams, giving individuals access to holistic services and supports that promote their general health, including reducing their vulnerability to HIV. The government response also includes integrated supports and funding programs that support collaboration and referrals across health and social issues, such as electronic case management database systems.