

# **FINDINGS FROM PAN'S 2020 BC TESTING NEEDS ASSESSMENT: Enthusiasm for HIV self-testing and needs for clarifications, guidelines, and collaboration**



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## BACKGROUND

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New testing options for sexually transmitted and blood-borne infections (STBBI) are being introduced to the market in Canada so that they are available and accessible for those who need them the most. These novel options include, among others, self-testing for HIV and hepatitis C and multiplex point-of-care (POC) testing for HIV and other STBBIs, such as syphilis.

One major change in the testing landscape happened on 3 November 2020, [Health Canada provided for Canada's first HIV self-test](#). Approval of this novel HIV self-testing (HIVST) option makes bioLytical Laboratories' INSTI HIV point of care (POC) test accessible for use by non-healthcare providers. HIVST is a process in which a person collects their own blood specimen, performs an HIV test and interprets the result on their own. This testing is often performed in a private setting, either alone or with someone they trust. The self-test results act as an initial screen for HIV, and a confirmatory laboratory test is required for HIV diagnosis.

HIVST means that a person can obtain or purchase their own test, do the test themselves and get their results immediately. In other words, a person does not go to a healthcare facility, clinic, or doctor's office for initial HIV screening. A [trial led by REACH](#) Nexus found that HIVST is an acceptable, safe, accurate, and effective way to reach people who are at risk and may not otherwise test.

For more detailed information on emerging testing technologies including HIVST, please see PAN's [New testing technologies for STBBIs](#) webpage.

## WHAT WE DID

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In this context of new testing technologies and a shifting testing landscape, PAN felt that it was an important time to engage with a broader audience to gauge interest and to support PAN's planning around testing activities for future.

Throughout July and August 2020, we talked to 17 PAN members and allied stakeholders across the province to ask about how community-based organizations (CBOs) and AIDS service organizations (ASOs) see their role in testing in this new context and the challenges and opportunities they might face. We asked the following:

- How do CBO and ASOs see their role in testing in this new self-testing context?
- How can CBOs and ASOs engage with the new testing technologies as they become available?

- Are there any potential challenges or opportunities they foresee concerning HIVST?
- What resources and tools would support CBOs' and ASOs' engagement in HIVST?

The information collected will help to inform PAN's work plan to support the work of CBOs and ASOs in BC as new and emerging testing technologies, including HIVST, are rolled out in the province.

We examined the notes from all of the interviews and pulled out a number of themes and major findings we will share below.

## FINDINGS

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### AREAS OF POTENTIAL OPPORTUNITY

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Participants expressed interest and excitement about new testing technologies. There was agreement that expanding testing in general was important and would be beneficial to people living in BC, including other testing technologies, such as dried blood spot (DBS), multiplex testing for other STBBIs, and self-testing for hepatitis C. More specific opportunities identified regarding HIVST included the following:



- 1) **Advantages of Self-Test:** Self-testing has the potential to reduce stigma surrounding testing. Some participants expressed concerns about confidentiality and potential stigma that have discouraged people from testing, particularly in smaller communities. Some participants thought that HIVST was a more private option that may work better for these people. Another advantage identified was that HIVST could reduce the need to travel to access a test in communities with fewer options for testing. Participants also felt that HIVST would be beneficial because it could increase a sense of autonomy and ownership over health for individuals and allow people to self-manage their testing and support individuals who want to test more often (for example, gay, bisexual, and men who have sex with men who may want to test regularly).
- 2) **Strengths of Community-Based Programs:** Many CBO and ASO stakeholders felt their organizations were well-equipped to distribute tests and were interested in the opportunity to do so. There was a clear sense that ASOs and CBOs are well-positioned to engage with this work because they provide space that is often less clinical and potentially more comfortable for clients to engage with testing and linkage to care. Many ASOs and CBOs use a case management approach and can offer wraparound services to self-testers, such as housing and harm reduction programs.

- 3) **Peer-Based or Non-Healthcare-Provider-Based Testing:** ASO and CBO stakeholders identified their strong relationships with people with lived experiences who access their services as a strength. Many organizations also had peer support workers or peer navigators working on staff. Building on these connections there was a strong desire from many of the participants to create peer-based or non-healthcare-provider-based testing programs in their organizations. This could be achieved through implementation planning and engaging health authorities for these types of programs. At the same time, participants stated that it was important to ensure there are diverse testing options and various access points for people to test, especially given specific needs of key priority populations.
- 4) **Working with Pharmacists:** Another potential opportunity identified by CBOs and ASOs to expand testing was through strengthening relationships with pharmacists and working with pharmacies as distribution sites for HIVST. Pharmacists could be positioned not only to support with distributing tests but could be a key resource supporting linkage to care and to community-based services for people interested in testing.

## AREAS OF POTENTIAL CHALLENGE


- 1) **Needed Clarity Around the Linkage to Confirmatory Testing and Care:** Participants raised concerns about how a person who receives a positive HIV result through HIVST could access confirmatory testing and support. Establishing access to confirmatory HIV testing was particularly important in small urban, rural, and remote settings. In these settings, access to services may be more limited, geographically dispersed, and confidentiality may be more challenging to maintain. Another immediate challenge was that many of these testing and follow-up services have been reduced or limited due to the ongoing COVID-19 pandemic. Participants strongly felt that a focus and clear pathway for linkage to care was needed.
- 2) **Meeting the Needs of Priority Populations:** Participants also acknowledged that some groups of people, such as people who are experiencing homelessness or people who use substances, may not be in a position to actively engage in HIVST. These people may need to be supported with a different implementation model, like peer-based testing or supported self-testing and with innovative approaches to ensure linkage to care. A potential point of engagement for these priority populations might be through harm reduction workers. One idea was that harm reduction workers could carry HIVST kits



and support their clients to test. Finally, some participants were concerned about the impact of HIVST on testing for other STBBIs, wondering if an increase in HIVST would translate into decreased and irregular STBBIs screening.

- 3) **Specific Concerns around Self-Testing:** Participants expressed the importance of promoting HIVST to a diverse group of people and across populations and geographies. Other concerns raised about HIVST were about the potential negative impacts of testing alone and unsupported and receiving a positive result. In addition, there was concern that an online platform for self-testing would make it difficult to reach people who are aging and who may not be familiar with this technology.
- 4) **Ongoing Needed Work on Stigma:** Stigma continues to be an area of potential challenge for testing and linkage to care on a number of fronts. While participants appreciated the potential privacy of an HIVST, they also raised questions about how confidentiality would be protected in the process of self-testing (e.g., how would someone follow-up with confirmatory testing? how would someone be alerted of their test results?) as well as any requirements for reporting to public health and to the health authorities should someone self-test as positive. One participant noted that it would be important to know what the legal requirements for reporting and linkage to care might be. Stigma was also acknowledged as something that exists within the larger healthcare system and work needs to continue in addressing this while planning and implementing pathways for confirmatory tests, linkage to care, and onward prevention for self-testers.
- 5) **Need to Build Support with Health Authority Partners:** Participants expressed there was a need to engage and build support around new testing technologies with health authorities and BC's Ministry of Health. Participants reported that in the past, when organizations wanted to take on new and innovative testing roles, health authorities were not supportive as it was felt that this was work for healthcare professionals. As new testing technologies like self-testing come online, it is important to continue to consider how to foster collaboration between health authorities, healthcare providers and community-based organizations. Innovation in implementation could help to reach more people who are not currently testing.

## NEEDS OF COMMUNITY-BASED ORGANIZATIONS AROUND HIV SELF-TESTING

- 1) **Clarity of Roles:** Participants identified the need for clear delineation of roles – they wanted more information on what their role would or could be within this initiative. They were also interested in the role of medical service providers and health authorities as well as the potential role of peers or other people with lived and living experiences. Participants expressed that communication and support in building relationships with providers and health authorities would be helpful in supporting self-testing – for example, a designated person from the local health authority that could aid in linkage to care. There have been challenges knowing where different roles lie and participants felt it would be important to have these relationships clarified in order to ensure linkage to care, quality assurance in testing, and access to confirmatory testing.
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- 2) **Importance of Giving People Access to their Peers:** Participants felt it was important to ensure that testers have access to peers available to them as supports. One participant noted that testing and pre/post-test counselling would be better offered by a peer than a healthcare provider; another noted that it was “more effective” for self-testing to happen via peers than without people with lived experiences involved. Participants felt that this engagement was important for follow-up and that testers should be supported in linking into peer supports.
  - 3) **Information on Linkage to Care:** Participants stated they would also benefit from more information about how linkage to care could be facilitated in a self-testing model. This could include clear guidelines on where to connect self-testers (e.g. supports through the online platform, self-testing hotline – especially important to provide connection to people with lived experiences for peer-based supports), information on confirmatory tests, and information on services and supports in the community, including prevention services for those who test negative. This step is particularly important for small urban/rural/remote communities that may have fewer options in which to connect self-testers to confirmatory testing and community supports.
  - 4) **Training:** Training was identified as a significant need, depending on the roles ASOs/CBOs would take on with self-testing. This included training for peers surrounding the testing itself and what to do to support someone should they test positive such as clear links to a clinician, confirmatory testing etc. As well, participants noted that a standardized protocol was needed for all tests and that it would be important to know what supports would be available to testers.

- 5) **Additional Funding and Human Resources to Support Testing:** Participants noted concern for additional human and financial resources to support this additional role in self-testing. For example, additional costs could be incurred if additional staff needed to be hired or current staff's job responsibilities expanded to include new testing responsibilities. Participants also raised concerns about the costs of sustaining self-testing e.g. the costs of the tests themselves and who would pay for them (PHSA? Regional health authorities?). Organizations noted that if they were asked to take on new testing roles there would need to be additional human resources for organizations or agreement from funders to shift contract deliverables. One participant noted that it would be important for self-testing to be free, particularly for groups who may want testing but could not otherwise afford to access it. Another participant suggested it would be important for tests to be provided through a funded program, both to manage costs and to track where tests were going. Some participants acknowledged that they simply do not have the capacity at this time to tackle all tasks involved in self-testing (e.g. supporting clients if they test positive).
- 6) **Documentation and Guidelines:** Clear resources and guidance on quality assurance was noted as a need from CBOs/ASOs. For example, concerns were raised about the timelines for tests being distributed across the province with regards to expiry dates, temperature conditions for the test to work in and positive controls.

Surveillance was an important issue for many participants, including clarity surrounding reporting positive results. One participant noted it would be important to be able to track who was being sent test kits; another participant noted it is important that if testers wanted to report confidential results that they have the option to do.

## CONCLUSIONS AND NEXT STEPS

New testing technologies and options offer both potential opportunities and challenges for CBOs and ASOs as they are rolled out in BC. The CBO and ASO stakeholders who participated in this assessment expressed enthusiasm for HIVST. A key finding from this assessment indicates the need for clear recommendations and easy to access resources for linking those who test positive through HIVST to confirmatory HIV testing and care.

Based on the findings from this BC testing needs assessment, PAN has identified the next steps for action:

- To develop a list of existing resources for linking people to confirmatory HIV testing, including resources on how to connect HIV self-testers to prevention and treatment care in BC and taking into account barriers to accessing service due to the ongoing COVID-19 pandemic

- To develop and continually update webpage resources on new testing technologies, including HIV, that PAN member organizations can access to learn about new developments such as the webpage and blogs PAN has already posted:
  - PAN's blog: [New Testing Technologies for HIV, Hepatitis C, and Syphilis Self-Testing & Beyond – What does this mean for Community-Based Organizations?](#)
  - PAN's webpage: [New testing technologies for STBBIs](#)
- To communicate how HIVST will be rolled out in BC and how CBOs and ASOs might be impacted by this roll-out
- To liaise with provincial and health authority stakeholders to develop novel ways for accessing confirmatory HIV testing across the province, but particularly in rural and remote communities where new easily-accessible and reliable methods for confirmatory testing may be beneficial
- To investigate any surveillance and public health reporting requirements that stakeholders at CBOs and ASOs might or might not have when a person tests positive for HIV through an HIVST
- To work the REACH Nexus in the development of its I'm Ready online testing platform and implementation science study that will provide access to up-to three, free HIVST kits for participants.
- To determine which CBOs and ASOs can be distribution or pick-up sites for people in BC who order an HIVST kit through the I'm Ready online platform developed by REACH
- To determine the extent to which stakeholders at CBOs and ASOs, including peer support workers, can provide direct support or guidance to those taking an HIVST given the approved distribution license of INSTI's HIV Self-Test kits in Canada
- To determine the legal responsibility, if any, for stakeholders at CBOs, and ASOs, including peer support workers, when a person undertaking HIVST at the premises of an organization tests positive for HIV
- To liaise with provincial health authority partners to determine the points of contact between HIVST and the publicly-funded provincial POC testing program, given that both use the same technology

We are very grateful to the participants in this needs assessment and will work to build a testing work plan for PAN. We will also share these findings with other partners and decision-makers to continue the conversation about opportunities and challenges related to novel testing technologies in BC. Testing is an essential step in reaching the undiagnosed, linking them to care and having a positive impact on the HIV epidemic in BC.

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For more information please visit:  
<https://pacificaidnetwork.org/new-testing-technologies-for-stbbis/>

Or email: [janice@pacificaidnetwork.org](mailto:janice@pacificaidnetwork.org)