



# HIV & Aging

## A 2013 ENVIRONMENTAL SCAN OF PROGRAMS AND SERVICES IN CANADA - COMMUNITY REPORT

Scan conducted at the request of the National Coordinating Committee on HIV and Aging - March 2015

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*“The needs of people aging with HIV are complex and extend across sectors, disciplines and agencies to include AIDS service organizations and programs, hospices, hospitals, housing providers, infirmaries and shelters.”*

Program Manager, Urban CBHO/Housing Organization, Central Ontario

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*This project was guided by the HIV and Aging Programs and Services Environmental Scan Project Team (the Project Team) consisting of: older PLWHIV, service providers, policy analysts and researchers.*

**This report outlines the results of a national survey** of programs and services which address the needs of older people living with HIV (PLWHIV) in Canada.

Finding out what programs and services are currently offered by community-based HIV organizations (CBHO), historically called AIDS service organizations (ASOs), HIV clinics and community health centres represents a meaningful first step toward empowering front-line and community-based health and social service organizations to better meet the needs of older PLWHIV. We used the scan to answer the following questions:

*What is out there in terms of HIV and aging-related programs and services being offered by HIV organizations across the country?*

*How are community-based HIV organizations and HIV clinics meeting the needs of the older PLWHIV they serve?*

## The Project Team

This project was guided by the HIV and Aging Programs and Services Environmental Scan Project Team (the Project Team) consisting of: older PLWHIV, service providers, policy analysts and researchers. The project was led by Charles Furlotte, a PhD candidate in the School of Social Work at McMaster University and fellow with the Universities without Walls (UWW) training program. The Project Team has been involved since the beginning, designing the study, creating and pilot testing the online survey, encouraging organizations to participate in the research, and ensuring that the results of the scan are accessible to and used by PLWHIV, community-based HIV organizations and others.

## Context

PLWHIV are now living longer thanks to combination antiretroviral therapies.<sup>1</sup> In 2008, people age 50 and older made up about 15% of the over 65,000 PLWHIV in Canada.<sup>2</sup> By 2012, the United Nations estimated that more than 30% of PLWHIV in Western and Central Europe and North America were age 50 or older.<sup>3</sup> New infections are on the rise among older adults too.<sup>2</sup> This trend will culminate in over half of all PLWHIV in North America, the United Kingdom and Australia reaching age 50 in the next few years.<sup>4-6</sup>



## The Survey

The Project Team developed a bilingual survey to be completed by service providers (paid or unpaid) from community-based HIV organizations, HIV clinics and community health centres (CHC) across Canada plus Centres de santé et de services sociaux (CSSS) in Quebec between October and December 2013.

This 30-minute, 30-question online survey asked providers about the structure of the organization they work in (the type of organization, number of employees and location) and whether their organization provides programming specifically focused on aging with HIV. Participants who said that their organizations did offer such programming were asked to complete a series of additional questions describing these programs. Participants who said that their organizations did not provide HIV and aging programming were asked to describe what contributed to this decision.

## Recruitment

The Project Team worked with several national and provincial organizations (CIHR Canadian HIV/AIDS Trials Network, Canadian AIDS Society, Ontario and Nova Scotia Associations of Community Health Centres, and the Canadian Working Group on HIV and Rehabilitation [CWGHR]) to invite their members to participate in the survey. Members of the Project Team also created a list of other relevant care providers and contacted them directly. Survey flyers appeared on the social media feeds of the Ontario HIV Treatment Network, the Pacific AIDS Network, and CWGHR. We estimate that, in total, over 400 organizations across Canada were invited to participate.

## Analysis

Data from the scan was summarized and open-ended responses were coded by a subgroup of Project Team members who shared an interest in data analysis. A draft research report was shared with all members of the Project Team as well as members of the National Coordinating Committee on HIV and Aging who had first identified the need for the scan. All were invited to review the draft, ask questions and respond to the findings. A draft of the community version of the report was circulated to members of the National Coordinating Committee on HIV and Aging's Programs and Services Working Group for final review prior to printing.

## Findings

The next section describes the organizations represented by survey participants. It also outlines what service changes these organizations have observed and experienced in response to an aging population of PLWHIV.

## Who are you?

A total of 92 service providers from diverse locations and organizations responded to the survey (Figure 1). Sixty-two respondents (67%) said their organization's mandate was to serve PLWHIV.

More information is needed to understand how geographic location impacts the availability of services for older PLWHIV. Urban or metropolitan areas are likely to have more resources for aging PLWHIV as they tend to have more resources in general.

A limitation of our scan is that we only heard from two ethno-specific organizations, one serving Asian communities, and one serving Black communities. Also, we only heard from one seniors' service organization.

## Is HIV and aging a priority issue for you?

Just over half (52%) of survey participants said that HIV and aging was a priority for their organization. Organizations with mandates to serve PLWHIV and community-based HIV organizations were even more likely to have made HIV and aging a priority - 67% of those with mandates to serve PLWHIV and 75% of CBHOs, respectively.

*"I don't believe we have the resources to provide services as rich in opportunities as a major center such as Toronto has."*

Facilitator/Educator, Urban CBHO, Northern Ontario

## Do you serve people living and aging with HIV?

Almost all of the organizations surveyed reported providing programs and services for PLWHIV. Almost half (48%) of those whose mandate involves serving PLWHIV said that greater than 90% of their clients were HIV-positive.

Survey participants were also asked how many of their organization's clients who are living with HIV are 50 years of age or older. One fifth of organizations (20%) we heard from serve a younger population of PLWHIV - less than 10% of their HIV-positive clients are age 50 or older. At the opposite end of the spectrum, about the same number of organizations (18%) said that half of their HIV-positive clients are 50 years old or older. As compared to all of the organizations surveyed, those with mandates to serve PLWHIV served older populations.

Notably, HIV sector organizations were more likely to know the number of older PLWHIV served by their organization as compared to service providers with a broader population mandate. Overall, only 41% of individuals who responded to the survey were able to refer to organizational data to determine the age of clients living with HIV, whereas 60% were only able to provide estimates.

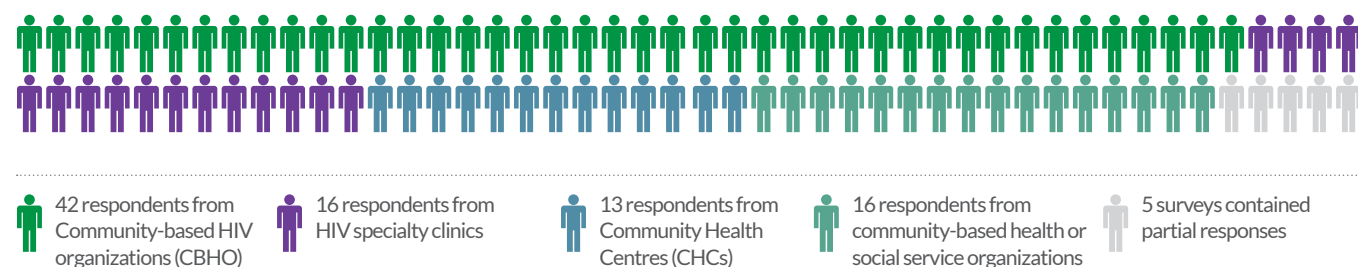
Among those whose answers were based on estimates only, more individuals reported potentially outdated information, for example, from a time when those age 50 or older made up a much smaller percentage of PLWHIV (i.e. 10-15%). Of concern is the fact that underestimates - which could be based in ageism, stigma, myth or lack of information - may make older PLWHIV less visible to service providers.<sup>7</sup>



## How has an aging population impacted programs and services in the HIV sector?

According to the people we heard from, in the past five years (2008-2013) changes relevant to community-based HIV organizations have included: increased awareness, knowledge-seeking, and priority-setting related to HIV and aging; adaptation of existing programs to meet the needs of PLWHIV who are age 50 and older, and development of new programming in this area. HIV-clinics have focused on the changing medical and care needs of aging PLWHIV and management of complex illnesses which occur alongside HIV, sometimes called comorbidities. Community health centers host vital aging-related programming for the general population and particular subpopulations.

FIGURE 1: SUMMARY CHARACTERISTICS OF SURVEY PARTICIPANTS (Total Respondents = 92)



- 62 surveys were completed by stakeholders whose organizational mandate was to serve PLWHIV
- 46 Ontario, 18 Québec, 13 British Columbia, 8 Prairies, 7 Atlantic, 0 Territories
- Urban areas: 51%, Large urban or metropolitan: 33%, Suburban: 7%, Rural: 8%

*"Our organization is informed by input from PLWHIV/AIDS, and they have identified HIV and aging issues as priorities in 3 of the last 4 years."*

Program Consultant, National HIV sector organization

*“The issue has been on the radar for several years. We have been attempting to prepare our community/service providers whose mandate it is to serve the aging population. Our goal is to make them aware of the complex issues of people living with HIV. As well as to assist in addressing stigma and discrimination not only for HIV+ individuals but also for the LGBTQ population as well.”*

Executive Director,  
Urban CBHO, Southern Ontario

*“Our organization has a Buddy Program that has been around for many years and we are currently exploring program development opportunities to use this program to better meet the needs of older people living with HIV who may need more support.”*

Front Line Worker, Larger urban or metropolitan CBHO, Central Ontario

## How has your organization changed to meet the needs of people aging with HIV?

We invited individuals to share how they thought their organizations have changed over the past five years (2008-2013) in response to the issue of HIV and aging. Responses show that organizations serving PLWHIV are at different stages of integrating HIV and aging into their work:

### CBHOs are including HIV and aging in organizational priority setting

Individuals from CBHOs reported that their organizations were well-supported in their priority-setting around HIV and aging by national HIV sector organizations, including CWGHR, CATIE: Canada’s source for HIV and hepatitis C information, the Canadian AIDS Society (CAS) and the Canadian Treatment

Action Council (CTAC). The national bleeding disorders group, the Hemophilia Society, has also acknowledged the impact of aging on the people who use their services.

### CBHOs are adapting existing programs to meet the needs of PLWHIV age 50 and older

Some survey participants indicated that their current programming largely meets the needs of their aging clients and remains relevant since many older PLWHIV in the communities they serve are “aging well” and are currently able to support themselves.

Several other CBHOs have already altered existing programming to respond to the needs of aging clients, or are preparing to do so. Service providers from these organizations said that as PLWHIV age, there may be more need for practical assistance and different types of mental health programming. Some organizations have adapted financial assistance programs to account for the high cost of getting older. Others report making

home visits or using online activities to increase accessibility for older adults who face challenges getting to their offices. Changes to education and support programs were also reported. Some agencies have reintroduced “buddy” programs which were first relied upon in the early days of the HIV epidemic to provide community-based, volunteer support for those who were seriously ill. Some counselling programs have shifted from bereavement, grief and loss to models of resilience.

### CBHOs are developing new programming to meet the needs of PLWHIV age 50 and over

Several individuals from HIV sector organizations told us they have introduced new programming to meet the care needs of older PLWHIV, including discussion groups, regular columns on aging in community magazines and brain fitness programs. Resources appear to be a limiting factor for some organizations.

### CBHOs acting as cross-sectoral leaders

CBHOs are playing a leadership role, educating partner organizations - especially those in the aging sector - and fostering collaboration between organizations serving PLWHIV and other health and social service agencies.

### Health Centres are focusing on chronic disease management

Many survey participants from community health centres said meeting the needs of aging PLWHIV is within the scope of their existing model of care. An Executive Director at a larger urban community health centre in eastern Ontario noted “we support our HIV+ older clients as people living with a chronic disease and refer them for additional supports and services to meet their individual needs.”

*“We are blessed with an aging population that are still able to support themselves within their means and are able to keep active within our services that are offered.”*

Services Coordinator, Urban CBHO,  
Southern Ontario



*"It has been a challenge to obtain cooperation from Management at the Long-Term Care (LTC) Facilities. Over the next 6 months, we plan to meet with staff from different homes hoping to educate staff and residents. Currently, we support someone in a LTC Facility and find the staff uncooperative regarding medical orders from the HIV specialist as well as assisting the client with daily routines and therapy."*

Case Manager, Urban CBHO, Southern Ontario

*"We routinely offer HIV tests to all patients admitted to our hospitals, and several new infections have been in adults 50+. Both our ambulatory and inpatient services are increasingly working with older adults, whose ageing is complicated through living with HIV. As a key HIV service provider, we are committed to ensuring that our services meet the needs of older adults."*

Executive Director, Urban health care organization, British Columbia

### HIV clinics are changing the way they provide care

Respondents from HIV clinics and speciality hospitals emphasized the changing medical issues facing older PLWHIV, including: hepatitis C co-infection; cognitive health issues; cancer; and increased need for social and emotional support. In response, they have seen: an increase in the number of older PLWHIV in both outpatient and inpatient services; re-evaluation of protocol related to discussions on end-of-life decision making; more routine screening for comorbidities; and integration of falls risk assessment into care.

### Housing for older PLWHIV is on the radar

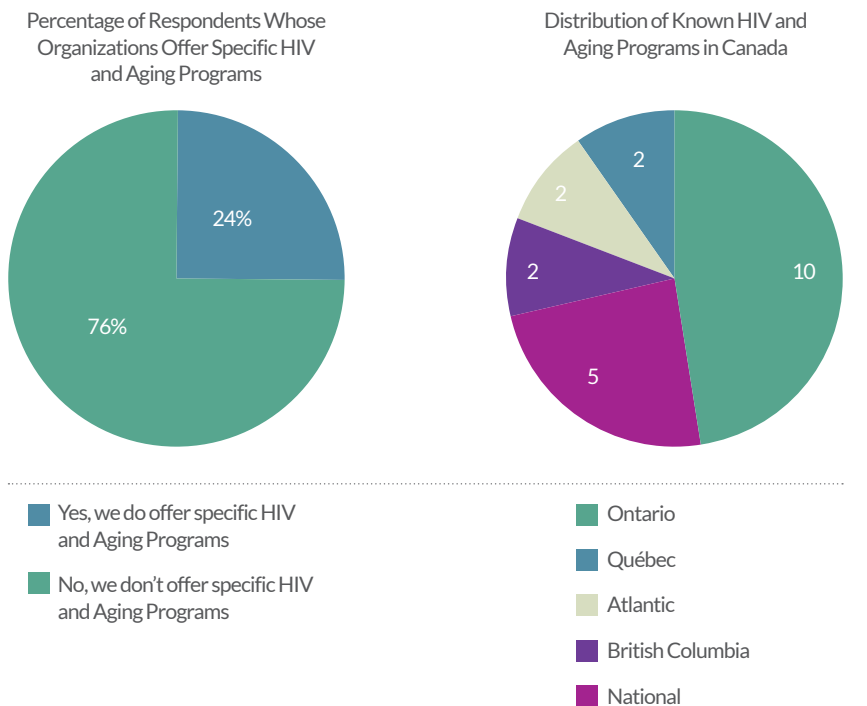
PLWHIV age 50 and older were commonly mentioned by housing-focused community-based HIV organizations, all of which were located in urban areas. The importance of stable housing, respite care, palliative care, home care, long-term care and retirement homes were mentioned. Housing organizations that serve PLWHIV have been seeing more clients with age-related issues. They report that clients fear encountering stigma in housing environments and there may be a need to educate long-term care staff and residents about the emerging realities of HIV. An individual at an Urban AIDS Hospice in Southern Ontario mentioned adding registered practical nurses to their frontline staff team in response to the changing care needs of their older clients.

### Programs and Services that Address the Needs of Aging PLWHIV

When the scan was conducted, the vast majority of organizations surveyed did not offer programs that specifically address the needs of older (age 50+) PLWHIV - 22 survey participants said their organizations did while 70 others said theirs did not. The scan ultimately identified 21 unique, active, promising programs that respond to the needs of older PLWHIV (Figure 2).\*

\*For brief descriptions of each program, see the Directory of Promising Programs and Services for Older People Living with HIV in Canada at [www.hivandrehab.ca](http://www.hivandrehab.ca)

FIGURE 2 - NUMBER AND DISTRIBUTION OF ORGANIZATIONS OFFERING HIV & AGING PROGRAMS



*“Promotion of something existing over the continual development of ‘new’ resources... funders and communities tend to like new things and forget about existing resources.”*

Executive Director,  
National HIV Sector Organization



Eligibility criteria vary across these programs and services. 16 welcome all PLWHIV; two serve people living with or affected by HIV; two are open to PLWHIV age 50+, and six are accessible to everyone, regardless of HIV status or age. A few programs were population-specific, two geared toward women and one toward gay men diagnosed before 1996. Some programs have additional eligibility requirements.

The 21 programs geared towards older PLWHIV could be divided into four categories:

- 1) Health, home care and practical support;
- 2) Support groups/peer groups;
- 3) Educational/informational programs; and
- 4) Coordination activities (Figure 3).

## The Context of Innovative HIV and Aging Programming in Canada

In this section we provide more information on the 21 unique HIV and aging-related programs and services that were described by survey participants.

### What makes a strong program?

Many program strengths were reported including peer involvement, program focus, program design, meaningful impact and strategic partnerships (Figure 4).

FIGURE 3 – HIV AND AGING PROGRAMS IDENTIFIED, BY TYPE

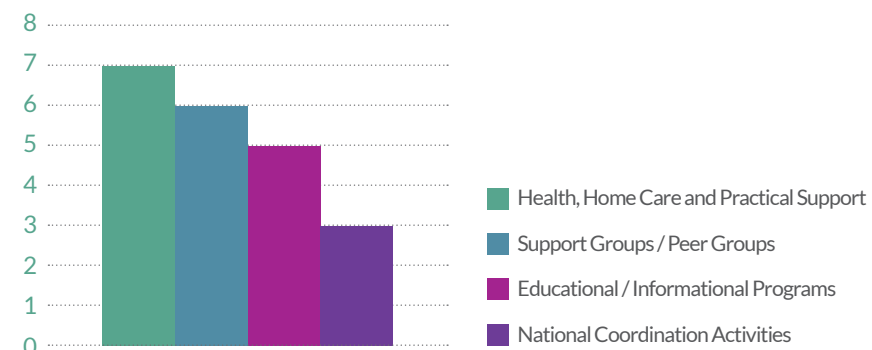


FIGURE 4 – FACTORS THAT CONTRIBUTE TO STRONG HIV PROGRAMMING FOR OLDER ADULTS

#### PEER INVOLVEMENT

PLWHIV are involved in program design and/or an integral characteristic of the program is peer support

#### PROGRAM DESIGN

Content is timely, participant-driven, comprehensive, and provides “wrap around” support while program delivery is flexible, self-guided, and focused on safety/comfort/inclusiveness/confidentiality

#### STRATEGIC PARTNERSHIPS

Collaboration is fostered during program design and across sectors

#### MEANINGFUL PROGRAM IMPACT

For example, decreased isolation and stigma or improved knowledge for PLWHIV

#### PROGRAM FOCUS

The program fills a critical service gap or increases access for a specific population (i.e., housing; women-specific)



### What are the challenges?

A variety of challenges associated with offering programming related to HIV and aging were also reported, including:

#### Systemic Barriers

- funding
- stigma and discrimination (i.e. HIV stigma, ageism, disability)

#### Operational challenges

- communication with collaborators/partnerships
- staffing/volunteer availability
- commitment and burnout
- containment and scope
- different, too many or incompatible reporting tools and client information systems

#### Challenges associated with the complex and diverse experiences of older PLWHIV

- cost, social stigma and discrimination reduce service access
- mental burden of social isolation, fear of the unknown, and uncertainty
- older PLWHIV may be unwell which could affect (meaningful) participation
- language/literacy barriers
- unique barriers faced by women
- diverse needs and conflicting responsibilities
- cognitive challenges
- some older adults may not self-identify as having age-related needs; and/or
- HIV and aging programs may attract too narrow a population.

*“We are struggling with the response to the needs of this population. We received a small grant for the last two years and we started some activities but the funding is not enough... to hire staff. While volunteers help it is not enough to answer all the need. We need trained staff and program specific funding..”*

Volunteer, Larger urban or metropolitan CBHO, Québec

*“It is difficult to refer our clientele to other HIV or LGBT specific services they do not provide their services in the French language or the French senior services do not have HIV or LGBT programs.”*

Volunteer, Large urban or metropolitan CBHO, Central Ontario

*“As the number of HIV+ hemophiliacs decreases due to deaths, the availability of those willing to work on the issues and services is also diminishing thus making it difficult to find volunteers within our community and the burn-out rate is high for those who have been involved for a long time.”*

Program Manager, National Hemophilia Organization



*“We do not have enough clients to warrant building HIV and aging specific programs.”*

Counsellor, Suburban Community Health Centre, Central Ontario

*“As part of a large hospital we do not necessarily have the funding to provide HIV and aging specific programming.”*

Physician, Larger urban or metropolitan hospital immunodeficiency clinic, Central Ontario

## Why not offer programs and services that meet the specific needs of older PLWHIV?

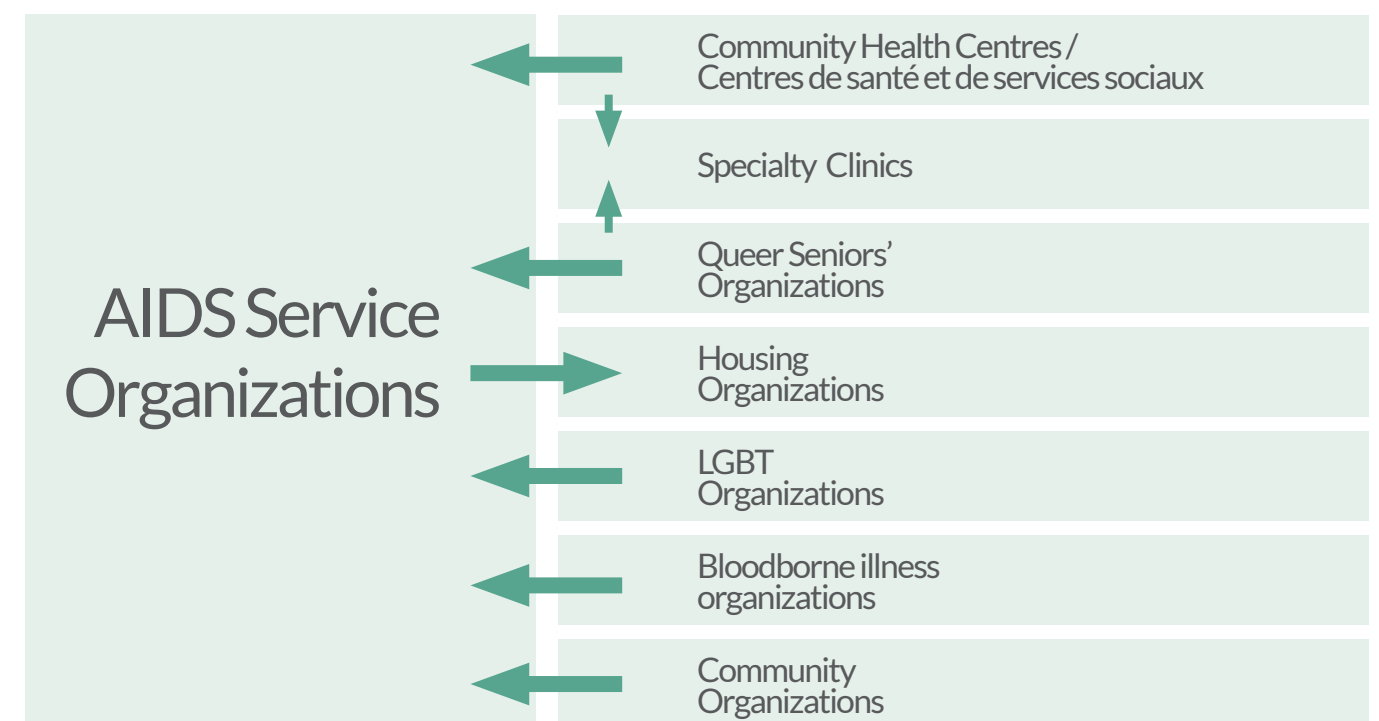
Sixty-nine organizations indicated that they did not offer services or programs directed at meeting the specific needs of older (50 years old and older) PLWHIV. When we asked why, survey participants gave the reasons shown in Table 1 below.

Thirteen (13) individuals noted that their organizations did not provide these types of programs because they felt that other organizations were better suited to do so. It will be useful moving forward to explore whether certain types of organizations are deferring to one another in a structured way (Figure 5).

Table 1 - Reasons given by organizations that don't provide HIV and aging programs

All responses (Total = 69)	Percentage (number)
Our existing programs and services generally address the needs of older people living with HIV	55% (38)
Lack of resources	28% (19)
Aging with HIV has only recently become an issue at our organization	20% (14)
Other organizations are more suited to provide these services	19% (13)
Other (HIV and aging not part of organization's mandate/not a target population; lack of evidence to support change; lack of resources; considering developing such programming)	19% (13)
Don't know/prefer not to say	4% (3)
We don't see a need	3% (2)

FIGURE 5 - SURVEY PARTICIPANT ASSUMPTIONS ABOUT WHO MIGHT LEAD AND/OR TAKE RESPONSIBILITY FOR HIV AND AGING-RELATED PROGRAMMING







*“We offer services in a multidisciplinary approach. A mental health specialist or social worker are part of that team and their focus would be to provide for specialized needs of a client group [age] 50+.”*

Counsellor, Urban Community Health Centre, Southwestern Ontario

## What referrals do you make for aging PLWHIV?

Based on the survey, it seems that a significant number of referrals are being made for people aging with HIV, both by organizations that offer programming for older PLWHIV and older adults vulnerable to HIV, and those that don't. The organizations we surveyed reported making referrals to an average of 12-15 different health services and 13-16 different social services. Mental health services were the most frequent type of referral made in terms of health services. Food banks were the most frequently indicated social support service referral.

These high referral rates demonstrate that no one type of organization or setting is equipped to provide the full complement of programs and services older PLWHIV need to address complex health and social challenges. Also, we see that health-focused organizations are making referrals to other health-focused organizations and to social support services. Similarly, organizations which primarily provide social and support services (CBHOs) are making referrals to other social services as well as to health-related services. It is critical that older PLWHIV feel more supported as a result of accessing a variety of services, not less. This may involve providing support for health care system navigation (i.e. peer navigators or case management), ensuring continuity of care from provider to provider, and ensuring that the functionality, energy levels and transportation requirements of clients are taken into account when referrals to new services are made.

## Most/Least Popular Health Service Referrals

We looked to identify the most popular referrals (those made by >40% of organizations) in the year prior to the survey.

The referral patterns for both health and social services may reflect: 1) the availability and accessibility of services; 2) the service needs of older PLWHIV; 3) the attitudes of service providers making/accepting referrals; and 4) organizational data collection/reporting strategies.

It is not surprising that referrals to mental health services, harm reduction and addictions supports, hepatitis services, home care and rehabilitation are common. Older PLWHIV who are living with mental health or addictions issues or whose function is limited are among those with the most complex needs and are more likely to require comprehensive health care. The fact that some of the most common social service referrals across all organization types are food security programs, benefits/insurance programs and emergency housing services speaks to the social determinants of health<sup>8</sup> for older PLWHIV. Because many long term survivors of HIV have not been able to maintain consistent employment over time on account of living with episodic disability, poverty is a common experience.

Table 2 – Most and least popular referrals made for older PLWHIV

	Most Popular (most frequent listed first)	Least Popular
<b>Health Service Referrals</b>	<ul style="list-style-type: none"> <li>• Mental health services</li> <li>• Addictions services and support</li> <li>• Sexual health</li> <li>• Clinical hepatitis services/ treatment information</li> <li>• Home care</li> <li>• Harm reduction</li> <li>• Nutritional counselling</li> <li>• Smoking cessation</li> <li>• Rehabilitation services</li> </ul>	<ul style="list-style-type: none"> <li>• Complementary therapies – acupuncture/ acupressure, mindfulness meditation, pet therapies, reflexology, reiki, yoga, chiropractic services</li> <li>• Geriatric services – geriatric day hospital, geriatric nurse, geriatrician</li> <li>• Heart and Stroke Foundation</li> </ul>
<b>Social Service Referrals</b>	<ul style="list-style-type: none"> <li>• Food security programs – food banks, community potlucks, meal delivery</li> <li>• Social assistance benefits</li> <li>• Provincial disability benefits</li> <li>• Home support services</li> <li>• Legal advice/services</li> <li>• Canada Pension Plan/Québec Pension Plan disability benefits</li> <li>• Transportation</li> <li>• Emergency housing</li> <li>• Volunteer opportunities</li> <li>• Caregiver supports</li> <li>• Health/medical insurance information</li> </ul>	<ul style="list-style-type: none"> <li>• Recreational activities</li> <li>• Spiritual services</li> <li>• Elder learning opportunities</li> <li>• Pet care</li> <li>• Conflict services – abuse/ violence supports, mediation</li> <li>• Relocation services</li> <li>• Emergency alert programs</li> <li>• Retirement/estate planning</li> <li>• Seniors groups*</li> </ul> <p>*except by Health Centres</p>



## WHAT ARE SOME OF THE PROGRAM ACCESS BARRIERS FOR OLDER PLWHIV?

### Lack of educational materials/resource links:

“There is a huge lack of resources and a growing need for more info and knowledge of community resources. I would be very glad to have any booklet or information pamphlets about aging and HIV with attached resources.”

Allied Health Worker, Suburban CBHO, Metro Vancouver Area, British Columbia

### Eligibility based on age results in exclusion:

“The health issues we see in our 50+ clients we also see in our youth and middle aged clients who are long term survivors, suggesting that HIV speeds up the aging process to an alarming degree. A 22 year old born with HIV may have the same heart and stroke risks as an older person due to high cholesterol and narrowing of the veins and arteries caused by medication and reduced levels of testosterone. They may also have serious bone density issues. This is one of the reasons we decided against age based exclusion practices and left support groups open to anyone who wishes to attend.”

Executive Director, Urban ASO, Southern Ontario

### HIV goes unrecognized in older adults, especially Aboriginal people:

“Information in regards to this population is lacking. Many individuals in this age category may never have been tested for HIV. Previous lifestyle may be a contributing factor to a higher number of individuals in this age category, who don’t know they are HIV positive.”

Nurse Manager, Urban Tribal Council, Southeastern Saskatchewan

With respect to health services, referrals to complementary therapies may be low because service providers, especially those working in healthcare environments may not be aware of and/or value their contribution to the well-being of older PLWHIV. In addition, these services may be expensive and/or require payment out-of-pocket which is a barrier to referral. The dearth of referrals to seniors’ groups may be explained by age-eligibility criteria for these programs. While we consider older PLWHIV to be age 50 or older, it is often the case that an individual must be over 65 years old to access traditional seniors’ services. It may also be that older PLWHIV have previously faced, or anticipate facing, discrimination when accessing mainstream seniors’ services.

*“Many of our clients who are over the age of 50 have been fitting in with existing programs. As of yet, there has not been a demand to specifically speak to this population about aging. If anything, a workshop on aging might occur but nothing ongoing.”*

Program Manager,  
Urban CBHO, Southern Ontario

*“Traditionally women are less likely to access services from an agency and will often turn to each other for support. This group welcomes and promotes a social environment, taking away the stigma of ‘accessing service.’”*

Paid Peer Worker, Urban CBHO, Ontario

## Implications and Discussion

We conclude that changing needs, available funding, and champion-initiated advocacy largely drive development and adaptation of programs and services for older PLWHIV in Canada. The findings of this scan, particularly the changing realities of service organizations, promising program examples and referral information, enhance our understanding of services for this population. In summary, here are the answers to the two questions we aimed to address:

### What is out there in terms of HIV and aging-related programs and services being offered by HIV organizations across the country?

There are programs and services out there for aging PLWHIV. Our scan identified 21 unique, promising programs designed to meet the needs of older PLWHIV in Canada, and we continue to hear about others which are in development. While it’s true that many organizations out there don’t have programs for older PLWHIV in place yet, it is clear that service providers are making a concerted effort to address gaps in their own programming through extensive referral networks.

There is also a high level of commitment out there. Over half of the service providers that we heard from say that HIV and aging is a priority issue in their organizations, in fact,

75% of community-based HIV organizations agree. The needs of older PLWHIV are being acknowledged by the organizations they have traditionally looked to for support.

### How are community-based HIV organizations and HIV clinics meeting the needs of older PLWHIV whom they serve?

As previously mentioned, organizations serving older PLWHIV, including community-based HIV organizations, HIV specialty clinics and health centres, are prioritizing HIV and aging in their respective settings and responding to demographic changes in their own ways. They are adapting existing programs and developing new ones to address the challenges of HIV and aging, including: fostering cross-sectoral collaboration with aging-focused service providers; educating key players about the impact of HIV on the aging process; examining the end-of-life care needs of older PLWHIV; more routinely screening PLWHIV for comorbidities common in aging; supporting chronic disease management efforts, especially through peer support initiatives; and modifying existing housing models to increase support for activities of daily living. These changes are being made in consultation with older PLWHIV, despite limited resources and diverse needs.

## What are the promising practices, gaps and barriers?

It was beyond the scope of this scan to evaluate the efficacy or impact of existing HIV and aging programs. Formal evaluation is just beginning as most of these services and resources, or at least the components that focus on HIV and aging, are still very new. Even so, this scan identified promising types of services, and promising ways of delivering these services. It also identified common barriers to planning and delivering HIV and aging programs. The Project Team has come up with recommendations to ensure that promising practices are evaluated and replicated, and to help organizations considering programming for older PLWHIV think about how they might overcome some of the barriers. We offer these to stimulate thought and discussion among individuals and organizations serving older PLWHIV and we look forward to hearing your ideas too!



Table 3: Promising Practices, Gaps, Barriers and Recommendations to Address the Service Needs of Aging PLWHIV

FINDINGS		RECOMMENDATIONS	
PROMISING PRACTICES	GAPS AND BARRIERS		
A demonstrated commitment on the part of service providers to understanding and addressing the specific needs of PLWHIV who are 50 years old and older, including creating new programs or adapting existing ones to meet these needs		<b>Programming:</b> <ul style="list-style-type: none"> <li>Keep a database of existing programs serving older PLWHIV in Canada, as well as documenting best practices for HIV and aging programming</li> <li>Introduce programming which fills critical gaps in service or addresses the needs of a specific population of older PLWHIV (i.e., housing support; specific focus on women)</li> <li>Routinely offer HIV testing to adults over age 50</li> </ul>	
Some community-based services are unavailable or insufficient (i.e. French-language services, supportive housing)		<b>Research:</b> Conduct and share the results of a pan-Canadian survey to document the assets and needs of older PLWHIV and compare how these needs differ across regions, ethnicities and genders	
Some individuals face barriers when trying to access programming relevant to their needs (cost, stigma, cognitive decline, isolation, physical health, mobility, conflicting responsibilities, etc.)		<b>Policy:</b> Sustain and/or expand existing evidence-based HIV programming for older adults instead of requiring development of new programs	
Flexible age eligibility requirements exist for some programs and services that have value for older PLWHIV. Aging is a lifelong process rather than an event that begins at a specific age. Longterm survivorship should be addressed in conjunction with aging		<b>Programming:</b> Consider whether the needs of older PLWHIV (i.e. end-of-life decision-making, falls prevention, retirement/financial planning), which may differ from those of younger adults or HIV-negative peers, will be adequately addressed through inclusion in all-ages or seniors' programming	<b>Research:</b> Evaluate existing programming for older PLWHIV in Canada to determine its strengths and weaknesses and build in evaluation when implementing new programs for this population
Peer involvement in program design and putting peer support at the heart of programming are integral to the creation of relevant services for older PLWHIV		<b>Programming:</b> Build individual and organizational capacity, fight ageism, and foster meaningful engagement of older PLWHIV by: <ul style="list-style-type: none"> <li>Facilitating their participation in program planning – older PLWHIV will best identify potential barriers to program access</li> <li>Creating opportunities for peer support, normalizing the experience of aging with HIV</li> </ul>	<b>Research:</b> Further explore the role of ethno-cultural and suburban/rural CBHOs in supporting marginalized, older PLWHIV
Cross-sectoral initiatives and strategic, interagency partnerships can strengthen service coordination		<b>Programming:</b> Work with other organizations within the HIV sector, as well as in the aging, home and community care, long-term care and rehabilitation sectors, to design strong programs, coordinate care and/or facilitate referrals to address service gaps for older PLWHIV	
Communication can be challenging when working in partnership, especially across sectors			
Taking steps to increase access to multidisciplinary care and services that are hard to get (i.e. physiotherapy, chiropractic care, complimentary therapies, and cognitive health interventions). Integrate HIV care into broader health care systems and services		<b>Policy:</b> Establish CBHOs as leaders in a cross-sectoral response to HIV and aging, providing funding for this role	

FINDINGS		RECOMMENDATIONS	
PROMISING PRACTICES	GAPS AND BARRIERS		
Engaging in knowledge translation and exchange (KTE) activities and training initiatives to increase service provider awareness of the complex issues facing aging PLWHIV (i.e. stigma and the social determinants of health), including education and training for longterm care and home and community care providers		<b>Programming:</b> Increase CBHO capacity to develop and/or adapt programming to meet the needs of older PLWHIV in Canada by creating accessible training resources and educational materials on HIV and older adults for CBHO staff as well as older PLWHIV	
Using online outreach, offering self-guided education, and designing programs based on safety, comfort, inclusion and confidentiality will decrease social isolation and stigma as well as helping to engage isolated aging PLWHIV		<b>Programming:</b> Increase knowledge, uncover and address stigma, and build skills among aging, chronic care and housing sector providers to improve their capacity to serve older PLWHIV	
Inequities in funding / resource distribution across geographic areas. Some organizations lack project resources (staff, volunteers, educational materials)		<b>Policy:</b> Engage in cross-sectoral dialogue to ensure that the values which underpin work in the HIV sector are reflected in the organizational policies of aging-sector providers (i.e. harm reduction, safe spaces for LGBTQ communities)	
Stigma and discrimination related to age and HIV status among the general population		<b>Policy:</b> Advocate for more HIV prevention, support and housing-related resources for older adults - investment will improve health outcomes and save the system money	
Incompatible reporting tools and client information systems		<b>Policy:</b> Combat all forms of stigma and discrimination, including that based on age and HIV status. Increasing awareness about HIV risk among older adults is a way of increasing access to testing for them	
Lack of local evidence to justify an organizational focus on the needs of older PLWHIV		<b>Programming:</b> Increase CBHO capacity for program development and/or adaptation to meet the needs of older PLWHIV in Canada by providing support for local/regional needs assessments	
Unanswered questions about the 'fit' between existing seniors' programs and services and older PLWHIV		<b>Research:</b> Encourage those responsible for public health monitoring to adapt data collection systems which enable reliable reporting on service utilization based on service user HIV status and age	
		<b>Research:</b> Study whether existing seniors' services are inclusive of older PLWHIV	



*“[There is] increased need for complex care for non-HIV related disease processes, some of which are complicated by the client also being HIV positive.”*

Executive Director,  
Large Urban or Metropolitan  
HIV specialty hospital,  
British Columbia

## What are the next steps?

We hope this environmental scan will have a resonant impact, whether it leads to new partnerships, increases referrals, raises awareness of existing programs or informs the development of new programming for older PLWHIV in Canada.

Brief descriptions of each of the 21 unique HIV and aging-related programs and services identified by the scan will be shared through a ‘living’ companion document which we have already updated since the scan was completed. CWGHR commits to reviewing this document over time to ensure new program examples are shared. This document is entitled Directory of Promising Programs and Services for Older People Living with HIV in Canada and it is housed on the CWGHR website at [www.hivandrehab.ca](http://www.hivandrehab.ca).

If you have an interest in programming for older PLWHIV, we encourage you to join the National Coordinating Committee on HIV and Aging, Programs and Services Working Group.

We look forward to continuing this dialogue with you and combining our collective efforts for change which benefits older adults living with HIV in Canada.

*Over half of the service providers that we heard from say that HIV and aging is a priority issue in their organizations, in fact, 75% of community-based HIV organizations agree. The needs of older PLWHIV are being acknowledged by the organizations they have traditionally looked to for support.*

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Please contact the Health Programs Specialist at the Canadian Working Group on HIV and Rehabilitation at [info@hivandrehab.ca](mailto:info@hivandrehab.ca) for more information on HIV and Aging initiatives, including the National Coordinating Committee on HIV and Aging