

# COMMUNITY ROUNDTABLE ON HIV, AGING, AND HOME AND COMMUNITY CARE: DISCUSSION SUMMARY

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## Background Information

### Who are older adults living with HIV?

Older adults living with HIV are people who are 50 years old or older and are HIV positive. They experience many more health concerns than people of the same age who do not have HIV. Living past 50 was unexpected for many people, but now over half of all people on HIV treatment are 50 years old or older.

### What is home and community care?

**The home and community care system includes three main services that help people with daily tasks, like bathing and taking medication. The three services are home care, assisted living and residential care.** In home care, the person lives in their own home and somebody comes to their home to help them with daily tasks. In assisted living and residential care, the person moves into a care home that is staffed by individuals who are trained to assist in daily tasks.

### What is this document about?

In May 2018, the Stronger Together initiative held a community roundtable on HIV, aging and home and community care. People living with HIV, professionals who work in home and community care settings, researchers and people from community organizations came together to discuss the home and community care system and the work that community organizations do to support older adults living with HIV. **This document is a summary of our discussions during the community roundtable.** The ideas from these discussions will help the BC Centre for Excellence in HIV/AIDS (BC-CfE) plan its next research project on HIV, aging and home and community care.



## Key Points from our Discussions

### What is working in home and community care?

- Some community organizations are able to take the time to plan their programs and can change these services according to participants' needs. This is making a difference for older adults with HIV.
- We didn't hear anybody say that government-provided services are meeting all their home and community care needs.

### What gaps are there in the home and community care system?

- Home and community care professionals—and sometimes older adults living with HIV themselves—expect partners, family or friends to give most of the care that people aging with HIV need. This is asking too much of loved ones and affects relationships.
- People get home and community care services when they can no longer do personal care for themselves; however, the services that would help keep people healthy and in their homes are not available.
- People need help with household tasks—like housekeeping, grocery shopping and cooking—which are unavailable unless they move into care homes. These are the services people really want to have access to.

### What could improve the home and community care system?

- Case managers are professionals who handle a person's needs and help them to get the right services. Case managers communicate with different services so that they can all work well together. Having a case manager for any person aging with HIV could make sure they don't fall through the cracks.
- Older adults living with HIV need stable housing that they can afford and that meets their needs in order for home care to work for them.
- Government-provided home and community care needs to provide a wider range of services to take the burden off of community members and community organizations.
- There needs to be more education for home care workers on HIV, HIV stigma and anti-discrimination. This education should be led by people living with HIV or who belong to the groups that experience discrimination for other reasons, such as the LGBTQ2SA and immigrant communities.
- Cultural safety in home and community care means that individuals receiving and providing services feel safe and respected in all their interactions. Cultural safety applies to all cultures. In BC, there is a specific need for Indigenous cultural safety and ceremony in home and community care.



## Key Points from our Discussions (continued)

### What should we learn about during our next research project on HIV, aging and home and community care?

- How being a part of minority communities, having a first language other than English, and being single or having a partner affects the experience of home and community care. People who are LGBTQ2SA, immigrants or refugees, Indigenous or use drugs are a part of minority communities.
- Who is falling through the cracks and not receiving the services they need, why and when does this happen?
- How do changes to home and community care services affect older adults living with HIV?
- How does seeing many different workers, sometimes in one day, affect the quality of care that older adults living with HIV receive?
- How do changes to community based organizations affect older adults living with HIV? This includes having fewer organizations provide more services, and the loss of support programs from community organizations.
- How does aging with HIV affect experiences of home and community care? Experiences of aging can include the mental health effects of aging with HIV, and the emotional experiences of being an older long-term HIV survivor.

### How should we share what we learn so that it will have an impact?

People who joined the community roundtable gave us some ideas about different ways to share what we will learn through our next research project. We'll keep listening to community members' voices throughout the research project. What we do with what we learn may look different from the ideas we heard. Our plans are not written in stone, but these ideas will help guide us.

- Train community organizations to prepare older adults living with HIV for older age.
- Hold community events to share what we learn. Have healers, elders and counsellors at these events to support older adults living with HIV.
- Share the stories of older adults living with HIV with policymakers, so that they understand the human experience of aging with HIV.

### Moving forward

- Over the next three years, the BC-CfE will conduct a research study about aging, HIV and home and community care.
- Our aim is to promote home and community care that will help older adults living with HIV stay safe in their homes, and maintain or improve their health.
- Adequate home and community care services would allow people to have time and energy to take care of themselves, contribute to their communities, and build and focus on their relationships.

