

Bringing self-collection kits for STBBI testing to scale for 2SLGBTQIA+ people in Canada: How should we do this?

Recommendations from a workshop at Summit 2022

Mark Gilbert, Aidan Ablona, Hsiu-Ju Chang, Stephen Juwono, Rayka Kumru, Chris Draenos

A collaboration between the Community Based Research Centre and the BC Centre for Disease Control

DiSHIresearch@bccdc.ca | [@DiSHIresearch](https://twitter.com/DiSHIresearch) | www.dishiresearch.com

Why does this issue matter?

- Two-Spirit, Lesbian, Gay, Bisexual, Transgender, Queer and/or Questioning, Intersex, Asexual, and additional gender and sexual identities (2SLGBTQIA+) people continue to face multiple barriers in getting tested for sexually transmitted and blood-borne infections (STBBIs) in Canada, requiring testing services that help overcome these barriers.
- Self-collection kits for STBBI testing are one option that is appealing for many people and are widely used in some other countries. No provincial or territorial jurisdiction in Canada has introduced self-collection kits on a large scale, although there are several small-scale programs in different parts of the country.
- Self-collection kits for STBBI testing are becoming available in some places from private companies on a for-pay basis, which is out of reach for many people.
- A key step in developing larger scale projects in Canada is making sure that these kits are designed and made available in ways that work for 2SLGBTQIA+ people.

What are self-collection kits for STBBI testing?

- Self-collection (also known as self-sampling) is when people collect their own specimens for STBBI testing.
- Self-collection kits allow people to do this outside of a clinic or doctor's office, by providing the materials and instructions they need. Kits can include a combination of any of the following: collecting blood samples (for testing for HIV, hepatitis C and syphilis), urine samples and throat, rectal or vaginal swabs (for chlamydia and gonorrhea testing).
- Once a person collects their specimens, they mail or drop them off at a lab for testing, with results typically being provided back to the person electronically, with connection to a healthcare provider for treatment and follow-up care.

Right: Example of the materials included in a self-collection kit for swabs for chlamydia and gonorrhea testing (courtesy BC Centre for Disease Control)



What do we know about their use by 2SLGBTQIA+ people?

We conducted a literature review of 15 self-collection kit programs or pilot studies between 2007 and 2022, all of which involved gay, bisexual, and other men who have sex with men.

- Acceptability of self-collection kits was high – in one study, approximately 9 in 10 (90%) participants reported good experiences with the kits and were likely to use them again in the future.
- We conducted a literature review of 15 self-collection kit programs or pilot studies between 2007 and 2022, all of which involved gay, bisexual, and other men who have sex with men.
- Acceptability of self-collection kits was high – in one study, approximately 9 in 10 (90%) participants reported good experiences with the kits and were likely to use them again in the future.
- Ease, convenience, and privacy were the benefits people most commonly saw in using self-collection kits for STBBI testing.
- Self-collection kits were also found to be an effective way of increasing STI testing uptake, reaching many that have not tested before.
- A major barrier to using self-collection kits was that people perceived themselves as being unable to self-collect specimens properly and did not return their kits for testing. This can be helped by careful design of instructions (E.g., having videos available) and providing clearly labelled kits (e.g., rectal swabs that include a line indicating how far deep to which the swab should be inserted into the rectum).
- Self-collection kits can help to improve equity by improving access to high-quality testing among remote or underserved areas. However, many of the studies reviewed involved using self-collection kits in large urban centres.

Will 2SLGBTQIA+ people in Canada use self-collection kits?

From a mail-home self-testing pilot in BC in Feb 2020, 229 people completed dried blood spot testing for HIV, Hep C and syphilis and mailed them back to the Community-Based Research Centre. More than 85% of the samples were good or very good quality for testing. Three-quarters of participants preferred this option to visiting their regular healthcare provider. Learnings from the study included challenges with delivering and returning results with private shipping and including clear instructions on how to collect samples. Future studies and programs have had success with utilizing Canada Post, simplified instructions with pictures and optional video and virtual peer-based support.

From the Sex Now 2019 survey, 69% of GBT2Q men would be likely or very likely to use a self-collection kit mail to their home. Interest was slightly higher (73%) outside of urban centres. Confidence to self-collect samples was consistently high, with 4 in 5 GBT2Q men confident they could self-collect finger prick blood (83%), urine (90%) and throat swab (83%), and rectal swab (78%).



- Studies have also found that people from higher-income groups and with higher education levels were more likely to use self-collection kits.
- Recommendations to address these unintentional impacts on exacerbating inequity included ensuring that self-collection kit programs for STBBI testing should be implemented at no cost for users and prioritized for non-urban communities.

Why did we do this workshop at Summit 2022?

We wanted to:

- Understand how best to design and put in place self-collection kit programs for STBBI testing to best meet the testing needs of 2SLGBTQIA+ people in Canada; and
- Shift the dialogue past developing pilot projects or small-scale programs to think about what would be needed to bring STBBI testing to scale for 2SLGBTQIA+ people (e.g., to be available across a province or territory).

We did this through a workshop at the Summit 2022 held in Vancouver, which is the Community Based Research Centre's annual national knowledge exchange and capacity building conference on the health of 2SLGBTQIA+ people that draws participants from across Canada.

Our goal in doing this workshop was to gather recommendations that could be useful for community organizations and health services developing self-collection kit programs.



What did the workshop involve?

Approximately 40 people attended the workshop.

We started the workshop with a presentation that provided an overview of self-collection kits for STBBI testing and described the five steps of the pathway a person would go through to use a kit (shown below) and possible options for each step.

We then divided up into small group discussions, each led by a trained facilitator and complemented with a participant handout. The discussion was organized in two parts.

- Part 1 focused on understanding **who would benefit the most** from self-collection kits.
- In Part 2, each step of the pathway and the options for each step were discussed as a group, to identify the **options that would work best** (see icons for each option discussed in this section below).



We asked participants to make notes on their handouts which we collected at the end of the workshop, with the facilitator also capturing ideas on poster paper. We then reviewed and summarized this information for this report.

Part 1: who would benefit most from self-collection kits, and why?

Who would use the kits?

Participants identified specific testing scenarios that might cause someone to use self-collection kits, including people who:

- Have an urgent need for testing (e.g., symptoms, concern about a recent encounter), or a higher ongoing need for testing such as people with multiple partners or in polyamorous/non-monogamous relationships

- Test frequently or regularly, who may just want to get tested without accessing other sexual health services or receiving pre- and post-test counseling (e.g., don't require extensive individualized health education)
- Are looking out for their own health and the health of their partners (e.g., with new partners, or clients)

Recognizing that people face many barriers in accessing clinic or provider-based testing, participants described ways self-collection kits could help overcome these barriers for people who:

- Are busy, or looking for a more convenient option
- Face challenges accessing existing testing services (e.g., transportation costs, do not have a GP, wait times for appointments)
- Lack access to respectful and affirming testing services
- Have had past experiences with healthcare providers leading to a lack of trust, fear of being judged or labelled, and avoiding talking to providers
- Are less out or not out to their healthcare providers
- Face stigma and discrimination in health settings due to homophobia, racism, or transphobia
- Want more autonomy and agency over their testing processes (e.g., prefer self-collecting their own specimens)
- Have high, ongoing anxiety over low risks of infection, who may not easily be able to access testing through a provider

Workshop participants described different groups of 2SLGBTQIA+ people who would use the kits:

- Transgender and gender diverse people
- Two-Spirit people
- BIPOC or racialized people
- People with fewer socioeconomic resources (under-housed, lower income, under or unemployed, people without health insurance)
- Students
- People who use drugs
- Sex workers
- People with physical or mental disabilities

Some participants also recognized that people who have resources to access existing testing services may also use self-collection kits (e.g., white cis men in communities with testing services).

In what settings would self-collection kits be most beneficial?

Many participants felt that self-collection kits were relevant everywhere, in all types of communities (from large urban cities to remote communities) and considered social circumstances to be more important than geography. Other participants suggested specific characteristics of communities where self-collection kits may be needed most, including:

- Smaller communities where privacy can be a challenge
- Settings with high levels of stigma, are conservative, or less affirming
- Places which without testing services or where distance getting to testing service is a challenge (e.g., healthcare deserts)
- Communities with extreme environmental or seasonal conditions that prevent travelling for testing (e.g., northern communities during the winter)

What is required for people to use self-collected specimen kits?

Many Participants identified the skills and experiences people would need to use self-collection kits, including having:

- The agency and confidence to complete the testing process
- Dexterity
- Depending on the program model, access to phone or internet (and skills to use them), or a mailing address
- Their own place which is private for receiving and using the kits
- Sufficient literacy and education, given self-collection kits can be complicated
- Ability to cover any costs required to use the service – free to end user
- Ability to read and understand language in which service is available

Many participants also spoke about system requirements that needed to be in place in order for people to use self-collection kits, including having supports and resources people could access throughout the testing process, including treatment or follow-up care if test results are positive, as well as needing institutional support and funding for implementing self-collection programs.



Part 2: What options for self-collection kits would work best?

STEP 1 : Options for getting a kit

Three options for getting a kit that were discussed: i) requesting a self-collection kit online; ii) getting a self-collection kit from a healthcare provider; iii) picking up a kit from a specific location.



- Participants supported all three options, and often felt having more than one option (or all options) would be needed to meet all peoples' needs and contexts.
- Requesting a kit online was the most preferred option compared to the other two options. Participants had various suggestions, such as including routine reminders to test, making the website simple and easy to load, not requiring an account, and developing an app. Kits would need to be delivered to someone's home in plain and discreet packaging. Results should also be available online, allowing people to see their results when ready.
- Participants also saw value in the other options, such as how getting a kit from a provider would allow for pre-test counseling. For picking up a kit in person, some thought this could be done through clinics, pharmacies, or community organizations or through non-health sites like public libraries. Being able to self-collect on site would be ideal, particularly if people are traveling to the site to get the kit, or for people who are underhoused.
- Participants also spoke to the importance of allowing a non-nominal option for testing (i.e., testing without using personal identifiers), as non-nominal testing options are generally less available. There would also be differences in the system requirements to consider across Canada, such as differences in provincial laboratory regulations and systems.

STEP 2 : Options for understanding how to use a kit

Three options for providing information about how to use the kit were discussed: i) providing written instructions; ii) providing a video showing how to use the kit; and iii) Talking to someone who could explain how to use the kit.



Read information



Watch video



Speak to someone

- Some participants felt multiple options for providing instructions on how to use the kits would be needed, to allow people to choose the method that suits them best and to account for different modes of learning.
- When providing written information, including pictures with written information as well having an accessible reading level was recommended.
- Using videos were felt to likely have the best uptake and meet the most needs, provided they were not too long, and that representation was considered in choosing the people to be shown in the video.
- Speaking to someone who could explain how to use the kit could also be done through other means (e.g., support by email).

STEP 3 : Options for which specimens to collect

Three options for types of specimens for testing were discussed: i) a blood sample for HIV, HCV and syphilis testing; ii) a urine sample for chlamydia and gonorrhoea testing, and iii) throat, rectal, or vaginal swabs for chlamydia and gonorrhoea testing.

HIV
Syphilis
Hepatitis C



Prick finger for blood

Chlamydia
Gonorrhoea



Collect urine

Chlamydia
Gonorrhoea



Throat, rectal, vaginal swab

- Participants supported having all three options available and provided some considerations for each.
- Fingertick blood samples, which would be applied to a blood spot card and dried, or collected in a mini tube, were considered the most difficult to collect, and some people may not want to collect their own sample. Some participants pointed out that there would be no point in doing this if the specimens couldn't automatically be retested to confirm positive results, although there could be a trade-off if people would not be able to access testing otherwise.
- Swabs were considered by some a better option than urine (e.g., vaginal/front hole swabs were preferable to urine for people with vaginas) and swabbing multiple sites preferable for detecting infections. However, some considered collecting swabs to be more challenging to do on one's own.
- Regardless of the options provided, having clear information about storage of specimens would be important (e.g., appropriate temperature range).

STEP 4 : Options for returning specimens

Three options for types of specimens for testing were discussed: i) a blood sample for HIV, HCV and syphilis testing; ii) a urine sample for chlamydia and gonorrhea testing, and iii) throat, rectal, or vaginal swabs for chlamydia and gonorrhea testing.



Mail



Courier



Drop-off

- Participants did not express a strong preference for any of the options but suggested that the method for returning specimens should be as simple as possible.
- Mailing specimens could be the easiest for people using self-collection kits although not all specimens can currently be mailed through Canada Post (currently only dried blood spots can be mailed). Having a pre-paid postage box would be preferable. Some participants raised concerns about mail not always being reliable or delayed, for example due to poor weather.
- Sending specimens by courier was felt to be a safer option compared to mail, although this would require scheduling a pickup.
- Including a map showing the location of drop-off kits was important if this option was used to return specimens.

STEP 5 : Options for getting test results

Three options for getting test results were discussed: i) view results online; ii) receive results by text message; iii) receive results from a healthcare provide by telephone.



View online



Receive text message



Get a phone call

- Generally, participants considered the ability to view results online the best option, particularly if the results were negative. This option would also give people more agency in being able to access results when they were ready.
- Receiving a text message about your results was considered to pose challenges for some users of self-collection kits. Phones may be shared and someone else may then see the results. Concerns were also raised about the possibility of texts coming when people were not mentally prepared to get their results, or not in a location suitable for receiving results such as a workplace.
- Participants discussed how phone calls may be preferable from a provider perspective but may not be optimal for the client. Some suggested a hybrid model could work well, as is used for BC's GetCheckedOnline service where users receive an email that their

results are ready, and they can log in to the website to see their results (if negative) or a message to call a provider (if positive).


- Many participants stressed the importance of ensuring treatment pathways were in place for treating people with positive results, and that it be clear where to go to get treatment. Several people spoke to their experience as providers and challenges related to having people present for treatment having seen a healthcare provider virtually, where the actual test results were not known (especially for interpreting Hepatitis C and syphilis results). Others recognized that positive results of self-collection kits would also need to be reported to public health.

What did we learn?



- Overall, workshop participants considered self-collection kits to hold potential for improving access to STBBI testing for 2SLGBTQIA+ people.
- Self-collection kits for STBBI testing were thought to overcome many types of barriers, particularly those related to distance or travel to testing sites and negative experiences with health care providers or in health settings (such as racism, homophobia, or transphobia).
- The groups of 2SLGBTQIA+ people that would most benefit are those who may have fewer socio-economic resources to access testing. This was paired with the concern that people who do have good access to testing already may be more likely to use self-collection kits, which has the potential of worsening health inequities.
- In addition, use of self-collection kits for STBBI testing was recognized to require a certain level of individual capacities, including agency, confidence and dexterity to use the kits, literacy to understand and carry out the instructions, and access to the ways in which services are implemented (e.g., internet access).
- It was clear from the discussions that there is no “one size fits all” approach for maximizing the benefit of self-collection kit programs, with multiple options being needed that are easy to use.
- Preference was highlighted for options that were available online, including ordering a kit and getting results, which may be related to the enhanced agency and autonomy of these options.
- While the design and content of self-collection kits are important this is not enough, as programs need to have defined, accessible, and well-connected pathways in place.
- Participants also asked that self-collection kit programs also incorporate features of other effective STBBI testing services, including testing reminders and having non-nominal options for testing.

What are the recommendations for organizations wanting to develop self-collection kit programs for STBBI testing for 2SLGBTQIA+ people?



Drawing from the information gathered and lessons learned, and interpreted through our organizations' experiences in implementing low-barrier programs for STBBI testing, we have identified ten recommendations for organizations planning to develop self-collection kits for 2SLGBTQIA+ people:

1. Developing a self-collection kit program should be centred on the needs of potential users, and carefully consider the client experience going through all steps of the pathway (for example, designing processes to be as simple as possible).
2. Identify and engage the groups in your community with facing the greatest barriers to accessing existing STBBI testing services that you are hoping to reach and incorporate their feedback in the development of self-collection kit program (i.e., the people who would benefit the most).
3. Online options for ordering test kits and for getting results may reach the most people and be most preferred compared to other options. However, not everyone will want or be able to use an online service, and other options should also be available.
4. Provide several ways for people to get instructions on using the kit. Written instructions accompanying the kit should be written using accessible language and accompanied by pictures or illustrations. Instructions should also be available by video online, and people should be able to call, email or text someone to help support their use of the kit.
5. Include an option for users not to use their real name through non-nominal testing (e.g., testing using a code).
6. The contents of the self-collection kit should be comprehensive and include as many specimen types as possible for STBBI testing (e.g., blood, urine, swabs).
7. How self-collection kits are returned to the lab for testing should be tailored to the population that may most benefit and the characteristics of the communities where it is available. Following up with reminders by email or text will help improve kit return rates.
8. Establish clearly defined pathways for people with positive results to speak to a provider and be connected to care for treatment, prior to launching the service.
9. Review any regulations or requirements for STBBI testing in your region that need to be met by a self-collection kit program, as these may differ across Canada and may impact how the program can be run (e.g., requirements for who can order STBBI testing).
10. Start with a pilot phase to determine barriers that may be unanticipated, and then adapt accordingly (e.g., challenges with courier, instructions for drop-off, process for returning results).