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Opportunities and Challenges of HIV Self-Testing for GBTQ2+ Men in Ontario

Perspectives from HIV/AIDS Service Providers

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BACKGROUND

This report has been commissioned by the Gay Men's Sexual Health Alliance (GMSH) in response to the potential approval by Health Canada of HIV Self Testing (HIVST) technology, specifically the INSTI HIV Antibody Test in the near future. Consultations were done with front-line service providers at HIV/AIDS Service Organizations (ASO) representing agencies in urban, rural, and northern communities. The staff who were consulted work in frontline positions, predominantly or specifically with GBTQ2S+ men. A representative from the AIDS Bureau at the Ministry of Health and researchers exploring the acceptability of HIVST technology in Canada were also consulted. This report will be shared with the provincial office of the Gay Men's Sexual Health Alliance who will in turn present the findings back to the ASO and front-line workers who contributed their knowledge and time to its creation.

INITIAL THOUGHTS FROM HIV/AIDS SERVICE ORGANIZATIONS

The front-line workers that I spoke with were, by and large, very excited about the potential that HIVST brings to their work with communities of GBTQ2S+ men. Many people I spoke with thought that this approval was long overdue and would become a useful tool, not only in their own work, but also in the community. All of the frontline workers I have spoken with also articulated that their ASOs have already engaged in discussions on the ways that they might utilize HIVST in their already existing programming or the new programming that they might develop to support HIVST. In discussions about potential new programs, frontline staff did not articulate how they would be funded. Nobody I spoke with articulated that their agency was interested in hiring new staff to support HIVST but rather their agencies were exploring programs that HIVST could be rolled into programs/services that staff were already responsible for overseeing. Lastly, while ASO's are engaged in discussions about how to implement HIVST, many are still looking for guidance, from either the GMSH or the Ministry of Health, on strategies that are the most effective and issues that ASO's should be aware of.

HIV/AIDS SERVICE ORGANIZATIONS' CONCERNS

In discussions with frontline workers, there were several issues that continued to arise across multiple organizations and regions of the province. Primary among concerns that front-line workers raised was the cost of buying HIVST kits for use in their clinics and/or programs & services. Many outlined that they were unaware of how their agency would be able to afford large orders of HIVST kits without new funding made available to them. The potential high cost of ordering kits was also a factor that impacted the way that front-line workers thought they might be able to disseminate kits (eg. 1 per person). In a similar vein, the majority of frontline workers repeatedly called for access to more funding to be better able to provide kits to their communities. The consultations did not probe frontline workers' perceptions of broader HIVST resources, such as promotional material, or the funding that might be required to develop them. Future consultations might benefit from speaking with management staff who might be able to provide more insight as well.

Many frontline service providers, particularly those that work at ethno-racial specific ASOs, identified language as a possible barrier to engaging the communities they work with in HIVST programs. Workers specifically named Hindi, Arabic, Mandarin, and Farsi as languages that they hoped to see materials provided in. Barring

language specific instructions, frontline workers hope that resources will be available that include illustrated instructions for people that are easy to follow so that a working or comfortable understanding of French or English is not needed to access HIVST technology.

Frontline workers were asked explicitly about their thoughts on HIVST and the role of pre- and post-test counselling. While many who were consulted felt that the lack of mandatory pre- and post-test counselling would not have a negative impact on GBTQ2S+ men, a couple of frontline workers were concerned that without the post-test counselling piece, GBTQ2S+ men who have a reactive test might enter into a mental health crisis state. While this was not a common perspective, the concern of GBTQ2S+ men entering into crisis was informing discussions on the ways that HIVST would be incorporated into ASO programming. One ASO is considering only making the HIVST available for in-agency use so that if there is a reactive test the client can access post-test counselling immediately. Other frontline workers also said that they were interested in offering HIVST kits for clients to use on site with one worker saying that on site HIVST testing offered opportunities to engage peer workers in frontline support work.

In line with their concerns about the lack of post-test counselling, several frontline workers expressed concern about how to ensure appropriate linkages to care in cases where there is a reactive test. This fear was particularly felt by those whose agencies serve rural and northern communities who articulated a lack of HIV specialists and primary care physicians and pharmacists who are aware of the issues that face people who are living with HIV. Specifically, they articulated a need for accessible resources that people who have a reactive test can easily find to get a referral to competent and respectful care.

Several people I spoke with highlighted their concern that point of sex (POS) testing, that is an HIVST done before a sexual encounter and used to screen sexual partners, that people from marginalized communities (specifically sex workers however no sex workers were explicitly consulted in this process and none of the frontline worker's agencies explicitly work with sex workers) might feel coerced into taking the test. While the research on experiences of coercion in HIVST is mixed, the fear that it could happen might act as a barrier to people accessing the test or ASO's handing out the HIVST technology more freely(Brown et al., 2014;Qin et al., 2017; Ong et al., 2018). Future resources to address this concern might be partnering with organizations like the Canadian HIV/AIDS Legal Network or the HIV & AIDS Legal Clinic Ontario to develop Know Your Rights materials or similar programming.

When asked about the possible benefits of HIVST, frontline workers' responses about privacy were mixed. Many felt that HIVST offered more opportunities for privacy by removing the fear that clients might be seen entering a sexual health clinic, but others felt that it also presented new possibilities for surveillance from community members (that community members might perceive or infer information about a person based on assumptions about HIV) which might lead to an unintended disclosure of sexual orientation or behaviour. Some workers were concerned that many GBTQ2S+ men would seek social support at the time of accessing an HIVST. Social support, while sometimes a benefit of HIVST, also allows for possible breaches in privacy, both in regard to sexual orientation and testing results. Resources designed to raise the consciousness of possible social supports (e.g. Supporting Your Friend Getting an HIV Test and How to Ask a Friend to Help with your HIVST) may help to

address issues of inappropriate disclosure. There were also concerns from front-line workers about GBTQ2S+ men ordering HIVST kits in the mail that might be opened by other members of the household, again potentially outing those who would take an HIVST. All testing materials should come in nondescript packaging and with the option to be delivered to local post offices, or other mail pick up location, so as to lower the possibility of being intercepted by someone other than the person who ordered them.

Related to the concerns about protecting GBTQ2S+ men's privacy were concerns about social supports not knowing how to support someone who had received a reactive HIVST. These include concerns of "not knowing what to say" or social supports reinforcing stigmatizing views of HIV. Resources like a Supporting Your Friend should include information on language, stigma and HIV to further build capacity within GBTQ2S+ men and develop broader networks for support.

Despite the HIVST that is likely to be approved by Health Canada being effective, front-line workers were unclear on how effective it is and wanted further information. They also believed that feeling unsure of the effectiveness of the HIVST might deter some people from accessing it. This is in line with a study of HIVST technology acceptability in a population of students in a university in Montreal(Pant Pai et al, 2014). The study found students were unsure if the HIVST was as accurate and were left wondering if the results could be trusted, even if the test came back negative. Further awareness on the accuracy/ efficacy of HIVST may help to make people feel more comfortable in accessing the test.

Lastly, some front-line workers were concerned that HIVST would be branded exclusively with language directed at GBTQ2S+ men. Many of the ASOs work with people who have never gotten a test before, have low levels awareness about HIV, or who do not identify as having sex with other men so would not be engaged by these messages. Front-line workers stressed the necessity of ensuring that there were materials that were branded more broadly in order to engage the diversity of their communities. This should include imagery that has diverse gender representation and relationship structures (ex: a man and woman holding hands) as well as language that does not centre identities (ex: two packages, one that says "are you a gay man worried about HIV?" and another that just says "Are you a man worried about HIV?").

MINISTRY OF HEALTH CONCERNS

The AIDS Bureau in the Ontario Ministry of Health is supportive and excited for the approval of HIVST by Health Canada. They currently do not have any plans in place to provide more funding to ASOs and community-based organizations to administer or to disseminate HIVST into communities of GBTQ2S+ men or other priority communities. Despite there being no plan to provide additional resources, the Ministry is supportive of ASOs and community organizations finding acceptable and effective ways to engage their communities in HIVST. One of the obstacles that the Ministry has highlighted is the limitation to ASOs participating in the administration of HIVST with individuals. The act of puncturing the skin for medical purposes is a controlled act in the province of Ontario and can only be administered by a regulated healthcare professional. Similarly, the act of interpreting medical results is also a controlled act that must be done by someone in a regulated healthcare profession. If ASOs were to participate in either of these actions they may be liable and in violation of the Regulated Health Professions Act. Resources outlining the limitations of ASO participation in the HIVST process, including

suggested language for supporting clients who are using HIVST kits (e.g. "I also see two dots"), would help ASOs better navigate regulatory legislation in their work.

SUPPORTING RESEARCH FOR CONCERNS

Even though Canada is only just approving HIVST technologies now, several jurisdictions have had broad public access to HIVST for the last decade, including the United States, China, and parts of Europe and Sub-Saharan Africa. This has led to many studies that we can look to in order to better understand the barriers and opportunities that HIVST might offer for community organizations in Canada.

Unsurprisingly, there is no one best practice for community organizations to incorporate HIVST into their community-based practice. ASOs should assess the acceptability of their programming and adjust based on feedback from the communities that they work with and the front-line workers who are administering them. Despite there being no one model of HIVST community-based programming to follow, there are some recommendations that have come out of the research that can benefit the implementation of HIVST in Ontario. While some research has found the instructions of HIVST accessible and understandable (Lippman et al., 2016; Estem et al., 2016), they still found that the perception that they might not be understandable acted as a potential barrier to some communities' engagement (Mathews et al., 2020). Similarly, some participants were not sure if they had administered their test correctly or were convinced that they could trust the result (Pant Pai et al, 2014; Figueroa et al., 2015; Frye et al., 2015; Estem et al., 2016; Mathews et al. 2020). Furthermore, while online videos that demonstrated appropriate HIVST utilization were useful, they would often not be watched (either because participants could not access them at the time of their testing or, simply because they did not want to watch the video) or universally understood (Estem et al., 2016; Frye et al., 2015; Mathews et al., 2020).

In order to engage specific communities of GBTQ2S+ men, particularly Black GBTQ2S+ men, some research highlights the importance of using strengths-based messages (e.g. Take Control of Your Health) (Mathews et al., 2020). This helps to not only address the stigma that continues to impact the lives of people living with HIV but also shifts the deficit-based narrative that often frames Black sexualities.

While there is some research that suggests that the harm experienced from feelings of coercive testing were not different from those who felt they had not been coerced (Brown et al, 2014), there are still multiple studies that have participants who have reported feeling coerced into participating in an HIVST (Qin et al., 2017; Ong et al., 2018). While it is unclear what coercion might mean in these individual's experiences or how they have understood them, the World Health Organization lists coercion as a threat to the dignity and human rights of people who are living with HIV (WHO, 2017) and needs to be accounted for in the adoption of HIVST.

Some other recommendations for programming that have proved to be acceptable and effective have been engaging community organizations outside of the healthcare space (e.g. churches, bars) to help disseminate or educate about HIVST(Mathews et al., 2020). Some research also recommends using pre-existing social and sexual networks to help disseminate HIVST to people who might not be engaged by community sexual health clinics (Fuqua et al., 2012; Xiao et al., 2020). Social support has been demonstrated to be a factor in early HIV diagnosis,

linkage to care, and HIV risk mitigation (Lauby et al., 2012; Kelly et al., 2014). HIVST kits offer unique opportunities for further utilization of these informal networks to reach GBTQ2S+ men to help support their sexual health.

Lastly, some research has found that even in jurisdictions where HIVST has been approved, finding a kit may still prove difficult and awareness of their existence might remain low. Pharmacies might not order HIVST kits, keep them behind the counter (requiring potential clients to request them from the pharmacist) or not advertise that they are available (Estem et al., 2016). This may require future partnerships with professional associations of pharmacists and the companies that run these businesses to help raise the awareness of the necessity of HIVST and the importance of its accessibility.

PROGRAM EXAMPLES FROM OTHER JURISDICTIONS

VENDING MACHINES, "CONDOM BOWLS" AND SITE SPECIFIC DISSEMINATION

ASO's, bathhouses, and other community organizations that cater to the needs of communities of men who have sex with men have long been sites of low barrier access to sexual health supplies and equipment. With the advent of HIVST, this has expanded to include low barrier ways to disseminate HIVST kits in community spaces. A method that is has seen some evaluation in the UK is the use of specific vending machines placed in gay bathhouses/saunas. Between 93% and 95% of men surveyed said they were open to the idea of accessing HIVST kits from a vending machine and, of those who accessed an HIVST kit, between 4% and 7.4% had never been tested previously (Vera et al., 2019). The vending machines were developed specifically for this purpose and are designed for users to order the HIVST kit using their smartphones. This allows for those who have ordered a kit to be contacted at a later date for follow up and to evaluate the effectiveness of the vending machine.

Other examples for site specific programming that have been suggested include placing HIVST kits in easily accessible places, akin to bowls of condoms on the counter, and free HIVST available at request from ASOs. Possibly due to the high cost of individual kits, however, there does not seem to be a lot of information on spaces where this has been done or evaluated.

MAIL DELIVERY

One large scale method for disseminating HIVST technologies is creating a mail delivery hub wherein an organization creates an online ordering hub that will mail

out HIVST kits to people's homes or pick up locations. Terrence Higgins Trust (THT), in the United Kingdom, has been funded by regional health authorities to mail free HIVST kits to residents of those regions throughout the UK (https://test.tht.org.uk/). These kits allow for anonymous testing and the THT provides direction on how to receive a kit to a location that is not your home. THT will mail kits to residents of the UK outside of those regions at cost (£15). THT operates a direct helpline for all who request a HIVST kit but is only staffed during regular business hours and between 10 am and 1 pm on the weekends. All residents who request a kit are asked to share their results with THT, regardless of result, to help THT track the effectiveness of the program. The THT website also has a function that allows participants who live outside of the regions where they can have an HIVST kit mailed to for free to enter their postal code and find out about free testing services in their region. The National Health Service (NHS) also sends out free HIVST kits to specific regions but are not anonymous (https://freetesting.hiv/). The NHS also sends out free kits anywhere in the UK during National HIV Testing Week (mid-November) but are different from the INSTI kits.

A pilot HIVST mail delivery program is currently being tested in the Ottawa region, led by researchers at the University of Ottawa(https://getakit.ca/). While the pilot is only in its infancy, in the first two weeks of operation they have mailed out over 100 kits to people who have requested them from across the city of Ottawa. So far, the pilot has received only positive feedback from respondents, with more than 75% of people who have received an HIVST kit connecting with the research team after completing their test. Everyone who reconnects to the research team is provided resources to support their sexual health, irregardless of test result. Those with nonreactive results are given information on condoms, PrEP, PEP and referrals to physicians who can provide prescriptions to PrEP. Those with a reactive test are asked to come in for a confirmatory blood draw and referrals to other HIV support services. Of those who have requested an HIVST kit so far, 25% have never been testing for HIV previously.

Despite how early into the project this pilot is, there are several lessons that may be more broadly applicable for HIVST mail programs in Ontario. Researchers found that language common in the HIV sector, like a "reactive" test, only confused participants who felt that any response from the test was a "reaction". Furthermore, many people who had requested tests were posting on social media, as well as requesting support from the research team on HIVST kit use over social media platforms (for example: Instagram). The research team also opted to remove the extra lancet from the kit as providing more tools than the instructions directed only further confused participants. Lastly, different mail services were used for different participant homes. For participants who lived in houses, Purolator was used as it is a much cheaper option ($4 vs $10 with Canada Post) however Purolator deliveries will leave a parcel outside someone's door if they are not home and potentially outing study participants. For those who lived in apartment or condo buildings, Canada Post was used as their delivery service can access private residence mailrooms, thereby keeping the package more discrete.

Of the participants who have responded so far to the pilot in Ottawa, there have been more reports of "invalid" tests than previous research would suggest. This may be a result of confusion over "reactive" testing language, concern over the validity of self testing technology more broadly, or some other issue that has yet to be identified. The pilot has also developed a relationship with a primary care physician whereby all

respondents are given a referral letter to an infectious disease or HIV specialist physician to prescribe PrEP or ART without an appointment.

PHARMACY VOUCHERS

One program that has been both researched and implemented in the United States is the use of pharmacy vouchers. ASO's and other community based organizations are given vouchers for free HIVST kits that they can then disseminate to clients. One study on the acceptability of such a program with African American men who have sex with men found that of the 641 vouchers that were given to ASO's, 274 were given to clients and 53 were redeemed(Marlin er al., 2014).

This program has been adopted by at least one ASO in the United States. Aunt Rita's foundation, an ASO in Arizona, has partnered with three large pharmacy or lab testing corporations from across the state to offer free HIVST kit vouchers (Aunt Rita's Foundation, 2019). They are offered free to any adult within the state of Arizona and facilitated by an online hub that the ASO coordinates (https://gettestedaz.org/). Despite how widespread the partner pharmacies and labs are across the state, there are no partnering organizations located in the Navajo Nation in the Northeast. The online hub can also be used to order HIVST kits to be delivered by mail across the state.

COMMUNITY DISSEMINATION

While some research done on HIVST has recommended using community networks to help disseminate HIVST kits through communities of GBTQ2S+ men, I have been unable to find examples of this in ASO's (Matthews et al, 2020). There is one evaluation study of community dissemination of HIVST technology in Malawi where community health workers went door-to-door to talk about and hand out kits but otherwise there is little research that explores effective strategies (Sambakunsi et al., 2015). This may be happening and supported by community-based organizations, like ASO's, but due to the informal nature of the spread is hard to track or research.

RECOMMENDATIONS

Following these consultations and a review of the current literature regarding HIVST in various jurisdictions, I would recommend the creation or development of the following resources to support the uptake of HIVST technology by GBTQ2S+ men across Ontario:

TESTING MATERIALS

- Materials provided to instruct on the use of HIVST kits need to be offered in diverse languages (including French, English, Mandarin, Hindi, Arabic, Mandarin, and Farsi).
- Instructions should also be given using an illustrated medium so that GBTQ2S+ men who do not read the above languages or with limited literacy can feel confident in their ability to administer a self test.
- Online videos are helpful for demonstrating the application of HIVST technology but cannot be solely relied on, particularly for communities that might not have access to the internet or smart phones.

RESOURCE DEVELOPMENT

- Resources to address community and ASO concerns about privacy and surveillance from community members such as Supporting Your Friend Getting an HIV Test and How to Ask a Friend to Help with your HIVST. Resources should include information on language, stigma, HIV, and local health resources to further build capacity within GBTQ2S+ men and develop broader networks for support.
- Partnerships should be sought with organizations with legal capacity to develop "Know Your Rights" resources to help GBTQ2S+ men understand their rights when it comes to point of sex or potentially cohersive testing.
- All resources for community members should be made available in the above mentioned languages.
- Resources should be developed to support ASOs' better navigation of the regulatory framework in Ontario in terms of providing HIVST on-site. This should include language that protects ASOs that might offer on-site HIVST kits to avoid being in violation of the Regulated Health Professions Act.
- Resources should be developed to support ASOs to use peer workers and volunteers in facilitating the use of HIVST kits on-site and in their communities. These resources should include how to use lived experience in a supportive and effective way, active listening and local HIV support resources.

MAIL DELIVERY

- Develop an online hub that allows GBTQ2S+ men to order HIVST kits that will be delivered by mail.
- All HIVST kits should be delivered in nondescript packaging that does not include any identifying information about the GMSH.
- Kits should be able to be mailed to home address, local post offices, or other mail pick up locations using different mail delivery services as required (Canada Post, Purolator, etc.).
- The online hub should contain copies of the above mentioned resources as well as information on

where an HIVST kit can be purchased or procured for free locally.

- The online hub should provide information on local GBTQ2S+ health resources and organizations, including HIV testing options and HIV specialists.
- All kits should include a request to anonymously report results of HIVST on hub so that hub can both provide referrals to local HIV resources and testing in case of a reactive test as well as track the effectiveness of the program.
- Develop local sexual health hubs across the province to refer people who request a kit to for future services and information.
- Develop a referral letter, with a local primary physician billing number, to connect people with care following a test.
- Create training materials for communications staff at ASO's to be able to answer questions about HIVST technology over social media and how to engage community social media posts that contain HIVST content.

ASO PROGRAMMING SUPPORT

- Disseminate all of the resources previously suggested to ASO's across the province.
- Develop training materials for ASOs to train peer workers and volunteers in HIVST technology and dissemination, ensuring that they know the limitations of their role.
- Discuss strategies with ASOs on possible sites for HIVST kit dissemination that might be effective spaces for engaging their communities (outreach programming, churches, etc.).
- Lobby government partners for increased funding to support the purchasing of HIVST kits by ASOs.
- Due to the high cost of developing an HIVST kit vending machine, coupled with the low uptake rate, I recommend that resources be expended on other options at this time and revisited later.
- Due to the necessary corporate partners needed to enact a pharmacy voucher program, coupled with the low uptake of vouchers in research studies, I recommend that resources be expended on other options at this time and revisited later.

CONCLUSION

The advent of HIVST in Canada, and Ontario specifically, provides for increased opportunities to address the continuing HIV epidemic and its impact on GBTQ2S+ communities. There are many ways that the GMSH can be central to the rollout of HIVST kits, including by developing an online hub for ordering HIVST kits through the mail and broader lobbying efforts for low barrier access for communities across the province. While ASO's have already begun to strategize on how to implement HIVST kits into their preexisting work, conversations with stakeholders should continue as there will undoubtedly be unforeseen issues with HIVST engagement by both frontline workers and community members.

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