WHAT IS THE HIV ENGAGEMENT CASCADE?

The HIV Engagement Cascade—also referred to as the HIV Treatment Cascade, or the HIV care continuum—is a system to monitor the number of individuals living with HIV who are actually receiving medical care and the treatment they need. It was developed to recognize the various steps necessary to engage an individual who needs HIV care, all the way from getting tested for HIV to being able to suppress the virus through treatment.

Engagement in care is important for two main reasons:

1. people living with HIV who have access to antiretroviral therapy (ART) and other care and support services have significantly improved health outcomes. Access to the full continuum of services enables people living with HIV live full and healthy lives.

2. the new science of viral suppression tells us that when people are engaged in care and taking ART to reduce the amount of virus in their body—known as undetectable viral load—it makes them less likely to transmit HIV to others.

The HIV Engagement Cascade is also useful to health systems and organizations in the HIV sector, which can use the Cascade to keep track of the progress individuals make after receiving a positive diagnosis and throughout their lives, and to measure how well local services are covering all parts of the care continuum.

WHAT IS “UNDETECTABLE VIRAL LOAD”?

When taken every day exactly as prescribed and directed, antiretroviral therapy (ART) can bring the amount of HIV in the blood down to below the level at which it can accurately be counted with routine tests. This low level is called “undetectable viral load.”(1)

Reaching and maintaining an undetectable viral load means that people with HIV can live long, healthy lives. We also know that people living with HIV who have an undetectable viral load do not transmit HIV to their HIV-negative sex partners.(2)
**From left to right, the HIV Engagement Cascade can be read as a series of steps:**

**AT RISK:** While anyone can be at risk of HIV infection, there are some people who are considered to be at higher risk due to a wide range of individual and community vulnerabilities. Despite decades of prevention work based on behaviour change and condoms, HIV transmission persists in Canada, with a disproportionate burden among ACB communities. In 2014, nearly 20% of new HIV infections in Canada were among ACB people (even though they make up less than 3% of the population). (4)

**HIV INFECTION:** Most people from ACB communities acquire HIV through heterosexual contact: 93% of HIV cases among ACB people are due to heterosexual contact. (4) ACB men who have sex with men and ACB people who inject drugs are also at higher risk of HIV, although HIV statistics are not available on these subgroups.

**TESTING:** The only way to know for sure that a person is infected with HIV is for them to take an HIV test. An estimated 20% of people living with HIV in Canada do not know they have HIV. (5) Increasing the frequency and rates of HIV testing will help diagnose people sooner after they have become infected with HIV. Currently, many people in Canada are not learning about their HIV status until late in their HIV disease, when they start to develop symptoms or opportunistic infections. (6) HIV-related stigma is the single greatest obstacle to HIV testing. (7) People avoid testing because they fear a positive result and they fear facing stigma. If they find out they are living with HIV, fear of disclosure means that the virus remains invisible. (8)

**DIAGNOSIS:** It is important that the results of an HIV test can be delivered as soon as possible after the test is administered, with sensitivity and confidentiality, and with adequate post-test counseling. (1) An HIV-positive test result should always be provided in person and ideally by the initial care provider. (9)

**LINKAGE TO CARE:** In spite of the fact that an HIV-positive diagnosis can be difficult news for some people, it is important to highlight the benefits associated with early diagnosis, such as more options in treatment and improved disease prognosis. Care providers should be prepared in advance by having information resources and support referrals at the ready for the client and be able to spend sufficient time to discuss the results and answer any immediate questions the client might have. They should be advised about strategies for managing HIV and they should be offered referrals to specialized counselling services that are equipped to provide newly diagnosed individuals with the specific supports and resources that they need to manage their health and wellness. (9) People newly diagnosed with HIV should also be linked to community-based support services, particularly those that are culturally-competent and ACB-specific.

1 Rapid point-of-care HIV testing is available in some parts of Canada. This technology allows people to be tested for HIV and know their HIV status during the same visit, usually in less than an hour.
Thanks to dramatic and ongoing improvements in HIV care, treatment, and support, most people with HIV are now living much longer than ever imagined possible. HIV is now considered a chronic illness, and with the right treatment and support, people living with HIV can live long, active and healthy lives. People living with HIV can think about their health from a long-term perspective. People living with HIV should be provided with access to healthcare and psychosocial and other support services required to achieve optimal adherence to HIV antiretroviral medications and to promote their health and wellbeing. This care and support should include routine medical care, addiction, mental health and sexual health services, harm reduction services and supplies, safe and secure housing, and nutrition support services. 

With proper care, treatment and support, people with HIV can live long, healthy and active lives. Clients should be made aware that HIV is now considered a chronic manageable condition. People who are newly diagnosed need to be aware of how to prevent the further spread of the virus. They also need support to make informed and autonomous decisions around disclosure of HIV status to others. It is important that people know that in Canada, people living with HIV have an obligation under the criminal law to tell their sexual partners they are HIV-positive before having sex that poses what the courts call “a realistic possibility of transmission.”

Primary and Specialist Care: Once a person knows they have HIV, it is important that they are immediately connected to an informed and competent HIV healthcare provider who can offer treatment and counseling to help them stay as healthy as possible and prevent passing HIV on to others. People should also be linked to community-based support services, such as peer-based support and capacity-building programs through local AIDS service organizations.

Antiretroviral Therapy: Because there is no cure for HIV at this time, treatment is a lifelong process. To stay healthy, a person needs to receive regular HIV medical care. Antiretroviral therapy (ART) is the recommended treatment for HIV infection. ART prevents HIV from making more copies of itself, using a combination of three or more antiretroviral drugs from at least two different HIV drug classes every day to control the virus.

Suppressed Viral Load: By taking ART regularly, a person living with HIV can achieve viral suppression, meaning they have a very low level of HIV in their blood. They are not cured. There is still some HIV in their body; however, lowering the amount helps keep them healthy, helps them live longer, and strongly reduces the chance of passing HIV on to others.

Optimal Health: Thanks to dramatic and ongoing improvements in HIV care, treatment, and support, most people with HIV are now living much longer than ever imagined possible. HIV is now considered a chronic illness, and with the right treatment and support, people living with HIV can live long, active and healthy lives. People living with HIV can think about their health from a long-term perspective. People living with HIV should be provided with access to healthcare and psychosocial and other support services required to achieve optimal adherence to HIV antiretroviral medications and to promote their health and wellbeing. This care and support should include routine medical care, addiction, mental health and sexual health services, harm reduction services and supplies, safe and secure housing, and nutrition support services.
WHAT HAPPENS WHEN THERE ARE GAPS IN THE CASCADE?

As described above, for a person living with HIV to achieve optimal health, they need access to a continuum of services: HIV testing and diagnosis, linkage to appropriate medical care (and other health services), support while in care, access to antiretroviral treatment if and when they are ready, and support while on treatment. Unfortunately, this sequence of steps—the HIV Engagement Cascade—isn’t seamless and some people “leak” out and are lost at each step, due to barriers to getting tested, staying in care, and starting or adhering to antiretroviral treatment. These barriers include (8,13):

- poor access to services;
- HIV-related stigma and discrimination;
- poverty, food insecurity and homelessness;
- mental health and addiction issues;
- uncertainty around immigration status; and
- anti-black racism in the health care system.

As a result of these leaks at different points in the continuum, not all people living with HIV are engaged in every step needed to achieve an undetectable viral load. Increasing engagement in the Cascade requires programs that address the multiple barriers. We also know that there can be significant delays moving from one step of the Cascade to the next. Thus, more attention needs to be placed on the time people spend between each stage of the continuum of care.(14)

HOW CAN SERVICE PROVIDERS SUPPORT THE CASCADE?

We do not know what the “ideal” Cascade should look like and aiming to get everyone living with HIV on successful treatment is not realistic, nor would it be ethical. It is critical that efforts to better engage people in services do not come at the cost of individual rights and that we make sure clients and patients are ready and willing to take each step. To ensure informed consent, the risks and challenges that come with testing positive for HIV and starting treatment need to be explained to clients and patients before they make these important decisions.

Service providers can help ACB people access all parts of the Cascade by:(8,12)

- Building greater awareness of HIV risk factors and linking community members to testing services.
- Addressing the social determinants of health that create vulnerability to HIV infection and act as barriers to access to care.
- Breaking down stigma around HIV by supporting the leadership and visibility of people living with HIV in ACB communities.
- Linking people to testing services that are respectful and sensitive.
- Providing information and support to people who are newly diagnosed with HIV so that they can make informed decisions about whether to take HIV antiretroviral medications, based on their own assessment of what is best for their health and wellbeing.
- Linking people living with HIV to peers who can give support and the perspective of lived experience in relation to living healthy, full and productive lives with HIV.
- Working with provincial, territorial and federal authorities to ensure that cost does not act as a barrier to people living with HIV who want to take HIV antiretroviral medications.
- Not coercing people to start or take HIV antiretroviral medications. People living with HIV must not be subject to penalties or withholding of healthcare or psychosocial or other supports if they choose not to take HIV antiretroviral medications.
- Building treatment literacy and ensuring that ACB community members are aware of the individual and public health benefits of HIV antiretroviral medications.
- Ensuring that they engage in professional development and training to be well-versed in the full range of health care and psychosocial supports needed by people living with HIV.
REFERENCES:
11. CATIE statement on the use of antiretroviral treatment (ART) to maintain an undetectable viral load to prevent the sexual transmission of HIV [Internet]. [cited 2017 Feb 5]. Available from: http://www.catie.ca/en/prevention/statements/tasp

This fact sheet was produced by San Patten for the Canadian HIV/AIDS Black, African and Caribbean Network (CHABAC). CHABAC is a national network of organizations, individuals and other stakeholders who are dedicated to responding to issues related to HIV and AIDS in Canada’s African, Caribbean and Black communities. March 2017