

National Collaborating Centre for Infectious Diseases Centre de collaboration nationale des maladies infectieuses

# National Forum on STBBI Testing and Linkages to Care: **Reaching the Undiagnosed**



Co-hosted by CIHR Centre for REACH 3.0 / MAP Centre for Urban Health Solutions, the National Collaborating Centre for Infectious Diseases & the Public Health Agency of Canada

# **Meeting Report**

February 4<sup>th</sup> and 5<sup>th</sup>, 2020





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Public Health Agency of Canada

Agence de la santé publique du Canada

# National Forum on STBBI Testing and Linkages to Care: Reaching the Undiagnosed

Meeting Report

February 4 & 5, 2020, Ottawa

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### **Executive Summary**

Co-hosted by the Canadian Institute for Health Research (CIHR) Centre for REACH 3.0 / MAP Centre for Urban Health Solutions, the National Collaborating Centre for Infectious Diseases (NCCID) and the Public Health Agency of Canada (PHAC), the National Forum on Sexually Transmitted and Blood-borne Infections (STBBI) Testing and Linkages to Care: Reaching the Undiagnosed was held on February 4<sup>th</sup> and 5<sup>th</sup>, 2020. The Forum was attended by over 100 stakeholders who brought a range of perspectives and shared current research and information on STBBI testing modalities and programs across Canada. The Forum created a space to discuss opportunities, challenges, and potential next steps for reaching persons with undiagnosed STBBI in Canada, to set the groundwork for the introduction of new STBBI testing technologies across the country.

Discussions from this Forum highlighted the complexities of STBBI testing and linkage to care and overarching themes focused on providing low threshold and wrap around services, to improve a health care system that is currently failing to provide non-judgmental and culturally relevant STBBI testing and care.

Key themes and opportunities to expand innovative strategies to reach the undiagnosed raised included working with and trusting communities to know what they need, as well as a need for guidance for community engagement, leadership, and ownership of STBBI initiatives. Expansion of peer or community health worker models could build capacity of communities, to provide culturally relevant STBBI testing, linkage to care and other services, and to engage disengaged communities.

Consideration of universal STBBI testing models to avoid missed opportunities and to reduce inequities, and STBBI screening as a standard of care could be used to normalize and routinize testing. The broader health system requires education regarding STBBI services and to have standards for quality and culturally competent STBBI testing and care and/or support is needed for community-based organizations or AIDS service organizations to provide confirmatory testing and linkage to care with low threshold and wrap around services. Provision or mechanisms for knowledge, learning, and sharing information of innovative STBBI testing modalities and initiatives, evaluation, and cost benefit analysis is necessary to rationalize funding for programs or interventions and to provide evidence for what modalities work in which circumstances, and when compromise in STBBI testing quality is substantiated to increase access.

Scale-up of innovative STBBI programs to implement evidence-based interventions was seen by Forum participants as essential to have the ability to learn by doing, to re-evaluate, and to adapt as necessary. Policy and governance needs to support innovative STBBI testing and linkage to care to have the ability to reach more people. There was interest in exploring the role of laboratories as command centres for STBBI diagnostics in Canada to provide training, quality assurance, collection and intelligence of surveillance data, and to conduct implementation research. Lastly, Forum participants discussed continuing issues of stigma, ongoing systematic disadvantages related to the determinants of health, the criminalization of HIV, as well as consent and data ethics that need to be resolved to increase access and to minimize harm from STBBI testing. Expanding innovative STBBI testing strategies was seen to increase the ability to reach the undiagnosed in Canada, and increases options for accessible, culturally competent STBBI testing and care.

#### Areas for Action Arising from the Forum Discussions

Develop best practices for leadership and engagement of communities

Develop best practices in the role of peers within the healthcare team

Support integrative, universal, and wrap-around STBBI testing and linkage to care services

Leverage digital technologies and build best practices for these technologies

Pursue sustainable STBBI testing & linkage to care programming funding

Create return on investment or business case analysis and templates that include downstream costs

Invest in laboratory infrastructure and explore the role of the laboratory as command center

Move to more coordinated efforts within federal, provincial and territorial, and jurisdictional systems for more unified approaches and to avoid wasted time reinventing systems

Leverage data to advocate for resources, while developing ethical data collection and use standards

Create mechanisms for communication and sharing between stakeholders about new testing technologies, emerging best practices and evaluation of interventions and programs

Use program science methodologies to evaluate programs and/or complex intervention combinations

Integrate frontline healthcare providers in the planning of programming and educate frontline staff to make provision for quality and trauma informed STBBI care, including cultural competencies

Use implementation science to identify what interventions work to provide successful and sustainable interventions or programming

Collect knowledge to align technologies to meet needs according to setting and population

Continue to address stigma within communities and within health systems

# Contents

Introduction
Objectives
Participants3
Day 1 - February 4th, 2020
Opening Remarks4
Bringing New Innovations in STBBI Testing with Linkages to Care to Canada4
Reaching the Undiagnosed – Voices from the Community7
Breakout Session #1 – Acknowledging Success10
Novel Approaches to Testing, Reach the Undiagnosed and Linkages to Care: Structural Interventions and Promising Practices
Breakout Session #2-Identifying Challenges for Implementation17
Day 2 - February 5th, 2020
Breakout Session #3- Identifying Potential Solutions21
Pharmacy-based STBBI testing21
Peer-based STBBI testing22
Self-testing
Conclusion25
Appendix A: Sexually Transmitted and Blood-borne Infections (STBBI) Testing and Linkages to Care: Reaching the Undiagnosed Agenda
Appendix B: Participant List

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### Introduction

In June 2018, the Federal/Provincial/Territorial Ministers of Health endorsed *Reducing the Health Impact of Sexually Transmitted and Blood-borne Infections in Canada by 2030: A Pan-Canadian STBBI Framework for Action*, demonstrating their joint commitment to reduce the impact of sexually transmitted and blood-borne infections (STBBI) in Canada and contribute to achieving global STBBI elimination targets. The Framework highlights STBBI testing and initiation of treatment and care as key pillars of action to reducing the health impact of STBBI in Canada by 2030.

Furthermore, the Government of Canada's response to the Framework, *Accelerating our Response: The Government of Canada Five-Year Action Plan on Sexually Transmitted and Blood-borne Infections*, identifies "Reaching the Undiagnosed" as a key commitment. This includes a commitment to playing its role in the development, regulatory approval and deployment of point of care testing and additional novel technologies and working with its provincial, territorial, First Nations, Inuit and Métis partners and stakeholders to ensure that health and community-based providers can support their implementation.

With many STBBI on the rise in Canada, the proportion of undiagnosed persons contributes to the ongoing transmission of these infections and to negative health outcomes for affected individuals. Current approaches to testing are not reaching all of those who could benefit, however, based on the experience of other jurisdictions, the emergence of innovative STBBI testing technologies and approaches hold promise to help reach the undiagnosed and hard to reach individuals. Potential solutions involve scaling up the use of existing technologies, the introduction of new diagnostic technologies to the Canadian market, and their rollout through tailored and community-based approaches.

On February 4<sup>th</sup> and 5, 2020, the Canadian Institute for Health Research (CIHR) Centre for REACH 3.0 / MAP Centre for Urban Health Solutions, the National Collaborating Centre for Infectious Diseases (NCCID), and the Public Health Agency of Canada (PHAC) brought together STBBI stakeholders from across Canada to a *National Forum on Sexually Transmitted and Blood-borne Infections (STBBI) Testing and Linkages to Care: Reaching the Undiagnosed*. The meeting provided an opportunity for attendees to share current research and information on a range of STBBI testing modalities and programs from jurisdictions across Canada, and to discuss opportunities, challenges, and potential next steps for reaching persons with undiagnosed STBBI in Canada.

#### Objectives

The objectives of the forum were to:

- Introduce new testing technologies and approaches and to share current implementation research (projects and programs) and evidence on STBBI point of care testing and linkages to care;
- Identify and discuss opportunities and challenges to facilitating scale-up of testing and linkages to care;
- Create a common understanding of the current policies related to the STBBI testing landscape and pending developments; and,
- Create a mechanism to support ongoing communication about best practices and lessons learned with the implementation and scale-up of projects and programs across the country.

These objectives align with the overarching strategic goals of the *Pan-Canadian Framework for Action: Reducing the Impact of Sexually Transmitted and Blood-borne Infections in Canada by 2030,* which are to 1) reduce the incidence of STBBI in Canada; 2) improve access to testing, treatment, and ongoing care and support; and 3) reduce stigma and discrimination that create vulnerabilities to STBBI.

#### Participants<sup>1</sup>

The forum was attended by approximately 100 stakeholders including people with lived experience, community-based organizations that work with communities or populations at greater risk for transmission of STBBI – including organizations that work with lesbian-gay, bisexual, queer, trans and two-spirited (LGBQTT) communities, First Nations, Inuit, and Métis communities, organizations for women and African, Caribbean and Black (ACB) communities, and people who use drugs. Participants from the health sector included community-based and outreach organizations; HIV and hepatitis C service organizations; researchers, Government of Canada departments including the Public Health Agency of Canada and its National Microbiology Laboratories, Health Canada, Indigenous Services Canada, and the Canadian Institutes of Health Research; Provincial and Territorial health ministries and public health program and laboratory staff; and the medical diagnostic industry. Attendees contributed a range of perspectives about what needs to be achieved to scale up innovative STBBI testing and linkage to care strategies to reach persons with undiagnosed STBBI – particularly people who are difficult to reach – and to link them to the care they need. Discussions focused on the importance of working with communities to identify testing modalities most appropriate for different contexts; the

<sup>&</sup>lt;sup>1</sup> Note that some invited guests were not able to attend due to the impending COVID-19 crisis and other reasons, including medical officers of health from Provincial Ministries, representatives from some First Nations organizations, as well as organizations representing HPV elimination. See appendix B for participant list.

critical importance of linkage to care after testing; the issue of stigma as a barrier to testing; and the challenge of scaling up promising practices into routine practice.

## Day 1 - February 4th, 2020

#### **Opening Remarks**

On the morning of February 4<sup>th</sup>, facilitator Jody Jollimore, Executive Director, Community Based Research Centre (CBRC) for Gay Men's Health in Vancouver opened the proceedings by acknowledging that the forum was taking place on the traditional and unceded territories of the Algonquin First Nation. This acknowledgement was continued respectfully by all speakers throughout the forum in their own way. Jody Jollimore acknowledged the participants and capacity in the room, but also the voices of those who may be missing including additional representation from First Nation, Métis, and Inuit communities, sexual and gender minorities, people of color, and newcomers. Elder Annie Smith-St.Georges provided opening greetings for the meeting as well as her perspective on what the meeting could achieve. Laurie Odjick, a fellow Algonquin Anishinaabe Cree woman, joined Annie Smith-St. George and contributed to the greetings as an act of honoring Anishinaabe women.

Kimberly Elmslie, Vice President, Infectious Disease Prevention and Control Branch, PHAC, provided opening remarks. With STBBI on the rise in Canada, she indicated that testing is the gateway to reaching the undiagnosed and linkage to care, whether that be treatment and support or health promotion and prevention strategies. She acknowledged Canada's commitment to global STBBI elimination targets by 2030<sup>2</sup> and the need for stigma-free<sup>3</sup> and novel approaches to reaching those who remain undiagnosed, and that reaching our goals is a shared responsibility across all jurisdictions and sectors. She noted that this meeting was an opportunity to look for solutions to increase access to STBBI testing using innovative strategies, technologies, and approaches that meet the needs of individuals and communities, while respecting jurisdictional roles and responsibilities.

#### Bringing New Innovations in STBBI Testing with Linkages to Care to Canada<sup>4</sup>

Chair of the session Geneviève Boily-Larouche, Assistant Scientific Director at the CIHR Institute of Infection and Immunity, moderated the discussion and introduced the speakers for the morning session to set the stage for scaling up innovative STBBI testing strategies in Canada.

 <sup>&</sup>lt;sup>2</sup> In June 2018, Canadian Provinces and Territorial ministers of health endorsed <u>Reducing the health impact of</u> <u>sexually transmitted and blood-borne infections in Canada by 2030: A pan-Canadian STBBI framework for action</u>.
 <sup>3</sup> The <u>Chief Public Health Officer of Canada's Annual Report 2019</u> focused on addressing stigma in Canada's health system and providing an <u>Action Framework for Building an Inclusive Health System</u> for health systems to reduce stigma in care, treatment, and support.

<sup>&</sup>lt;sup>4</sup> Powerpoint presentations are available at <u>https://nccid.ca/stbbi-testing-and-linkages-to-care/</u>

Setting the Stage: Scaling-up testing technologies in Canada with pragmatic approaches to reach the undiagnosed with HIV, hepatitis C (HCV) and other STBBI - and link people to the care they need Sean Rourke, Director of the Centre for CIHR REACH 3.0 and scientist for the MAP Centre for Urban Health Solutions, welcomed everyone and provided the context for the meeting to reach the undiagnosed. He deliberated on the expertise in the room and working together towards Canada's commitment to the elimination of STBBI and the opportunities for action as outlined in the Pan-Canadian STBBI Framework for Action, He also referenced CanHepC's Blueprint to inform hepatitis C *elimination efforts in Canada*. He provided examples from the UK and Brazil, where they were able to decrease HIV incidence with increased access and strategic testing along with HIV viral suppression. He shared recent modelling studies in the United States indicating that 80% of HIV transmissions are from undiagnosed people. He also highlighted testing as a way to connect people to the health system stating that there is no one size fits all model for testing and that people need to have local access to STBBI testing that suits their needs. REACH 3.0's many activities support bringing new STBBI tests to the market in Canada by building private and public partnerships with industry to support strategies such as dried blood spot (DBS) testing, point of care tests (POCT), multiplex tests, pharmacy-based interventions and peer provider strategies, along with linkages to care across the country, in a variety of communities and geographies. Sean spoke about partnerships and collaborations between the health sector and community-based opportunities to bring STBBI tests directly to people, and talked about testing scaleup and the need for indicators for monitoring and evaluation, as well as economic evaluations of programming. He ended by reiterating that the information (evidence, documents, guidelines) necessary already exist and it is time for action in Canada. He posed the question for the forum, "What is going to work in our context?"

#### What is working in the real world: A Canadian STBBI point of care testing realist review

Yoav Keynan, Scientific Director of the NCCID and infectious disease specialist, presented on the recent NCCID realist review about STBBI POCT in Canada<sup>5</sup>. The review highlights evidence about how STBBI POCT works in real world settings, the enablers and barriers to implementation, as well as what Canada can learn from countries that have integrated STBBI POCT more broadly. Yoav summarized the evidence regarding patient-centered care, feasibility, and impact outcomes (including traditional serology versus POCT; single versus multiplex tests) and provided key considerations according to populations and settings relevant to the Canadian context including outreach, community and STBBI clinics, emergency departments (ER), hospitals, pharmacies, and other non-conventional testing sites. The review found that STBBI POCT is feasible for relevant communities and can add to testing capacity by finding people that are not testing using conventional methods and may provide opportunities to identify infections earlier as well as reach more first time testers; and careful planning of STBBI POCT to ensure the intervention matches the setting is critical to success and to ensure linkage to care. Yoav added that Canada is facing a syndemic of STBBI across the country, particularly across the

<sup>&</sup>lt;sup>5</sup> See: <u>Point-of-Care Testing for Sexually Transmitted and Blood-Borne Infections: A Canadian Realist Review</u>

prairies along with the increased use of crystal meth. He stated that POCT is not as a replacement for other testing modalities, but is additive to reach people not being reached by other means; and that testing for one STBBI, particularly where higher incidence of HIV infections are still occurring. He ended by indicating that Canadian evaluation data from different settings and in different populations will be critical, and encouraged the use of program science frameworks to evaluate effectiveness of complex combinations of interventions for specific populations to understand what works or doesn't work, in what settings, and for whom.

#### Global lessons on access to testing and linkage

Rosanna Peeling, Professor and Chair of Diagnostic Research at the London School of Hygiene and Tropical Medicine, spoke about the United Nations (UN) Sustainable Development Goals and the Global Pledge to leave no one behind, stating that doing this meant empowering communities with social and technological innovation. She talked about the historical top-down approach versus the successes of asking communities what they need to increase access to STBBI testing and linkage to care, and outlined examples of global lessons learned from working with communities. She shared lessons learned about quality assurance and communication noting that if you get the wrong result, there can be many consequences. Rosanna discussed the global health use of the acronym ASSURED for community testing, summarized as Affordability, Accuracy and Accessibility. She noted that rapid syphilis testing was introduced in seven countries with different settings, and building trust and listening to communities to be able to provide testing were essential. Rosanna spoke of social innovation as a solution developed by communities, civil society, and public and private sectors to deliver health care to be more inclusive and effective (equity, dignity, empowering people), noting that the need to reduce stigma, be technologically sound, be politically viable, and sustainable. She stated that laboratories can take on a role of Command Centre, providing training, quality assurance and oversight, collection and intelligence of surveillance data, and for conducting implementation research. She talked about the opportunities with the creation of new tests and provided the example of a gonorrhea test with the ability to detect anti-microbial resistance in 30 minutes to provide real time effective treatments for infections, to reduce loss to follow up, to extend the life of current last-line treatments, and for cost effectiveness. She also shared the example of using less accurate, but more accessible tests (HIV Orasure test) and spoke about a risk-benefit model showing the number of new HIV infections identified and the number of transmissions averted to outweigh the individual risk of false negative results within a year time frame. She concluded by commenting on the development of a framework for how countries have accelerated their access to quality-assured diagnostics.

#### **Questions and Discussion**

During the discussion, the issue of the usefulness of accessible Canadian analysis of the range of options of what works in specific situations was raised and it was noted that we learn by doing and that we need

to act, monitor, evaluate, and communicate our results and share the lessons learned. A presenter commented on the importance of learning from communities, noting that technologies are only one part, and that cultural, political, and health systems considerations will guide testing strategies.

An audience member commented that communities have known about all of these barriers for STBBI testing for a long time, and that we need to address that the system responses had been slow, and that it is important to be able to talk to each other and find ways to communicate.

#### Reaching the Undiagnosed – Voices from the Community

Stephanie Van Haute, Director of Programs and Engagement at the Manitoba HIV Program, moderated informal presentations and discussion from individuals working in community based organizations (CBO) representing voices from the community. As a Métis woman, she introduced herself by her spirit name "Circling Hawk", meaning messenger.

Denese Frans, Research Coordinator and Programming Assistant, Women's Health in Women's Hands Community Health (WHWH), started the session by speaking about WHWH providing primary care for racialized and marginalized communities in the Greater Toronto Area, focusing on African-Caribbean (ACB), Latin American, and South Asian women. HIV rates in ACB women in Toronto have increased and WHWH has needed to consider the barriers that these women face including stigma, transportation, and other barriers related to the social determinants of health. Denise spoke of the Know Your Status campaign to encourage HIV testing and prevent infections and to make HIV testing more accessible and equitable. They have wanted to take HIV testing into the community and have piloted testing in homes during social gatherings, in community spaces for women's groups (faith-based groups, colleges, Universities) and outreach at PRIDE festivals, AFROfest and the Afro-Caribbean Festival in Toronto. She said women were extremely satisfied with testing by peers from their communities who provided culturally competent care, stating that 97% would test again in this way. Denise specified that pilot programs are research funded and are difficult to sustain, but they are finding ways to continue. They have recently started a care collective with African and Caribbean Council on HIV/AIDS in Ontario (ACCHO), a social media campaign, and are testing in hair and beauty salons, where women can have comfortable conversations about HIV prevention and testing.

**Daryl Luster**, who works with the Pacific Hepatitis Network, talked about despite there being a cure for HCV, there continues to be transmission with many people being tested without linkage to care and treatment, recognizing this is often a situation among people using drugs. He said that there is a continued need for testing and he talked about a pilot project in a British Columbia (BC) health authority where teams of peers, nurses, and community members work with community-based organizations to provide education, HCV POCT and serology for positive tests, and linkage to care. He said they learned a lot as they planned this pilot, but are learning more on the ground as they implement it. He said that organizations and community members are engaged and want to continue, stating that a one-day

testing event can reach people, but regular events can reach a lot more. Daryl said that he used to think that testing was enough, but he now knows it is not enough without linkage to care. He also acknowledged that timing is important, particularly for people who are living more chaotic lives, stating it is important to make linkage to care simple and painless for people. He indicated that evaluation data would be available in the future and said that BC is looking at geographical areas where data indicates there is a need, also noting that communities can also be relied on to communicate need. He talked about having a collaborative synergy and connection with communities to do this work.

**Raye St. Denys,** a Métis women and Executive Director of Shining Mountains Living Community Services, shared that she does not like the word Indigenous because she has been called many things over the years (Aborginal, etc) and states she still inhabits the same body. Since first looking for Métis-specific materials while working with Canadian Aboriginal AIDS Network (CAAN) 20 years ago, she has worked to create resources for her people. She told a story of talking to young people about HIV where one youth told her they believe Métis people are immune because there was no HIV information specifically for Métis communities. She said it has taken many years to communicate to the Métis people that they are not immune. She spoke of a successful pilot recently that provided STBBI DBS testing for her community, but indicated that once people are tested and know their status, "then what?" She commented that there are two places in Alberta that her community members can go to for treatment and care, but she said many people do not have transportation or the resources to get there. She ended by stating that without options for treatment, testing is not useful.

**Scott Elliott**, Executive Director of the Dr. Peter AIDS Foundation, began with a story about missed opportunities for STBBI diagnosis indicating that regular testing is not necessarily recommended in healthcare environments even for people in higher risk groups. He said that he works with people who are living more chaotic lives that may be using drugs, or have HIV, or other complex medical needs, suggesting they need good links to on-going care. He said that though many people were not tested because they were not eligible for treatment under previous criteria, his organization is now testing and 60% have HCV. He said that they have recently started an intravenous opioid agonist therapy (OAT) program and six of the 12 participants (despite knowing their status) were not taking their medication, because their focus was on survival, indicating that a wider approach is needed to link them to care. He talked about being lucky to live in Vancouver where there is excellent HIV and HCV care if you are a nice, middleclass, and articulate person. On the other hand, he says that if you do not fit into the mainstream practice or who need community support, it is not the same outcome. Scott ended by sharing that community organizations serving these populations have recently closed their doors in British Columbia, and thinks that if we do not take measures to look at this and talk about HIV, HCV and other STBBI, there will be problems in the time to come.

**Len Tooley,** Evaluation and Advancement Director at the Community Based Research Centre in BC, began by saying he thinks part of reaching the undiagnosed will mean challenging assumptions that underlie current strategies. As a volunteer at the Toronto Hassle Free clinic, he saw a huge demand and lineups for standard serological HIV testing, and often people did not get their test results. Later on,

when rapid HIV testing was provided in clinics and bathhouses through a medical directive there were initial worries, but much was learned from implementation. Many of his own initial assumptions were wrong and people in bathhouses were ready to be tested, wanted to get tested and were able to manage their results. He said that he thinks that we need to trust people to know what they are able to handle. He said that rapid HIV testing then became the preferred and standard test, but added that some people were no longer opting to have further testing, including for syphilis [at the time of a syphilis outbreak]. He said that even 10 years ago the change in technologies were affecting who was getting tested for what and stated that today is an opportunity to think about new ways of doing things and challenging our assumptions.

#### **Questions and Discussion**

The session Chair started by asking how public health and primary care can support the work of community. One presenter answered that it sounds simple, but the tendency is to work in siloes, and that clinicians and leadership need to be serious in looking for ways to remedy this to remove barriers. He added that technology speeding up testing and linkage to care is useful and added that community are asking why they are not testing for other STBBI. Two presenters commented that many clients have experienced trauma in their life from doctors and it is important for health care providers (HCP) to understand cultural competencies and learn to work with and understand populations to stop contributing to stigma. Another presenter added that it costs money to reach remote communities and if governments are serious about reaching everyone, Federal and Provincial governments need to work together to provide funding, adding that community organizations have something to contribute.

A member of the audience asked, if all of the solutions were available for testing and linkage to care, how should STBBI testing be implemented in your communities? A presenter indicated that funding, not more research, was required to implement existing commitments. A micro-elimination project in Pakistan was given as an example of an intervention that could be adapted to Canada. Another audience member commented that we are not always reaching the right people and said that it is necessary to teach frontline workers like herself [a trusted community member] to provide services. She said that information is not being shared with them because there is no funding to implement the programs. Another presenter pointed out that relationships are essential and take time, providing an example of an individual walking and looking into their art therapy program for two years before feeling safe enough to come in the door. He added that this is happening in community-based settings, not in doctors' offices, and that it would take time to link people to care. An audience member added that healthcare must be involved and provided ideas like testing for HIV automatically or opt-out in hospitals, and the importance of maintaining confidentiality in providing results and ensuring people are not stigmatized

An audience member provided an example of a proposal that included information about cost effectiveness because testing can prevent otherwise large expenses for treatment and care by limiting transmission of infections. She noted that they had a convincing case, but governments did not want to spend money on highest risk individuals who were incarcerated, or gay men and other men who have

sex with men. She was encouraged to see these conversations about resources for individuals at highest risk as an example to other nations.

Another audience member pointed to funding reductions under the Federal Initiative to Address HIV/AIDS in Canada, introduced in 2004 and that annual STBBI investments of \$88 million fell short of the House of Commons Standing Committee on Health recommendation that the federal government invest \$100 million annually in the HIV response. He added that while there are benefits for people to test for HIV, it is important to ensure that data cannot be used to harm people, which are rational reasons to avoid testing. He stated that how data are gathered, used, and flow needs to be examined to prevent its misuse to reduce stigma and mistrust, providing the example that data collected during HIV testing can currently be used to prosecute people. There are ways prevent the data from being misused, to reduce stigma and mistrust, and to minimize harm.

An audience member raised the First Nations principles of ownership, control, access and possession (OCAP) of data, including data collected through DBS testing.

#### Breakout Session #1 – Acknowledging Success

In the late morning of the first day, participants broke off into twelve small groups to discuss the questions:

1) What is currently working well within your setting/organization/system that is helping to facilitate successful STBBI testing and linkages to care? And;

2) How can strengths be leveraged in a way that would help organizations and systems to succeed in its testing and linkage to care programs and policies?

The results of these discussions were posted on the walls for the remainder of the forum. The following is a compilation of the notes as recorded.

Of the twelve groups, eleven brought up community engagement and leadership as working to increase access to testing and linkage to care. Building trust and partnerships, including trusting community to lead and drive program initiatives, were identified as important, noting this requires flexibility in approaches and meeting people where they are at. Eight groups identified engagement of peers in initiatives for testing and linkage to care as successful and suggested that peers should lead the design and organization of testing events. Groups also identified peers as valuable for health navigation and accompanying individuals to medical appointments. It was frequently acknowledged that it was essential for these roles to be sustainable paid health care positions.

Digital health technologies (including apps, websites, and chats) were identified by eight groups as successful, noting that they should be leveraged to increase access to testing. It was suggested that social media support could be used to enhance testing and to reduce stigma. Five of the groups mentioned the British Columbia (BC) program Get Checked Online as a successful strategy.

Six groups talked about epidemiological data and surveillance as a success noting that effective policy and surveillance impacts programs. Three groups indicated that while data collection is a success, it is important to avoid contributing to greater harm with criminalization or discrimination against people or communities and rather to provide protection from legal and punitive consequences.

Five groups talked about wrap around care and embedding STBBI programs with other wellness programs or a more integrated approach. Many groups mentioned the work of CBO as well as the importance in engagement of primary care, while one group noted that effective programs are resource intensive. One group said that including front line staff in sharing information and participating in meetings was important, while another group said that while some HCP are updated regarding the STBBI testing conversation, other HCP in hospitals are not included in these conversations.

Normalization of STBBI testing was brought up as successful in increasing access to testing by five groups, while one group suggested integrated testing for all STBBI as a success. Five groups talked about the importance of addressing the determinants of health and one stated specifically to utilize evidence around social determinants of health to support strategies. Four groups talked about addressing stigma, while three groups acknowledged cultural safety and trauma-informed care as important components for testing and linkage to care.

Regarding specific modalities of STBBI testing, four groups suggested POCT, DBS, and pharmacy-based STBBI testing initiatives as a success. Three groups talked about self-testing in other countries like the US and Vietnam, as a success to increase access for people who want to remain anonymous or are at higher risk. One group indicated that self-testing has corporate interest. Three groups discussed outreach or mobile services to bring testing to people, while one group suggested alternative delivery methods such as along with other services like veterinary outreach.

Programs with universal access, promotion of pre-exposure prophylaxis (PrEP), and treatment for STBBI, including HCV, were seen as successes to increase access to STBBI testing and linkage to care. One group suggested incentives for STBBI testing, while another group said that incentives for linkage to care were successful. U=U awareness was named as successful as well as progress in expanding prescribing for HCV treatment. Sex education was identified as a successful, while another stated that testing models needed to decentralize and task shift to expand the scope of practice using unregulated HCP and peers. One group identified that laboratory buy in and improved quality control laboratory turnaround times were important successes.

Canadian strategies specifically identified as successful programs included prenatal HCV testing, testing more frequently in pregnancy, HCV reflex testing in Nova Scotia, as well as HCV testing included in immigrant screening. Strong DBS programming in rural SK, as well as POCT pilots in targeted communities, and good engagement with peer mediators were identified as a success. Other programs included low barrier programs like Hassle Free clinic in Toronto, federal correction screening and treatment programs, adding HIV testing in labs at patient request in BC Interior Health, and unrestricted provincial screening. Programs that were identified as successful regarding linkage to care were centralized programs in BC, sexual student health programming in Prince Edward Island, the Downtown

Outreach Addictions Partnership team in Calgary, and real time linkage to care in the HIV program in Manitoba.

Overall, the successes outlined by groups suggested community engagement and leadership, use of peers, low threshold and wrap around services, and approaches adapted to context were successful practices in increasing STBBI testing and linkage to care. While options for different testing options and modalities were identified as important, the outcome of universal access without stigma or judgements was the recurring theme for testing and linkage to care to reach people who are undiagnosed. Other successes that could be seen as overarching themes included a strengths-based approach, implementation science, knowledge of STBBI, micro elimination projects balanced with general broad approaches, supporting funding models that allow risk taking and associated failures to achieve outcomes, and by sharing strategies and evaluations across the country. One group suggested that it was necessary to continuously set higher targets for engagement and to evaluate for continuous quality improvement.

# Novel Approaches to Testing, Reach the Undiagnosed and Linkages to Care: Structural Interventions and Promising Practices<sup>6</sup>

Chair Jordan Feld, from the University Health Network at the University of Toronto, introduced the presenters and moderated this session about specific STBBI modalities and their use.

#### Self-testing innovations for reaching those with HIV/HCV

Nitika Pant Pai, a physician, researcher, and professor at McGill University, began her presentation by talking about the history of supervised and unsupervised HIV self-testing innovation beginning in 2012, to the 2016 WHO HIV self-testing guidelines, to over 60 countries (and more in development) having HIV self-testing guidelines or policies in 2020 with current work towards distribution models. She pointed to 280 self-testing studies in the literature which show that self-testing is an effective way to engage populations that are not well served by conventional methods, noting that self-testing needs to be convenient, confidential, affordable, and non-invasive. Evaluation of strategies used in Malawi, South Africa, and in Canada have provided evidence of feasibility, quality, cost effectiveness and impact. She talked about HIVSmart!, an integrated smartphone, tablet, or web-based HIV self-testing program created in 2009<sup>7</sup>, which educates users on HIV, and guides them through the HIV self-testing process with an ease of conduct and interpretation. It assists with surveillance, expanded access timely linkages to counselling and care and retention in care. Nitika stated that communities will use a strategy if it can be customized to their preferences and context. She spoke of her involvement in piloting AideSmart!, an application based multiplex self-testing strategy offered by HCP and peer navigators. In a recent survey, 60% of participants wanted self-testing but were concerned about accuracy and linkage to care. She noted that there is very little evidence of harm resulting from self-testing and that people are comfortable to do it themselves. Nitika concluded by asking participants to reflect on how would self-

<sup>&</sup>lt;sup>6</sup> Powerpoint presentations available at <u>https://nccid.ca/stbbi-testing-and-linkages-to-care/</u>

<sup>&</sup>lt;sup>7</sup>. For more information, see <u>http://nitikapantpai.com/hivsmart/</u>

Testing and Linkages to Care: Reaching the Undiagnosed

testing affect the business model of current HIV testing strategies? How should we engage priority populations in Canada to end the epidemic? And how should self-testing be offered in Canada?

#### Advancing testing innovation among gay, bisexual, queer, trans, and two-spirit men

Kiffer Card, researcher with the CBRC, started with sharing CBRC's three-year vision to strengthen community infrastructures through partnerships by building capacity and training in peers to provide culturally relevant and accessible testing, to increase testing options, and to create broader sexual health and harm reduction frameworks (including other STBBI other than HIV). CBRC wants to provide 100,000 tests and linkage to care with peer driven and peer-based community-based strategies, but are currently funded for 10,000. He said that CBRC has traditionally provided annual sexual health surveys, but in recent years have moved to event-based testing. CBRC wishes to expand mail-home Self-Collection DBS testing beyond events, and are creating a National Peer-Based Linkage Line to manage returning results, while exploring delivery of results by digital application. CBRC is particularly interested in understanding the acceptability of new testing technologies among Two-Spirit communities across BC, and in building relationships with Indigenous people across the country to further national reconciliation efforts in Canada. He asked the question, how do we conduct implementation science and make sure that we have appropriately adapted what we are doing and that we are not trying to apply a one-size-fits-all approach? He thinks this entails choice, respecting autonomy, listening, partnerships and collaboration, and addressing intersecting stigmas. Kiffer ended with noting that it is easier to look at a cascade of care targets on a population level, but that there are many communities that are not close to achieving targets and that we need to be reaching those targets at the community level.

#### Novel dried blood spot models for reaching hard-to-reach populations with HIV and HCV

John Kim, Chief at the National HIV and Retrovirus Laboratories Division of the Public Health Agency of Canada's National Microbiology Laboratories (NML), presented NML's successful community-led STBBI DBS testing initiatives in Métis and First Nations communities across Canada, highlighting the Saskatchewan's Tribal Council systems and programming strategy as the potential model for DBS in Canada. He talked about initiatives for HIV and HCV testing with anonymity to decrease stigma in the health system, including mail-in testing, as well as outreach initiatives provided at the same time as free veterinary care to under housed people. He highlighted that racism hinders testing among Indigenous people in Canada. DBS testing is currently validated for HBV, HCV, HIV, and syphilis screening, including confirmatory testing for HIV and HCV, but there are also options for broader testing including herpes simplex 1 & 2, human T-cell lymphotropic virus, latent tuberculosis, clinical chemistry, and hemoglobin (Hgb) A1C; in addition to ongoing work to validate dried urine samples for gonorrhea and chlamydia testing. This broader range of testing, particularly for Hgb A1C, has created interest from the First Nations and Inuit Health Branch of Indigenous Services Canada and in Canadian Indigenous communities. He noted that DBS has worked to re-engage people in care particularly with confirmatory testing for HCV. In light of significant increases in syphilis infections in Manitoba (300%) and frequent coinfections with HIV (15%) and unprecedented congenital syphilis cases across Canada, he discussed the limitations, but also the opportunities of syphilis screening by DBS. John reiterated the importance of

the laboratory as command centre in these initiatives for diagnosis, clinical monitoring, epidemiology and surveillance.

#### HIV-STBBI testing in rural and remote areas in Manitoba (MB)

Mike Payne, Executive Director of Nine Circles Community Health Centre and administrative lead of the Manitoba (MB) HIV Program began by talking about their approach to employ the MB HIV-STBBI Collective Impact Network to connect innovators (including researchers, healthcare providers, government, community, and most importantly people with lived experience) working collaboratively for systems change to increase access to testing and care of HIV and other STBBI in Manitoba. The program understands the need to establish routine STBBI testing as a normal part of sexual health and to avoid HCP choice in who is offered testing, while acknowledging that testing frequency may depend on individual choices and behaviours. They have worked toward a Test for One, Test for All (meaning test for all STBBI) approach to avoid missed opportunities. Mike noted that the Manitoba HIV Program supports HCPs giving care and offers guidance regarding testing and care of HIV. Their goal is to provide the same access anywhere in MB, although this has not been achieved yet. In partnership with Manitoba Health, MB HIV Program is improving surveillance to have a greater and timelier ability to adapt programming; the improved surveillance showed increased STBBI screening in all health regions and evidence of identifying HIV infections earlier. He spoke of a successful pilot of implementing universal HIV testing in a downtown Winnipeg ER, noting that noting that people who are not well connected to the healthcare system often use the ER for routine care and that the project is no longer funded during the current STBBI outbreaks. Through collective impact strategies they want to increase options and innovations, ensure culturally safe and equitable access to care, to build and invest in peers and family, community engagement and leadership, as well as work to redesign systems to change models that perpetuate stigma, including decriminalization efforts. He finished by asking, how do we change the model of primary care to a low threshold service to shift the service model, rather than waiting for people to change their behavior?

#### **Questions and Discussion**

Chair Jordan Feld asked the presenters how pilot projects could be scaled up and made a standard of care in Provinces/Territories (P/T). A presenter replied that this work is not research, but rather implementation science that needs to be shared and scaled up. The example provided was DBS testing in particular which is no longer innovative and could be taken over by the P/Ts from NML's laboratory system; stating there are currently inefficiencies in the system to be remedied. He reiterated that if laboratories are command centres, they need to accommodate new modalities and the modification of the public health laboratory system in Canada needs to be discussed. Another presenter noted that instead of bypassing the democratic governance system to implement programs, pressure needs to be applied on that system to ensure that equity interests are matched with efficiency interests adding

there will never be success by pursuing alternative grant funding mechanisms, outside of mainstream public health funding. A participant, observing the successes internationally, said that there has to be a funding commitment beyond research and CBOs have a major role to play. Another participant shared their disappointment that some provincial leaders were not at the meeting, and that we need to continue to identify successes and use this to put pressure for the implementation of these strategies, and that it sometimes means figuring out how to do this work anyway, while the system catches up.

A participant commented that in the face of diminished investments and the closing of some community-based organizations (including two organizations serving women with HIV in Canada), that it was important to talk about where these individuals would be sent when the tests are completed.

# Dual syphilis and HIV point of care testing to improve access to testing among inner city, remote, rural and hard to reach populations in Alberta

Ameeta Singh, STBBI clinic medical director from the University of Alberta, talked about current syphilis outbreaks in Alberta with a rapid increase in cases, particularly in Edmonton. She said that they are exploring whether a syphilis POCT would help with the response to this outbreak and noted a similar project ten years ago where they found that tests needed to be user friendly in order to be utilized. She talked about who is affected by infectious syphilis in Alberta, particularly women aged 20-34, and noted 63 congenital syphilis cases and 13 stillbirths; with crystal meth use potentially driving the outbreak. They have estimated loss to follow-up or significant delays to treatment in 20-30% of cases. They are working on a research project to be able to evaluate the field performance of two Canadian HIV/syphilis POCT as well as its utility in the management of syphilis infections for higher risk and hard to reach populations. The Addiction Recovery and Community Health Clinic team will be recruiting 1,500 individuals meeting higher risk criteria from the Edmonton STI Clinic Outreach Team sites, two First Nations communities in Alberta, the Edmonton Remand Centre, and the Royal Alexandra Hospital Emergency Department. Pending approvals, there is a tentative date set for training in April of 2020 and they hope to be able to share their findings in the future.

#### Population-level approaches to increase STBBI testing

Jason Wong, physician epidemiologist at the British Columbia Centre for Disease Control (BCCDC), presented on the application Get Checked Online (GCO), an online STBBI testing service in seven sites in BC in partnership with the BCCDC, BC Public Health Laboratories, and the regional health authorities. It is integrated with current STBBI clinical and public health practices at the BCCDC Provincial STBBI Clinic. He said they wanted to increase their capacity, to reach populations with higher rates of STBBI and who face barriers to access, and to scale up provincially. They are currently testing approximately 1,000 individuals per month and in 2018 implemented a survey that found GCO clients were significantly less comfortable with testing in clinics and were more likely to have delayed STBBI testing in the last year. He said that one in five of people are testing for the first time and almost half are testing more than once using GCO, noting that 5% of those tested are diagnosed with an STBBI. They have learned from the project to involve stakeholders early and to develop partnerships with clinicians and community laboratories. Jason also discussed implementation of universal HIV testing in 2014 with the *HIV Testing Guidelines for the Province of British Columbia* to reduce the number of new HIV infections, identify

earlier infections, and reduce stigma by normalizing and routinizing HIV testing. He said this has contributed to increased HIV testing volumes, decreased median inter-test intervals, earlier identification of infections, and increased testing for other STBBI. He said they have learned to engage with clinicians to increase testing to ensure awareness using Continuing Medical Education (CME) and audits, and to work with community stakeholders.

#### **Pharmacy-based interventions for STBBI**

Christine Hughes, Professor of Pharmacy at the University of Alberta and clinical practitioner at the Northern Alberta HIV Program, talked about community pharmacies being well-positioned to increase access for testing due to being community-based with extended hours in most communities across the country. Christine added that pharmacists have expanded their scope of practice in the last ten years and could provide public health services including education, outreach, vaccination, access to Pre-Exposure Prophylaxis (PrEP) and Post-Exposure Prophylaxis (PeP), and harm reduction supplies. In alignment with the Pan-Canadian STBBI framework to increase access and equity, there are also opportunities to initiate treatment and provide ongoing care and adherence support as well as linkage to care. Developed with stakeholders in 2016, the APPROACH study is a pharmacist-delivered HIV POCT program in community pharmacies in Newfoundland and Alberta. The model was found to be feasible and a highly acceptable experience. They found that it was effective at reaching at-risk clients except for people who inject drugs, and they are thinking about opportunities to add testing for other STBBI and to improve accessibility and reach by incorporating into existing OAT programs and harm reduction services. Currently, they are considering an APPROACH 2.0 study and are creating processes to see if a pharmacy-based STBBI testing program increases the number of people tested, finds new diagnoses and generates good value for money. They are looking at expanding to provide testing for other STBBI by DBS testing and want to improve health outcomes and increase efficiency of the health system.

#### **Questions and Discussion**

Jordan Feld asked how HCV treatment prescribing by pharmacists in Alberta came to be and their first impressions of the program. A presenter replied that the Alberta STBBI strategy has provided the opportunity to leverage partnerships and capacities, and HCV treatment prescribing was expanded to primary care providers and pharmacists to increase access for treatment through the extension for community healthcare outcomes (ECHO) project, while pharmacists were already providing OAT. There was no evaluation data available, but anecdotally there has been success in providing treatment initially collaboratively with specialists, and now with support as needed.

A participant asked Jason Wong whether primary care in BC used opportunistic approaches to implement HIV testing guidelines or whether patients were called in for testing with a system or electronic medical record alert and whether there was an interest in expanding these guidelines toward a test for one, test for all approach. Jason replied that the guidelines were to offer HIV testing when providing routine bloodwork and CME provided direction for physicians to know how to have

conversations when offering HIV testing to clients, but he was unaware of patients being called in specifically for HIV testing. He said there are currently discussions about different options to increase testing, such as inpatient testing and that physicians will generally screen for other STBBI when screening for HIV and they are looking at different co-testing models.

A question was asked about the unintended consequences and lessons learned from the BC HIV testing guidelines regarding Indigenous people spoken about in his presentation. Jason Wong replied that the *From Hope to Health: Towards an AIDS-free Generation Progress Report 2015/16*<sup>8</sup> provides information regarding this, but stated that one of the key issues was that being Indigenous is not a risk factor for having HIV and the guidelines have the potential to stigmatize and harm an entire group of people.

A question was asked about whether the professional body of pharmacists were receptive to expanding their role in innovative ways and it was noted that the regulatory body in Alberta is supportive, with recent standards in place to order tests within the province, while the advocacy body has not yet made this a current priority.

A participant shared a story about advocating for STBBI POCT within a general POCT care committee noting because STBBI POCT was not a replacement for standard testing, there were pressures to remove resources to ensure funding. A presenter agreed this was an issue with the ethics board with the question of whether a positive STBBI POCT would be notifiable. The plan was that it would not be notifiable because it would be confirmed with a standard laboratory test. There was discussion about the importance of thinking and providing data (including cost effectiveness) with holistic effects to linkage of care and treatment. There was a story of the early days of community based testing in Barcelona in a program called Checkpoint, where they provided 1% of the testing for the city, but identified 30% of the positive cases, and having that data provided the rationale for the modality of testing.

#### Breakout Session #2-Identifying Challenges for Implementation

In the final session of Day 1, participants broke into thirteen multi-disciplinary groups to discuss and identify challenges for implementing of innovative strategies to increase access for STBBI testing and linkage to care.

Eleven of the groups brought up funding and affordability as a challenge to implementation noting funding cuts to supports in community as well as competing priorities with other health and infrastructure issues. Five groups mentioned themes like austerity with health care, decreased funding for scalability, and fixed envelope challenges. It was stated that it was important to guarantee sustainable funding for testing and linkage to care programming rather than one time or piece meal

<sup>&</sup>lt;sup>8</sup> From Hope to Health: Towards an AIDS-free Generation Progress Report

funding. Three groups suggested needing return on investment information for approaches to testing, while one comment indicated that affordability needed to be assessed broadly and account for downstream costs, and another suggested a program science approach to evaluation. It was suggested that there is a need to invest in laboratories to absorb the influx of testing and it was suggested that government may wish to purchase test kits in bulk to provide more competitive pricing and noted that self-test kits need to be free for many people who need it.

Eleven groups discussed policy or governance challenges saying that there is a lack of interest or responsibility from governments in testing and linkage to care. Three groups mentioned lack of political will, government commitment, and competing priorities in the health system including commitment to HCV elimination targets. One group said that federal policy may change, but provincially they have not, leading to confusion and barriers, while another noted that changing governments have impacts on public health funding, priorities and activities. One group mentioned that it was important to break down barriers between federal and provincial jurisdictions to create seamless care and to avoid people falling through the cracks, particularly provision of care for First Nations communities. It was reiterated that improvement in leveraging data and analysis of cost effectiveness are needed to advocate and address the gap in political will. Finally, it was noted that there needs to be a meeting where decision making bodies are included.

Eight groups talked about challenges with communication in terms of knowledge of what technologies are coming down the pipeline. It was stated that while there is communication between stakeholders, there is not enough sharing and collaboration between governments and community groups. One group said that there is not enough knowledge transfer across the country, while another noted the lack of conversations about how initiatives have not succeeded at reaching populations and discussion of what different approaches they plan and take. Two groups talked about the silos and lack of integration and power sharing between relevant stakeholders including the health systems (CBO explicitly), public health, and ministries of health stating that we need all stakeholders on board including education and buy in from laboratories and public health. There was discussion of a lack of awareness to real experiences on the frontline. The question was posed, how can this network function and connect knowledge where privileged people are making policy? It was identified that how they understand higher risk populations makes a huge difference, while one group noted that we need to remember that we are asking a lot of community.

Eight groups talked about lack of education of frontline staff or a lack of trust in the healthcare system. It was discussed that it is important to identify realistic ways to address health inequity and stated that expanding STBBI testing should not be a way to let an inaccessible and failing healthcare system off the hook by creating alternative testing strategies because STBBI testing rates are low in healthcare environments. One group identified discomfort among health professionals to discuss sexual health, while two groups pointed to a lack of training and support for the front line. Another group identified staff turnover and the lack of quality control for STBBI testing for frontline staff, including informed consent and management of data. Another group said that HCP lack knowledge about who to test and knowledge of therapies (e.g. HCV). One group said that HIV testing policy has been rigid historically and identified that it was taking a long time to break out of this. Three groups identified a lack of cultural

appropriate engagement within the health sector and identified the need to improve accessibility and acceptability of health care services. It was identified, that there needed to be cultural, and not only regulatory scopes of practice for professions. One group particularly noted that there is a lack of cultural competency in care providers and a knowledge gap about the health systems serving First Nations, Inuit, and Métis people and who pays for what and for whom. And lastly, clinician protectionism or being territorial about non-clinician STBBI screening was also seen as a challenge.

Seven groups discussed laboratory or STBBI diagnostics as challenges. While one group stated that laboratory processes such as reflex testing may be a challenge, another identified that there is resistance within laboratories to move budgets, retrain staff, and understand and communicate the value of POCT among public health actors. One group stated that laboratories need to develop roles as a command centre for validation of POCT, ensuring the system can receive test results and quality oversight. One group said that the Canadian Public Health Laboratory Network has looked at HCV reflex testing and found it acceptable stating that there shouldn't be a need to reassess this in each jurisdiction for implementation. It was also stated that it is a challenge that there are differences in provincial testing strategies across Canada. Two groups suggested having the ability and knowledge to align technologies to meet needs according to setting and population, and it was identified as important to consider test properties with clinical and public health considerations to understand when compromise is justified to increase access. One group noted that there are a large volume of individuals being lost between stages of HCV screening, while another group pointed out that the STBBI POCT window period (time period from transmission to when the test can detect infection) is longer and can result in harm if this is not communicated. Another was concerned about reporting and asked the questions whether these tests would be reportable, and if so, how will they be reported? One group pointed out that in the current system if a provider tests, it increases their responsibility, workload, and liability to deal with the results. Another group stated that it will also be important to remember that especially when looking at mobile application or internet-based strategies, there could be a loss in human connection in the testing process, particularly when it comes to linkage to care and other services. It was stated more than once that one size and location does not fit all for STBBI testing.

Seven groups discussed the challenges of linkage to care, while one group asked how grassroots community organizations could be supported and identified that social determinants of health impact linkage to care. They asked how people can prioritize care and treatment when they require support with housing and food insecurity. It was stated that even in the greater Toronto area, a person living with HIV may have challenges to find a primary care physician or HIV specialists and general practitioners think it is more complex to manage HIV due to their lack of knowledge or training. It was also suggested that people who are hiding their identity will have poorer linkage to care and the onus currently is on the person to seek care. It was identified that people who are difficult to reach are difficult to link and to retain in care and suggested that the current injection drug use epidemic will have impact on the spectrum and scaling up linkage to care. Another group stated that there are ethical considerations as to the importance of linkage to care was just treatment or do other standards including stability in life need to be included. And lastly, one group asked the question, how can community and

the health sector work together to offer wrap around services, identifying a lack of a case management approach.

Five groups talked about peer and community workers, noting there are barriers to including them in testing work, including that compensation for peers is important and is not always provided. It was stated that community workers are unable to test due to regulation in many jurisdictions and that hiring people with lived experience can conflict with policies that staff cannot also be service users. It was also acknowledged that there is insufficient peer support to contribute to programming.

Five groups mentioned stigma and how lack of knowledge causes stigma. One group mentioned stigma around harm reduction, while another group stated that we need more public awareness campaigns. One group said that Indigenous women are not valued to the point that their voices and lived experience are not ever heard or sought, while another mentioned lack of knowledge for rural and remote northern communities. They said that it is very complex and varied contexts need to be unpacked and addressed, it takes a commitment to listening and starting from lived experiences of each specific population, specifically Indigenous women.

Regulatory barriers for new tests were identified five times as challenges, with approvals for the regulatory processes for new testing kits as well as regulations that create obstacles to alternative strategies for STBBI testing. Bureaucracy was mentioned four times noting both limits to task shifting and who can test and where they can do it, in addition to bureaucracy even within organizations. Groups said that legal constraints at the provincial level to task-shift were barriers to decentralization. It was suggested that it will be important to define "lay user", "trained professional" and "healthcare provider" as users of STBBI POCT and that scope of practice and lack of standardization across jurisdictions was mentioned twice each as a barrier to increased access to STBBI testing. One group stated that there was a lack of medical directives and partnerships to support medical directives, while two groups mentioned that Public Health needs to take more leadership.

In summary, challenges for implementation to increase access to STBBI testing and linkage to care identified by groups included limited funding and affordability (meriting the need for cost benefit analysis), policy and governance challenges to support innovative strategies, and lack of communication mechanisms for sharing new information and evaluation findings across the country. Many groups discussed lack of education of frontline HCP to provide STBBI care in general, but also to provide culturally competent STBBI testing and care services. Other challenges included regulatory approvals for diagnostics, or laboratory challenges to expand testing strategies, as well as linkage to care options and barriers to STBBI services provided by peers or community health workers. Finally, stigma was noted as a significant challenge to implementation of STBBI strategies to increase testing and linkage to care, particularly for Indigenous women.

## Day 2 - February 5th, 2020

Day Two opened with greetings from facilitator Jody Jollimore. Geneviève Tremblay, Director of the STBBI Programs and Partnerships Division at PHAC, provided an overview of the key themes raised by participants and presenters the previous day. She reminded participants of the disproportionate impact of STBBI among First Nations, Inuit, and Métis communities and of the importance of youth and women. She talked about community ownership, leadership and engagement, and the importance of collaboration between the healthcare and community-based sector, as well as a patient centred approach. She spoke of breaking down silos within health systems and challenging our assumptions. She talked about Canada's STBBI successes and stated we have treatments, evidence, and we know that integration works and we need to scale up effective interventions. She asked the group to continue the work building on strengths to decrease and address intersecting stigmas, build relationships and trust, and to evaluate, learn, and share.

#### Breakout Session #3- Identifying Potential Solutions

During a final breakout session, groups were asked to build a program or strategy for either peer-based testing (using DBS/POC/self-testing), self-testing, or pharmacy-based testing. Program strategic plans were to address the following issues including: community engagement and leadership, linkage to care, champions and partnerships, bridges to health systems, monitoring and evaluation data, laboratory role and infrastructure, and privacy and confidentiality. Each of the groups were asked to identify how funding would be used and priorities for implementation. Participants self-selected a group where they wanted to contribute. In summary, among many questions and discussions that took place within the groups, planned programs or strategies leveraged strengths and existing programs or infrastructure to identify solutions to challenges addressed in the first day.

#### Pharmacy-based STBBI testing

One group planned a strategy for pharmacy based testing to expand distribution of STBBI testing across the country. Their plan was to identify who needed to be reached in community and to partner with health professionals, agencies, and community workers. They suggested an HIV 411 number to provide information where testing was available. This group identified that it would be important to work with the local health authority to establish referral processes into new or established programs and noted that relationships between pharmacists and other healthcare providers and public health would be important. Other partnerships identified as important were with industry for STBBI testing and treatment, regulatory bodies, and universities for training pharmacy students. A stepwise model for STBBI treatment could be incorporated into pharmacy testing models and accessible health records would be used to bridge to the healthcare system. Established frameworks would be used for

monitoring and evaluation to measure cost effectiveness in reaching new people and linkage to care as well as acceptability of the program.

It was suggested that laboratories could provide standards, best practices and expertise for performing tests in pharmacies and connection for confirmatory testing. Privacy and confidentiality concerns included needing to establish privacy and reporting standards and more practical needs like a private room for counselling in pharmacies. They indicated that funds would be used to purchase testing kits and quality assurance processes, though also discussed other models such as offering tests in pharmacies, or offering online ordering for tests kits and providing the test in pharmacy, or with models similar to naloxone distribution. The priority steps were to establish goals, analyze regulatory structures, engage partners, train and increase capacity for partnerships with public health, laboratories, and for linkage to care. It was noted that the cost of developing and implementing this programming would depend on private and public partnerships.

#### Peer-based STBBI testing

Three groups discussed strategies for peer-based STBBI testing noting that peers will know where to find the people with higher risk for STBBI. One group stated that the benefit of peers is not only to diagnose, but to link people to health and community services and to decrease stigma associated with testing. One group said that it would be important to define what a peer is and that this definition would depend on the objectives of peer engagement, while another group said that there would be a need to identify communities who would benefit from receiving services from peers. Two groups suggested a community health worker model and one group said that CBO should organize and determine who peers are. One group said that care needs to be timely, welcoming and culturally competent and that communities need to define the competencies required by peers to provide care and support. Centres for Excellence in each province were identified as a resource for creating consistent and updated training. All of the groups identified the importance of peers needing to be paid.

It was suggested that peers should be able to offer many types of testing including DBS, POCT, and phlebotomy and that these strategies could be used for incarcerated people, women's health including labour and delivery units, in ERs, and in universities. It was stated that for some communities, events need to be more broadly health focused. One group suggested medical directives using physician leadership and working guidelines, while two groups thought that these programs should be under Chief Public Health Officer leadership, while another suggested maximizing telehealth.

Peers were seen as important contributors to the health system beyond testing and linkage to care, but also for retention in care, communication, education, advocacy, and counselling. Two groups talked about peers providing resource incentives for testing, receiving results, and linkage to care. Another talked about linking to primary care instead of only to specific clinics. It was discussed that having access to hotlines (1-800 numbers, websites, or remote telehealth) would be useful to inform peers of local resource access, acknowledging potential differences in information access.

In terms of bridging to health systems, there was discussion that policy regarding regulation, license requirements, and accreditation will need to change to accommodate for peer testing and reporting. One group suggested to develop national standards of care with key messages including cost effectiveness of screening programs. Some examples of models that could be used to build programs were the BC HIV testing guidelines, Ontario scope of practice law, BCCDC peer engagement work, and Ontario mental health peer support guidelines. All in all, it was suggested that there needed to be task shifting research for training, supervision, and support. Champions were seen as public health at all levels and non-governmental organizations.

Robust monitoring and evaluation data, including the number of people that had never been tested, positivity rate, and linkage to care were identified as essential, including cost analysis to show long term value of the program. It was suggested that there should be federal funding to incentivize peer testing activities in communities and to support goals and elimination targets.

As in other breakout sessions, the laboratory as the command centre and building relationships with laboratories for quality assurance and surveillance purposes was discussed for all peer testing models and modalities, along with the need for funding to expand programming within laboratory systems was acknowledged.

One group suggested that funds would be used for peer wages, education and training, purchase of test kits, communication, and bringing people together.

#### Self-testing

Three groups discussed self-testing, including STBBI DBS or POCT, where models included selling test kits through pharmacies or vending machines, or there was distribution through CBO to people at higher risk. Supervised self-testing by HCP or peers was also suggested. There was a lot of discussion about the need for education as one group talked about communities having a poor or misinformed understanding of technologies and options for STBBI testing, while another group said that they need to have an understanding of the quality and accuracy of tests including window periods. They talked about providing education and awareness about testing and why it's important, treatment, and existing localized options for linkage to care. They also stated that this needed to include prevention education including safer sex, harm reduction, access to PrEP and education beyond HIV to multiplex testing, as well as community resources. They suggested a 1-800 number and/or an application with 24-hour support available inside the kits, noting that the US Food and Drug Administration have mandated manufacturers to provide this in the United States. One group suggested using existing CATIE localized information for individuals who have tested positive for HIV. One group added that regulations for public health reporting and partner notification along with limitations and alternative options should also be available in the test kit. It was acknowledged that self-testing may not be the best option for

some people, but also acknowledged individual choice, and suggested gender analysis as this may be feasible and empowering for women in unsafe relationships.

In terms of linkage to care, one group thought that it was important for there to be multisectoral collaboration in the health system (including private, public, and hospital), while another thought ASO could facilitate follow up and provide a bridge to the health system. There was acknowledgement that people link to care in different ways.

There were concerns about the collection and use of data within provinces/territories and federally identified by two of the groups, particularly regarding linkage to care after testing. Another group felt that self-test kits should collect data at all stages (including a post evaluation survey), but that this data should be de-identifiable to ensure confidentiality. One group noted that there were lessons learned from naloxone kit distribution where not all kits were tracked or used, but access was important, and therefore data was only needed to demonstrate positive impact. One group suggested that companies should provide post-market data. Two groups also thought it was important to show a return on investment or cost benefit analysis, with particular focus on equity and access.

Laboratories were seen as champions for education and advocacy, accuracy versus accessibility, removing barriers, and evaluation. It was stated that there was a need for multisectoral collaboration including community, industry, public health programs, CBO, general practitioners, all levels of government, and laboratories.

Self-testing was seen as private and confidential because the test could be done safely in private and would likely be used by individuals interested in more anonymous testing. One group also noted that use of phone or internet services could also lend itself to be less confidential for self-testing.

Groups who talked about funding suggested using funds to provide tests kits for those most at risk and for supports for linkage to care providing cost analysis in reaching undiagnosed people along the way. Another group outlined that funds would be used to support self-testing facilitated through community distribution, providing training for follow up, and subsidizing test kits to bring costs down. It was also suggested that government should consider mass purchasing similar to vaccines to distribute nationally.

Priorities for first steps were accessibility and affordability, because a sales model would mean that tests are only available to those who can afford it. It was suggested that there needed to be national guidelines from PHAC regarding feasibility for specific communities to provide individual empowerment by self-testing (like a pregnancy kit). Another group thought that first steps should be to start with using the data we have through PHAC surveillance reports to target distribution of self-test kits to reach the undiagnosed, noting the limitations of data. They suggested a trial and re-evaluate approach involving CBO in data collection and capacity-building in communities. They noted that a user feedback/evaluation survey could be incentivized. The last group thought the first steps would be to train and engage community while waiting for test kit approval. They felt like development of a linkage model was important as well as the involvement of the laboratories. They also felt it was important to enhance the roles of health care providers for fear of job loss and to promote peer to peer championing.

## Conclusion

Discussions from this forum highlighted the complexities of STBBI testing and linkage to care and overarching themes focused on providing low threshold and wrap around services, pointing to a health care system that is currently failing to provide non-judgmental and culturally relevant STBBI testing and care.

Key themes and opportunities to expand innovative strategies to reach undiagnosed people included working with and trusting communities to know what they need, as well as a need for guidance for community engagement, leadership, and ownership of STBBI initiatives. Expansion of peer or community health worker models could be routinized to build capacity of communities, to provide culturally relevant STBBI testing, linkage to care and other services, and to engage disengaged communities. Consideration of universal STBBI testing models, a Test for One, Test for All approach to avoid missed opportunities and to reduce inequities, and STBBI screening as a standard of care could be used to normalize and routinize testing. The broader health system requires education regarding STBBI services and to have standards for quality and culturally competent STBBI testing and care and/or support is needed for CBO/ASO to provide confirmatory testing and linkage to care with low threshold and wrap around services. Provision or mechanisms for knowledge, learning, and sharing information of innovative STBBI testing modalities and initiatives, evaluation, and cost benefit analysis is necessary to rationalize funding for programs or interventions and to provide evidence for what modalities work in which circumstances, and when compromise in STBBI testing quality is substantiated to increase access.

Scale-up of innovative STBBI programs to implement evidence-based interventions were seen by Forum participants as essential to have the ability to learn by doing, to re-evaluate, and adapt as necessary. Policy and governance needs to support innovative STBBI testing and linkage to care to have the ability to reach more people. There was interest in exploring the role of laboratories as command centres for STBBI diagnostics in Canada to provide training, quality assurance, collection and intelligence of surveillance data, and to conduct implementation research. Lastly, Forum participants discussed continuing issues of stigma, ongoing systematic disadvantages related to the determinants of health, the criminalization of HIV, as well as consent and data ethics that need to be resolved to increase access and to minimize harm from STBBI testing. Expanding of innovative STBBI testing strategies was seen to increase the ability to reach undiagnosed people in Canada and increases options for accessible, culturally competent STBBI testing and care. When the forum wrapped up at mid-day, there was a palpable energy and new connections among participants to continue this work.

In closing, Jody Jollimore thanked everyone for their time, attendance, and for providing their expertise to participate in this work and for their commitment toward STBBI elimination. Elder Annie Smith St-Georges closed the session in prayer.

Appendix A: Sexually Transmitted and Blood-borne Infections (STBBI) Testing and Linkages to Care: Reaching the Undiagnosed Agenda

February 4 <sup>th</sup> , 2020		
8:30 am to 9:00 am	<ul> <li>Welcome         <ul> <li><u>Facilitator</u>: Jody Jollimore, Community-Based Research Centre</li> <li>Opening invocation – Elder Annie Smith St-Georges</li> <li>Opening remarks from Public Health Agency of Canada – Kimberly Elmslie</li> <li>Review of agenda, meeting objectives and introductions</li> </ul> </li> </ul>	
9:00 am to 9:45 am	Bringing new innovations in STBBI testing with linkages to care to Canada	
	<ul> <li><u>Chair</u>: Geneviève Boily-Larouche, Canadian Institute for Health Research</li> <li><u>Setting the stage</u> - Sean B. Rourke, Centre for REACH 3.0 and MAP Centre for Urban Health Solutions</li> <li><u>What is working in the real world: A Canadian STBBI point of care testing realist review</u> – Yoav Keynan, National Collaborating Centre for Infectious Diseases</li> <li><u>Global lessons on access to testing and linkage</u> - Rosanna Peeling, London School of Hygiene and Tropical Medicine Q/A and Discussion (15 min)</li> </ul>	
9:45 am to 10:00 am	Nutrition break	
10:00 am to 11:15 am	Reaching the undiagnosed – Voices from the community	
	<ul> <li><u>Chair</u>: Stephanie Van Haute, Nine Circles Community Health Centre</li> <li>Scott Elliott, Dr. Peter AIDS Foundation</li> <li>Raye St. Denys, Shining Mountains Living Community Services</li> <li>Len Tooley, Community-Based Research Centre</li> <li>Denese Frans, Women's Health in Women's Hands Community Health Centre</li> <li>Daryl Luster, Pacific Hepatitis Network</li> <li>Q/A and Discussion (15 min)</li> </ul>	
11:15 pm to 12:15 pm	Breakout session – Acknowledging success	
12:15 pm to 1:00 pm	Lunch and Networking	
1:00 pm to 2:00 pm	<ul> <li>Novel approaches to testing, reaching the undiagnosed and linkages to care:</li> <li>Structural interventions and promising practices</li> <li><u>Chair</u>: Jordan Feld, University Health Network</li> <li>Self-testing innovations for reaching those with HIV/HCV - Nitika Pant Pai, McGill University</li> </ul>	

2:00 pm to 2:15 pm	<ul> <li>Advancing testing innovation among gay, bisexual, queer, trans, and two-spirit men – Nathan Lachowsky, University of Victoria</li> <li>Novel dried blood spot models for reaching hard-to-reach populations with HIV and HCV – John Kim, National Microbiology Laboratory</li> <li>HIV-STBBI testing in rural and remote areas in Manitoba - Mike Payne, Nine Circles Community Health Centre</li> <li>Nutrition break</li> </ul>
2:15 pm to 3:15 pm	<ul> <li>Cont'd: Novel approaches to testing, reaching the undiagnosed and linkages to care: Structural interventions and promising practices</li> <li>Dual syphilis and HIV point of care testing to improve access to testing among inner city, remote, rural and hard to reach populations in Alberta - Ameeta Singh, University of Alberta</li> <li>Population-level approaches to increase STBBI testing – Jason Wong, British Columbia Centre for Disease Control</li> <li>Pharmacy-based interventions for STBBI – Christine Hughes, University of Alberta Q/A and Discussion (15 minutes)</li> </ul>
3:15 pm to 4:15 pm	Breakout session –Identifying challenges for implementation
4:15 pm to 4:30 pm February 5 <sup>th</sup> , 2020	End of day 1 wrap-up Facilitator: Jody Jollimore, Community-Based Research Centre
8:30 am to 8:45 am	Welcome and recap of day 1 <u>Facilitator</u> : Jody Jollimore, Community-Based Research Centre         • Genevieve Tremblay, Public Health Agency of Canada
8:45 am to 10:00 am	Breakout session – Identifying potential solutions
10:00 am to 10:15 am	Nutrition break
10:15 am to 11:30 am	Cont'd Breakout session – Identifying potential solutions (report back and discussion)
11:30 am to 12:00 pm	<ul> <li>Next steps and closing of meeting</li> <li><u>Facilitator</u>: Jody Jollimore</li> <li>What we heard – successes, challenges, gaps, innovations, potential solutions</li> <li>Closing invocation – Elder Annie Smith St-Georges</li> </ul>

#### Appendix B: Participant List<sup>9</sup>

**Participant Name** Organization Andrew Pringle Canadian Foundation for AIDS Research (CANFAR) Amanda Lang Saskatchewan Health Authority - Roy Romanow Provincial Lab Ameeta Singh University of Alberta Andrew Matejcic Canadian Association for HIV Research (CAHR) Aslam Anis University of British Columbia Bersabel Ephrem Public Health Agency of Canada Community Health Nurses of Canada (CHNC) Catherine-Anne Miller Celeste Hayward Alberta Community Council on HIV Chloé G. Healy Public Health Agency of Canada **Christine Anne Hughes** University of Alberta Canadian Foundation for AIDS Research Christopher Bunting Dana Paquette Public Health Agency of Canada **Daryl Luster Pacific Hepatitis C Network** David Strong Alberta Health Services Deb Schmitz **Pacific Hepatitis C Network** Debbie Lepine Health Canada - Medical Device Directorate Deborah Khursigara **CIHR-Institute of Infection and Immunity** Deidre Elizabeth Falck Government of the Northwest Territories Denese Frans Women's Health In Women's Hands Community Health Centre Chris Archibald Public Health Agency of Canada Johnmark Opondo Saskatchewan Health Authority - Saskatoon Susan Kilborn **Community Veterinary Outreach** Elaine Michelle Proctor-Simms Nova Scotia Advisory Commission on AIDS Elizabeth Parenteau Institut national de santé publique du Québec (INSPQ) Emal Stanizai Unity Health Toronto Eva Slawecki Canadian Society for International Health Fanny Tzelepis Health Canada - Medical Devices Directorate Fiona Kouyoumdjian **Ontario Ministry of Health** Floyd Visser The SHARP Foundation Gary Lacasse Canadian AIDS Society Geneviève Boily-Larouche CIHR - Institute of Infection and Immunity Geneviève Tremblay Public Health Agency of Canada British Columbia Centre for Disease Control Geoffrey Ford Geoffrey Graham **OraSure Technologies** Newfoundland & Labrador Public Health Laboratory George Zahariadis Gina Coleman Public Health Agency of Canada Alberta Provincial Laboratory for Public Health Graham Tipples Health Prince Edward Island Greg German

<sup>&</sup>lt;sup>9</sup> Map representation available at <u>https://nccid.ca/stbbi-testing-and-linkages-to-care/</u>

Greg Penney Canadian Public Health Association Helena Maria Swinkels **First Nations Health Authority** Jacqueline Gahagan Dalhousie University Jami Neufeld National Collaborating Centre for Infectious Disease Janet Rowe PASAN Jasmine Pawa Department of Health, Government of Nunavut Jason Wong British Columbia Centre for Disease Control Jennifer Jones Pacific AIDS Network Society Jennifer Lowe Public Health Agency of Canada Jennifer van Gennip Action Hepatitis Canada Jody Jollimore Community-Based Research Centre (CBRC) John Kim National Microbiology Lab Jordan Feld University Health Network Kednapa Thavorn Ottawa Hospital Research Institute Kehinde Ametepee University of Saskatchewan Kiffer G. Card **Community-based Research Centre** Kethika Kulleperuma Department of Health, Government of Health Laurie Edmiston CATIE Laurie Ojdick Native Women's Association of Canada Lee Hodge Casey House Leigh-Anne Gillespie Canadian Agency for Drugs and Technologies in Health Leonard Tooley **Community-Based Research Centre** Lisa Freeman First Nations and Inuit Health Branch Lisa Lockie Saskatchewan Ministry of Health Ludivine Veillette-Bourbeau Université du Québec à Montréal Luke Shankland Aviro Health Margaret Haworth-Brockman National Collaborating Centre for Infectious Disease Hotsa Consulting Ltd Matthew David Clayton Maureen Owino **Committee for Accessible AIDS Treatment** Michael James Payne Nine Circles Community Health Centre Michael Kwag **Community-Based Research Centre** Michelle Louise Zaharik bioLytical Laboratories Inc. Michelle Sumner-Williams Unity Health Toronto Naglaa Shoukry Canadian Network on Hepatitis C (CanHepC) Nitika Pai McGill University Pamela Coreen Beattie MedMira Laboratories Inc. Paul Sandstrom Public Health Agency of Canada Paul Van Caeseele Cadham Provincial Laboratory, Manitoba Health Peeling, Rosanna Wai Wan London School of Hygiene & Tropical Medicine Penny Higdon GNB, Department of Health Gay Men's Sexual Health Alliance Phillip Banks Quoc C Pham OraSure Technologies, Inc

Raye St Denys	Shining Mountains Living Community Services
Richard Elliott	Canadian HIV/AIDS Legal Network
Richard Galli	CIHR Centre for REACH in HIV/AIDS 3.0
Roxanne Ma	Canadian Foundation for AIDS Research
Ryan Joyce	Canadian Foundation for AIDS Research
Sarah V McFarland	The Allan Clinic
Scott Elliott	Dr. Peter AIDS Foundation
Sean Rourke	CIHR Centre for REACH in HIV/AIDS 3.0
Shannon Ryan	Ontario AIDS Network
Stacey Burns MacKinnon	Prince Edward Island Department of Health and Wellness
Stephanie Smith	Native Women's Association of Canada
Stephanie Van Haute	Manitoba HIV Program/University of Manitoba
Tamara O'Donnell	Canadian Aboriginal AIDS Network
Theodore Geatros	Consumption Co.
Todd F Hatchette	Nova Scotia Health Authority
Tom Wong	Indigenous Services Canada
William Flanagan	Queen's University
Yoav Keynan	National Collaborating Centre for Infectious Disease