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National Deliberative Dialogue on Integrated Approaches to HIV Treatment and Prevention (T&P)

Meeting Report

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1 Background

The divide between HIV treatment and prevention has existed since the beginning of our response to the HIV/AIDS epidemic. The two have long been viewed as separate silos and, until recently, there have been few coordinated efforts to integrate them in terms of both funding and programming. Emerging research evidence, particularly in recent years, however, has provided growing support and immediacy to the need for an improved, more comprehensive, combined approach to treatment and prevention.

1.1 The evolving response to the HIV/AIDS epidemic

In the early years of the epidemic, our response to HIV/AIDS focused on the delivery of behavioral prevention interventions to HIV-negative individuals through a network of AIDS service organizations (ASOs) across Canada. Over time, prevention programs aimed at people living with HIV ('positive prevention') started to emerge along with improved testing technologies to diagnosis HIV infection. A growing evidence base showed that the majority of people living with HIV, once they became aware of their status, took measures to reduce their chances of passing HIV to others, emphasizing the important link between testing and prevention.

Treatment for people living with HIV was initially seen to be solely under the control of doctors. CATIE emerged from the need for community-based organizations to focus on health and treatment information for people living with HIV. Along with other organizations for people with HIV, CATIE also critiqued the lack of (or poor) response from government, physicians and researchers, and asserted that people with HIV could learn how to manage their own health, inform research priorities and direct government funding toward treatment.

With the development of HAART in 1996 came substantially reduced morbidity and mortality for people living with HIV and an even greater need to exchange treatment information in order to enhance the health of people living with HIV. Once the benefit of HAART became apparent, doctors were initially aggressive in prescribing it. However, as it became clear that HAART had limitations in terms of side-effects, drug resistance and adherence, doctors and patients increasingly delayed therapy and this was reflected in treatment guidelines. Around the same time as the introduction of HAART, there was the development of viral-load testing and the first indications that antiretrovirals may have a role to play in decreasing HIV transmission, such as in reducing vertical transmission and post-exposure prophylaxis.

1.2 “Treatment as prevention” and other emerging research

In recent years, evidence has been quickly amassing that shows HIV treatment may drastically reduce the risk that a person living with HIV passes the virus to others through sex and injection drug use. At the same time, better-tolerated treatments have been developed, and research is beginning to show the benefits of early treatment for the health of people living with HIV. Treatment guidelines are again being revised to recommend earlier treatment to both improve health and reduce infectiousness. Adherence to treatment is important not only for the health benefit of the person living with HIV, but also for prevention to ensure that the viral load, and risk of HIV transmission, remains low. Care and support for people living with HIV, which focus on issues such as mental health, addictions and housing, have become critical to improve quality of life and support adherence.

At the 2006 International AIDS Conference, Montaner *et al* at the BC Centre for Excellence (BC-CfE) proposed a new approach to controlling the HIV epidemic based on the hypothesis that increasing the number of people on treatment in a population will reduce the “community” viral load and lower HIV incidence. According to this model, HIV prevention and treatment programming work together in taking a pro-active, public health approach to the identification of people living with HIV and then linking them and retaining them in care. This type of approach is variously referred to as “treatment as prevention” (TasP), “STOP-HIV/AIDS” “treatment 2.0” and “seek and treat.” Pilot implementation-research projects are now underway in British Columbia and the United States.

Since its initial proposal in 2006, evidence on the use of HIV treatment as a prevention method has become much stronger. The strongest evidence, a randomized controlled trial called HPTN 052, was released at the 2011 IAS Conference and confirmed the effectiveness of treatment as prevention. In this randomized, controlled trial, early HIV treatment reduced the risk of HIV transmission by 96% among heterosexual, serodiscordant couples who mostly had vaginal sex, received regular adherence and prevention counselling, free condoms, viral load tests and regular screening and treatment for other sexually transmitted infections. Unfortunately, it is not yet known how well this prevention strategy will work “in the real world”, nor the extent to which the prevention benefits of HIV treatment are found in other populations, such as men who have sex with men or people who use injection drugs. Ongoing research is attempting to provide answers to these outstanding questions.

Several other developments in research, as well, have implications for improved frontline practice. Evidence suggests that prevention and treatment of other STIs, among both HIV-negative and positive individuals, can reduce the risk of infection and transmission. Research suggests that roughly one quarter of people living with HIV are undiagnosed. This hidden population may account for more than 50% of new HIV infections, particularly among people who are recently infected and have high viral loads. There is a significant number of people who are not being diagnosed until the later stages of HIV infection, such as advanced HIV, and are not, therefore, benefitting from earlier treatment.

Evidence is also emerging around the potential benefits of new HIV prevention technologies, such as the use of antiretroviral treatment by HIV-negative individuals to reduce their risk of becoming infected, (pre-exposure prophylaxis (PrEP) or post-exposure prophylaxis (PEP)). Although these technologies are considered to be “biomedical,” it is apparent that they will not be effective if provided in the absence of complementary behavioral interventions.

Also, it has become clearer that increasing the number of people living with HIV who benefit from an “undetectable” viral load will require significant improvements in a whole continuum of HIV/AIDS services including testing, treatment, care and support.

1.3 Emerging perspectives and controversies

Although evidence supporting a “treatment as prevention” approach is very strong, awareness of the implications of this evidence for program planning and development remains limited. There is currently a great deal of confusion and concern among policy makers, program developers, public health workers, clinicians, people living with HIV, community workers and others about various aspects of the treatment and prevention – and, in particular, the implementation of the research evidence through various programs and policies.

While “treatment as prevention” has the potential to re-invigorate HIV programming in Canada by building on the opportunities inherent in the newly-proven overlapping aims of one with the other, it has also generated controversy because the approach raises new ethical, programmatic and evaluative issues. Some of the main areas of concern that have been raised about “treatment as prevention” are

related to maintaining a clearly-articulated rights-based context for treatment and prevention programming and addressing the potential conflict between public health objectives and clinical objectives.

There is also concern that existing community-based prevention programs, which are known to be effective, will be sidelined in favour of ,more clinically-based “TasP” programs with an exclusively bio medical approach. With an integrated approach to T&P, it will be important to consider *existing* prevention programs and ensure that they are able to incorporate new knowledge about HIV transmission into these activities. Likewise, programs that focus on treatment for the sake of treatment also need to be maintained and research into new treatments and a cure must continue. Thus, we propose the term “Integrated approaches to treatment and prevention (T&P).”

1.4 Integrated Treatment and Prevention

“Integrated treatment and prevention (T&P)” recognizes prevention, testing, care, support and treatment as mutually reinforcing elements of an effective response that must be integrated in a comprehensive approach to the epidemic. An integrated T&P approach includes four intersecting components that need to be addressed: 1. Prevention with engagement and linkage; 2. Testing and diagnosis with engagement and linkage; 3. Optimal treatment with engagement and linkage; 4. Care and support with engagement and linkage.

Furthermore, this broader term recognizes the need for prevention work that does not necessarily involve a treatment component and the need for treatment work that does not necessarily involve a prevention component. The “Integrated treatment *and* prevention” term recognizes “treatment *as* prevention” as one important element of a comprehensive/combination approach to the HIV/AIDS epidemic which will require improved integration of a continuum of HIV/AIDS services in order to be successful.

Within this context of uncertainty and controversy about the implications of emerging research knowledge, there is a need for open dialogue on this new approach and its implications for frontline HIV prevention, care, treatment and support programming in Canada. The dialogue must consider the

development and implementation of integrated T&P strategies which ensure a continuum of care across outreach, prevention, testing, treatment, care and support. Initiatives within these realms can no longer be seen as stand-alone entities– the programs must fit together to ensure a coherent and integrated continuum of care.

2 National Deliberative Dialogue on Integrated Approaches to HIV Treatment and Prevention (T&P)

Responding to the need for a national dialogue about emerging biomedical research (including HIV treatment as prevention) and its implications for front-line work, CATIE organized a national knowledge exchange meeting on October 17-18th, 2012. There were a total of 43 external participants, including nine Ontario representatives, five from Quebec, eight from British Columbia, six from the Prairies, three from the Atlantic Region, 11 national representatives and one international speaker from the U.S. Within each region, we sought to strike a balance with representation from clinical, public health, research, community and policy backgrounds. There were also 11 CATIE staff facilitating in the event. The primary role of CATIE staff was to listen, facilitate discussion where appropriate and to take notes of discussions. As such, CATIE staff were primarily event “observers” rather than dialogue participants.

The dialogue focused on the exploration of efforts to integrate HIV Treatment and Prevention (T&P) and other emerging biomedical research in different regions of Canada. This included the challenges and lessons learned from these activities and the identification of priority areas that would need to be addressed in policy, programming and knowledge exchange in order to facilitate the implementation of integrated T&P models regionally. The dialogue also facilitated discussions of the benefits and limitations of integrated T&P by encouraging open discussions. However, there was a sustained effort to move beyond polarization in the debate by clarifying assumptions and identifying common ground and priorities.

The central question for exploration during the dialogue was ***in light of new and emerging biomedical knowledge about HIV, what could we be doing differently in our front-line response in order to fully integrate combination approaches to T & P across all sectors in the response?*** The foundation of this approach is knowledge that prevention, testing, treatment, care and support are mutually reinforcing

elements of an effective response that must be *integrated* to form a comprehensive approach to the epidemic. The primary aim of this approach is to ensure engagement across a continuum of HIV prevention, testing, treatment, and care and support services for people living with and affected by HIV.

The goals of the dialogue were to:

- Identify tension points, common ground, gaps and divergent opinions regarding the implementation of T&P programs ;
- Share regional experiences and models related to the development of integrated T&P programs;
- Identify priority areas and challenges for change at the level of health systems, policy development, program development and program implementation;
- Identify areas where knowledge exchange is needed to bridge the gap between research evidence and current practice in HIV programming ; and
- Inform CATIE's development of the *Planning Roadmap for Integrated Approaches to Treatment and Prevention* — a framework for a renewal and integration of, and dialogue around, T&P programming.

In order to help ensure a successful event, CATIE relied on several strategies.

The Process: Direction and Engagement

CATIE used a variety of pre-dialogue methods to ensure there was external input into the development of the event and to enhance engagement at the event. Firstly, CATIE developed a National Advisory Committee (NAC) which was composed of 16 representatives from community, clinical, research and policy backgrounds. This committee met four times prior to the event in order to provide feedback on all the background materials, the participant list, and the meeting itself. This helped to ensure that the NAC members were fully engaged in both the development and delivery of the event.

CATIE worked closely with 7 regional experts to develop high-level overview presentations that reflected the regional response to HIV in British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec and the Atlantic region. CATIE staff provided feedback and support to ensure each presentation covered the essential elements to lay the foundation for the dialogue. The regional experts consulted with others in their region to ensure that the presentation reflected their regional response.

CATIE also worked closely with 16 experts in prevention; testing; treatment; and care and support to develop and refine the overarching framework which guided the dialogue and in shaping the discussion groups. These experts then led the breakout discussions on day two. This not only brought expertise to each of the discussions but enhanced engagement of the experts during the event.

The Process: Ensuring an inclusive dialogue

In order to ensure an inclusive dialogue that would facilitate reflection and open discussion, and recognize the multiple perspectives in the T&P debate, select individuals were invited to attend. Selection of participants was meant to ensure regional and occupational diversity – including front-line workers, public health workers, researchers, policy makers and people living with HIV.

The Process: Ensuring a common understanding

In order to ensure that all participants came to the meeting with a common understanding of the new science, CATIE provided them with various reading materials as well as two preparatory webinars.

The Deliberative Dialogue Agenda and Structure: Going from a point-of-view to a view-of-points

The final agenda was structured to maximize facilitated discussion among participants. The goal was not to reach consensus; but rather, to share experiences and insights, concerns and challenges, and to identify common ground and priorities to move an integrated T&P model forward regionally.

The meeting was started with short provincial presentations on multicomponent HIV responses in each region that address the full continuum of an integrated T&P approach. The presentations were followed by a large group discussion to seek further clarification on regional approaches and differences. This opening session set the stage for the two-day meeting.

The second day was structured to ensure a balance between small group and larger group discussions on how new biomedical knowledge and integration might change our approaches in each of four components: prevention, testing and diagnosis, care and support, and treatment. Four short presentations were developed by CATIE staff in consultation with 16 participant experts on each of the components to synthesize the framework and to provoke discussion and reflection.

There were also two international presentations: one on the San Francisco experience in shifting the county-wide model to a more integrated T&P approach, as well as a presentation on lessons learned globally with relevance to Canada's response. Given the October 5th, 2012 HIV non-disclosure Supreme Court Ruling, there was also a short presentation on the potential implications to front-line work.

3 Key Themes

The purpose of the deliberative dialogue was to explore the issues raised by the central question, *in light of new and emerging biomedical knowledge about HIV, what could we be doing differently in our front-line response in order to fully integrate combination approaches to T & P across all sectors in the response?* The dialogue was not intended to create consensus. The following thematic analysis is based on notes taken during the dialogues that occurred throughout the two-day meeting in both small and large group discussions.

3.1 Overarching themes related to integration

3.1.1 It is important to develop a vision for integration

A vision for integration must reflect regional similarities and differences

All the regions of Canada are exploring the integration of HIV prevention and treatment to some degree. There are many common issues between the regions, and the participants welcomed this rare opportunity to share experiences and lessons learned at the frontline. However, there are also significant differences between regions which impact how they approach integration. Most notably, the epidemiology of HIV differs between regions to such an extent that they are experiencing different types of epidemics. For example, in large urban areas such as Vancouver, Toronto and Montreal, gay men and other MSM are the most affected population, whereas in the Prairies Aboriginal communities are the most affected.

There are also significant differences in the way HIV services are provided. In provinces with large urban centres, HIV services tend to be differentiated (both differentiated from other types of health services and differentiated with respect to distinct target populations); the challenge of integration is to link these services with other parts of the health and social systems of care. Other regions do not have the capacity to provide differentiated HIV services. To a large extent their services are already "integrated,"

and the challenge is to build the capacity of existing services to include HIV in their programming, and address the unique challenges related to HIV services, for example ensuring confidentiality.

Geography is also a major challenge in most regions. For example, specialized HIV care (including infectious disease specialists) may only be available in a few locations in the province. Travel is a barrier, both for people living with HIV who need to travel to receive care and for health workers who need to travel in order to provide outreach and care throughout their region.

It should be noted that these regional differences do not necessarily follow provincial boundaries. Within many provinces there are significant regional differences, and migration between provinces to receive care and support is also an important issue in some places.

Integration should be holistic and multidisciplinary

It is important to develop a definition and vision for what needs to be integrated and what that integration should look like. This vision should be holistic and multidisciplinary, including the active involvement of people living with HIV and communities at risk. Ideally, it should be community-led and informed by frontline work. While the focus of the deliberative dialogue was on the integration of HIV treatment and prevention, integration may involve other aspects of health as well. Therefore, the vision should provide clarity about the scope of integration. For example, to what extent should integration include mental health, chronic diseases such as cardiovascular disease and diabetes, or other related infections such as sexually transmitted infections, viral hepatitis and tuberculosis? Some of the key inter-sectoral issues that should be addressed in the vision include: providing decision-making power for communities; developing strong partnerships between clinical, social and community services; and establishing mechanisms to inform decisions by frontline perspectives. Because integration involves systemic change, one of the most difficult challenges to developing a vision is establishing a process that equitably engages the multiple players who are needed to move the work forward.

Many participants expressed concern that if integration is not guided by a community-based, multidisciplinary vision it could be misused as a strategy to redirect funding to clinical services at the expense of community-based services. It is important to be cognizant of this in our discussions of integration. For example, it is not helpful to have high-level policy discussions that oversimplify the complexity of the issues or that occur out of context of the frontline reality. On the other hand,

participants felt that it is very helpful to hear about specific strategies and initiatives, with an emphasis on *how* integration was approached “on the ground” and what lessons were learned.

Integration is iterative and requires self-reflection

Participants who have been actively engaged with integration shared a few key lessons learned.

Integration takes time – and our vision for integration should reflect this. San Francisco, for example, has been working on integration for more than five years. Integration is iterative. It is an ongoing process of experimentation and refinement in which evaluation is central. For integration to be successful there must be a willingness of those involved to self-reflect and challenge their own assumptions. Creating a safe environment for this reflection is important; a funding context in which organizations are competing for limited resources can be counterproductive.

3.1.2 Integration is about providing client-centred services

Holistic, client-centred services are important

The client must come first in our models of service delivery. One of the main reasons why integration has emerged as an important issue is because existing service delivery models are fragmented and clients are lost to follow-up and care. In order to improve health outcomes, most participants felt that we need to improve our engagement with clients as individuals and holistically address their health-related needs. Not only does this mean integration of the range of HIV-related services provided to a client, it also means seamless integration of these services with those that address other health issues as well as the social determinants of health. Case management was felt to be a very effective approach. Outreach workers can also play a key role in helping people engage with and navigate health and social service systems.

Support for self-care and health systems navigation is effective

One important client-centred approach to integration which is being explored in many regions is peer-based support. The peer navigator program of Positive Living BC and St. Paul’s Hospital is one example of a peer-based program that involves hiring and training people living with HIV to support people living with HIV to manage their illness and to navigate the sometimes complex health care and social service systems. In the various regional models, peers may take on a number of different tasks including: providing health or treatment information, providing referrals, accompanying clients to appointments,

supporting informed decision making, or providing encouragement and emotional support. Peer-based programs can be particularly helpful for bridging clinical and community-based settings. Participants felt that this approach was very valuable and recommended sharing promising practices.

Low-threshold programs are important that engage marginalized populations where they are. For example, Direction 180 in the Atlantic region is a low-threshold methadone program for people who use substances, the program works with an ID specialist to facilitate access to HIV and HCV treatment. It overlaps with mental health services and also works with corrections to facilitate ongoing continuity of care across jurisdictions.

Systems-related fragmentation of services should be addressed

While it is important to tailor services to meet client needs, sometimes too much specialization or differentiation of services can have unintended negative consequences. For example, services are often differentiated based on the sero-status of clients. However, in some circumstances, such as prevention counselling, it might not be helpful to distinguish between people who are positive and those who are negative—such distinctions can “bog down” service delivery. Similarly, having too many different types of services can fragment the care that a client needs. In order to overcome this challenge, San Francisco has collapsed multiple services that were formerly provided by many different people into a single position, called a “behaviouralist.” Behaviouralists are trained to respond in a holistic way to a range of needs that clients might have.

Bringing multiple services together in one location is another strategy to reduce fragmentation that can be caused by the existence of multiple, specialised services. Nine Circles in Manitoba (where clinical and community services are coordinated and housed together) was suggested as a “one-stop-shop” that might serve as a helpful model. It is also important to identify the best setting for HIV services based on the needs of the client. Some regions are exploring new models of integration in which HIV is embedded within a broad range of related services, such as harm reduction services, mental health services, reproductive health services, or gay men’s sexual health services.

Guidance is needed for developing client-centred strategies

Client-centred support often involves tailored approaches to each individual. However, developing an individual approach can be resource intensive and not everyone needs or wants this approach. More

guidance is needed on how to plan and implement appropriate, cost effective strategies for improving the client experience with engagement and linkage, including when and how to provide tailored services.

3.1.3 Integration involves systemic change

Inter-sectoral and jurisdictional considerations are key when making system change

Integration involves rethinking entire systems of health care and community support. Not only is it necessary to look at individual programs and services, it is necessary to assess how the diverse package of HIV-related services work together within the overall system of health and social services. To be successful, changes must happen at multiple levels, such as funding structures, health policies, institutions and organizations, and individual programs. Therefore inter-sectoral and jurisdictional considerations are important to consider in developing integration strategies.

Integration must consider all four pillars of HIV, namely: prevention, testing/diagnosis, care/support and treatment. It must also address the social determinates of health that drive the epidemic. Engaging all stakeholders in the process is very important. Participants particularly identified community engagement as crucial to successful systems change. This includes ensuring the voices of people living with HIV are front and centre and that there are mechanisms to support their ongoing engagement in the process. This can mean shifting or sharing control over how programs are funded and operated.

Research and evaluation can facilitate system change

Regions that have approached integration systemically have found that research and evaluation is central. It is important to look at the regional and local epidemiology, including the geographical distribution of incidence and prevalence. It is also important to research the continuum of HIV services, including the “treatment cascade” to identify strengths, gaps and places where people are lost to care. This may include mapping where clients go for services.

There is also a need to consider systemic issues that facilitate or challenge the integration of treatment and prevention; for example, regionalization of health authorities, institutional policies, community engagement or inter-sectoral partnerships. Once the landscape is fully understood, then a model can be applied that will work for the region. Participants spoke of the implementation of integration as an

ongoing process of quality improvement. Systems change happens through trial and error, so evaluation systems are needed to determine what is working, what doesn't work and what needs to be improved. It is important that the implementation process is responsive to the outcomes of evaluations. For example, The Vancouver STOP HIV Project (a collaboration between Vancouver Coastal Health and Providence Health Care) evaluated new programs or initiatives at six month intervals in order to determine further changes that might improve services.

Identifying different types of system change is helpful

Participants identified many different types of system change that they have found to be helpful. For example, removing organizational barriers that limit the ability of service providers from different organizations to work together; collapsing leadership teams and budgets across multiple organizations or jurisdictions to improve care and reduce duplication; or developing partnerships across sectors to enhance holistic care. Networks and communities of practice were found to be helpful for promoting quality improvement and practice change. For example, in British Columbia, a care planning counsel, a prevention counsel and provider networks to support regional system integration have been established. In Ontario, the Gay Men's Sexual Health Alliance was established to address improvements to services for gay men's sexual health across the province.

Challenges and concerns related to system change should be addressed

An integrated approach to treatment and prevention requires strong integration between clinical and community-based settings. This has emerged as a significant challenge for many regions. Often healthcare providers are reluctant to engage with community-based organizations (CBOs) and CBOs are potentially intimidated by clinical settings or don't see the relevance of clinical settings to their work. Yet each can provide complementary services that are important for clients. BC's peer navigator program emerged as one successful model. While some healthcare providers were reluctant at first to participate in the program, once it was in place they became champions of the value added.

Another challenging area of integration is mental health services. Participants spoke of the need to embed HIV services within the mental health system and to create stronger linkages to mental health services within existing HIV services. While it was not a specific topic of discussion, participants also identified the integration of sexually transmitted and blood borne infections (STBBIs) as an emerging

challenge for which guidance is needed. Some provinces have moved towards more integrated STBBBI approaches.

Several important concerns were identified regarding how the integration of treatment and prevention is approached at a systems level. It is important that primary prevention work continue to be valued in any model of integration. It is also important that structural interventions to address the social drivers of the epidemic are taken into consideration. If integration is not done properly it may place undue pressure on people to access testing and treatment before they are adequately informed or ready. Poorly designed integration could also skew programming towards a medical model of clinical care at the expense of important community-based work. These concerns should be taken into account in any approach to system change.

System-level monitoring/evaluation is an important consideration for integrated approaches, as mentioned above. Many participants felt that there needs to be more work done in this area. The HIV “treatment cascade” has recently emerged as one mechanism for assessing gaps in service delivery. However, we know very little about the HIV treatment cascade in Canada. It would be very helpful to monitor this cascade of services at the provincial and local levels. However, many participants pointed out that this tool is based on convenient clinical markers involving people living with HIV, and it is not clear that these markers are the most appropriate to monitor overall success of integration at the population level. For example, these markers may not adequately reflect improvements in health and quality of life for people living with HIV. Significantly, primary prevention outcomes are not represented in the cascade. For example, the success of a testing program may involve more than just reducing the number of people who are undiagnosed; it may also involve important prevention outcomes that are not part of the treatment cascade.

There are significant risks in relying too much on surveillance of people living with HIV as indicators of success. One unintended negative consequence which has been noted in BC is the creation of a new identity of “the unsuppressed”—people living with HIV who do not have undetectable viral loads. There are many reasons why people living with HIV may not be on treatment or may not have an undetectable viral load (including personal choice, the need to address other health priorities first, etc.). We need to be careful that our approaches to integration do not contribute to further stigma.

3.2 Themes related to the four pillars of integration

3.2.1 Prevention services within an integrated framework

Prevention plays an important role in integration because it is often the point of entry into the continuum of HIV care.

Include a greater range of health and service providers in HIV prevention

Participants spoke of a need to broaden the reach of prevention work. Typically frontline workers are only reaching those who access the services of their organizations or are within their immediate reach. There is a need to embed HIV prevention within other services and environments which are relevant to communities at risk. Physicians, nurses and other clinicians (not specializing in HIV) can play a particularly important role in prevention.

However, often these service providers are not knowledgeable about HIV risks and/or do not begin the dialogue about risk behaviour with their clients. For example, one region in British Columbia found that healthcare providers were generally reluctant to ask their patients about sexual orientation or discuss risk behaviour. As a result they developed a capacity building program for physicians around health issues for gay men and other MSM. Healthcare providers may also feel they do not have the tools to prevent HIV in people they know are at ongoing high risk. The school-based educational system is another environment where HIV prevention needs to be improved. This includes helping to support conversations in the home about sexuality.

Sexually transmitted infections (STIs) can increase the risk of HIV transmission. Often services for the prevention of STIs are disconnected from HIV prevention. However, some organizations, such as Hassle Free Clinic in Toronto, provide integrated STI prevention/testing services.

There is also an important linkage between HIV and mental health. However, due to the siloed nature of these areas, it is difficult to create services that integrate both components. Many participants felt this is an area that needs more work. One mental health issue that is often overlooked despite being an important factor in HIV transmission and HIV care is alcohol addiction as was noted by a participant from northern BC.

Expand HIV prevention programs to better meet the needs of specific communities

Participants mentioned several populations for which we are not doing the basics of prevention very well. These include LGBT youth, people in prisons, newcomers and communities with low HIV prevalence.

For Aboriginal communities, prevention needs to be envisioned as larger, broader and deeper than just HIV. Programs need to understand and incorporate issues of colonization, self-determination and systemic abuse. There is also a need within Aboriginal communities to integrate HIV into other conversations in a culturally appropriate way.

It is very important to include people living with HIV in prevention. We need to recognize that the healthier someone living with HIV is, the more likely they are to participate in prevention. This changes the way we think about positive prevention because the focus is much more than just transmission. Some organizations are developing new models of positive prevention based on this paradigm shift such as Toronto PWA Foundation.

Include new and reconsidered knowledge in HIV prevention work

Participants felt that the field of prevention is not adequately prepared to respond to new developments in the biomedical science of HIV transmission and prevention. One challenge is the communication of messages regarding risk. There is a need to develop clear messages about risk in the context of viral load, for example.

There is also a need to grapple with the complex nuances of risk messages and determine what messages are appropriate for broad audiences (such as the general public) and what messages are appropriate for targeted audiences (such as individual risk counselling). We also need to determine how to talk about risk when different combinations of prevention are used intermittently by individuals. Currently there is a lot of confusing and contradictory messaging about HIV risk. Several organizations are developing tools and resources in this area.

Another challenge has to do with the erosion of the idea that HIV prevention is a shared responsibility. The focus on viral load as a determinate of HIV risk can give the false impression that people living with HIV have the biggest role to play in prevention. We need to explore models of prevention counselling

that are inclusive of all sero-statuses (HIV negative, unknown, and HIV positive). Many organizations are also rethinking the way we talk about risk behaviours. For example, the term “condomless sex” is not as loaded with negative meaning as “bareback sex” and may be preferable to use in some contexts.

Participants also questioned whether the health authorities have adequately prepared for new prevention methods. For example, many provinces are not prepared to talk about PEP and PrEP because of concerns about costs. There is a need for guidance from health authorities regarding the use of new prevention methods which is currently not being met. This is particularly concerning because people are making decisions about the use of these methods in the absence of public health or clinical guidelines.

Broaden HIV prevention efforts to address social determinants of health

The social determinants of health that drive the epidemic impact all aspects of the HIV continuum. Lack of stable housing, food insecurity and lack of employment are significant determinants of health inequity and need to be addressed at all levels (national, provincial, and local).

Stigma is also a major factor, both from the general population and from service providers. There is a need to unpack stigma and how we approach it. Many clients report that their stigma does not come from their HIV-status but rather from racism or judgements about how people live their lives (eg. sex work, injection drug use). Stigma related to mental illness is also an important issue. One participant cautioned that we need to ensure we are not further stigmatizing people with anti-stigma work in HIV. For example, we may wrongly assume people living with HIV are experiencing stigma when that is not the case—this could inadvertently cause people living with HIV to feel exceptional when they prefer not to be identified that way. It is also important to consider the ways in which healthcare practice itself perpetuates stigma.

Ensure prevention is specifically included in any integrated strategy

Many participants felt that the importance of prevention work has been lost in the current dialogue about “treatment as prevention”. Others felt that considering multiple approaches to prevention within the discussion of the HIV continuum of services provides an opportunity to engage in conversation about how they work together. This helps to overcome the discourse that pits treatment against prevention.

3.2.2 Testing services within an integrated framework

HIV testing, which naturally bridges prevention with care and treatment, was the most discussed topic during the dialogue. Almost all regions are actively involved in improving their testing programs.

Build capacity related to HIV testing

Many regions are engaged in capacity building for existing testing services. There is a lot of misinformation about testing in the community, with service providers and with healthcare providers. There are also many missed opportunities for testing at-risk populations. Often people at risk for HIV interact with the health care system, but are not asked about their risk, are not offered a test, and/or do not ask for a test. Many patients wrongly believe they have been tested for HIV as part of their routine care. Several regions have developed tools and resources for clinicians to increase their awareness and knowledge of HIV testing. Ontario has also developed tools for outreach workers to improve their knowledge of HIV testing for gay men.

More focus needs to be placed on improving linkages after testing. This includes not only post-diagnosis linkage to care and support, but also addressing the current “vacuum” of linkage for people who test negative. Guidelines about post-test counselling and follow-up support for negative results would be helpful. Guidelines about testing frequency for different populations would also be helpful. ASOs can potentially play an important role in bridging the clinical and community-based aspects of HIV testing and linkage to care.

Carefully consider counselling and informed consent

Counselling and informed consent are important elements in HIV testing. What this looks like was discussed by participants. Some participants felt that a client-centred approach should be used which is adapted to the specific information needs of the individual. For example, many clients who test regularly for HIV find that a lengthy counselling session is a barrier to testing when they already know the information. It was suggested that different models of counselling for different clients might be appropriate and that the depth of counselling should be negotiated between provider and client. Others felt that less counselling would translate into no counselling, whereas there is a responsibility to ensure clients are adequately informed.

Healthcare providers need to have a basic understanding of HIV testing and they need to educate their patients. Informed consent should not be seen as a barrier to HIV testing; people have a right to consent. In some settings, such as corrections, clients may require other needs be met before they are in a position to provide informed consent for an HIV test and this must be factored into the discussion. The issue of informed consent has become even more pressing in light of the recent Supreme Court decision regarding the legal ramifications of HIV non-disclosure. Guidance for providers on how to discuss the legal implications of a positive HIV test result with their clients is needed.

Carefully consider routine offer and targeted approaches to HIV testing

There were divergent opinions on the relative merits of routine testing compared to targeted testing. In Manitoba testing rates are very low and people are presenting to care late in HIV disease progression. In response, Manitoba is focusing on broad awareness and offering of HIV tests and education of clinicians. As a result, they have seen an increase in positive tests. Ontario initially adopted a general testing strategy in part to reduce stigma. However, they found that the incidence rates in high risk populations continued to rise. Adopting a targeted testing strategy was more effective both in terms of positive test results and cost. Ontario has not experienced an increase in people presenting late.

Many participants felt that pitting routine offers of HIV test against targeted testing creates a false dichotomy; both may be needed depending on the regional epidemiology. Some forms of routine offer of HIV testing are actually quite targeted. For example, hospital-based emergency-room offer is good at reaching marginalized populations who use the emergency room as primary care, such as people who use drugs and street involved people. Furthermore, targeted testing can fail to reach its intended audience. For example, one region in BC discovered that a significant proportion of a population targeted for HIV testing was presenting to care late. They discovered that these people had accessed the health system a few times in the past year but had not been offered an HIV test in part because healthcare providers were not asking about their HIV risks. For this at-risk population, routine offer is more effective because it does not require individuals to self-identify with a specific population nor providers to accurately assess risk. Guidance on how to develop cost effective testing strategies would be helpful.

Explore HIV testing in different settings

New settings for HIV testing are being explored. Quebec found that there were structural barriers to HIV testing in clinical settings, such as long wait times, walk-in clinics that are full, medicalized offices that do not create a favourable climate for testing. This region developed a low barrier, community-based testing site which includes warm reception, no requirement to disclose sexual orientation and no requirement for a health card. Some regions are using peers or community workers as testers and/or counsellors in clinical and non-clinical settings, such as bathhouses, parks, and at community festivals. Two regions have undertaken testing campaigns targeting people experiencing acute HIV infection.

Participants remarked that there is a need to connect with other places in the health system where testing is happening to improve counselling and linkages, such as fertility clinics. They also expressed interest in couples or family-based testing as a potential model of care.

Consider adopting new HIV testing technologies

New testing technologies are an emerging area for program development. Point of care testing has been very successful in the regions in which it has been rolled out. However, there are stark differences in access to point of care testing depending on province, region or city. Based on experience with this technology, participants recommended the development of national guidance about the *implementation* of testing technologies, including when to use a technology, how to use it, what systems are needed, how to balance potential benefits and harms, how to assess cost-effectiveness and how to evaluate the implementation of a testing technology. For example, point of care testing is more expensive than standard testing so guidance is needed about when it is cost effective. Also point of care testing is only feasible in settings where training and quality assurance measures can be reasonably implemented, so organizations need guidance on suitability of their environment for this technology.

Implementing new testing technologies may also require systems changes. For example, in order to implement rapid testing in an emergency room (ER) setting, there is a need to coordinate between ER staff and the HIV team, ensure accountability with the hospital lab and negotiate follow-up with public health workers. There is also a need to coordinate with the provincial surveillance system in order to ensure accurate reporting of HIV statistics.

Home-based HIV testing has been approved in the US and some participants expect it will be coming to Canada in the near future. Home-based testing is convenient and may remove barriers for people who are discouraged from testing in public settings. Some people may opt for this strategy out of fear of criminalization. However, there are many concerns with home-based testing. Education campaigns may be required because the home-based test might not be as accurate as other forms of HIV testing (for example, the home-based test currently available in the US is not as accurate as other forms of testing). Additionally, people using the home-based test may not understand important issues such as the window period. Structures will need to be put in place in order to ensure access to support and counselling as well as linkage to further care. Affordability is also a concern. Preparation for this coming technology is needed so that providers understand the test, are ready for it and can put out accurate information about the test.

3.2.3 Care and support services within an integrated framework

Care and support form the foundation of the continuum of HIV services. A holistic view of care and support that places clients at the centre is important. Building trusting relationships with clients and providing individualized services, such as case management, are important components of care and support that are often undervalued. These approaches can keep people in care and improve their health outcomes. Community-based agencies need secure funding to sustain support networks over the long-term. Healthcare providers also need appropriate funding models. For example, in at least one province primary care physicians have been able to negotiate a payment structure that recognizes the different time and type of services required to support people living with HIV.

Respond to the shift to holistic, inter-sectoral, long-term care and support

Care and support programming has changed as HIV care has evolved from acute to chronic disease management. Participants noted that we are increasingly recognizing the importance of long-term approaches to health and wellness for people living with HIV that address the complex issues people face as they age with HIV. This includes sexual health programming that supports people living with HIV as they navigate their sexual lives in ways that we never expected would be possible in the early years. Support for disclosure is another area where programming needs to be developed and promising practices shared. Disclosure can be difficult, can lead to emotional and mental stress and can cause

difficulties with intimacy. Conversely, not disclosing can also cause stress, withdrawal and/or avoidance of intimacy.

Many participants felt that there is a need to de-silo practices, to encourage more inter-sector partnerships and to integrate clinical services with community services in order to help people navigate health systems and support them with their ongoing care. There is also a need to better integrate mental health services with community-based support. Elder care and support for people living with HIV is an emerging challenge as existing long-term care facilities are often not prepared or equipped to deal with the complex issues of HIV. Guidelines on sharing health records in integrated environments would be helpful, for example guidelines around collective case management.

Consider peer self-management support services

Peer support/navigation programs resonated with many participants as a promising practice for improving care and support; many regions have implemented some form of this programming. Peer programs have improved reach in underserved regions and regions where stigma is a major barrier to service access. They have supported disclosure and relationship building for people living with HIV. They have helped educate healthcare providers. They have supported people living with HIV to make treatment decisions and to navigate health systems. Peer programs have also been found to be cost effective. Many participants felt that there is a need to share peer programming practices nationally and create joint learning opportunities for developing such programs. There is also a need to develop best practices about how to support peers, including ensuring that programs enhance the experience of peers. For example, some organizations have found that without adequate support some peers may become reluctant to access services to meet their own needs.

Consider care and support for people who are HIV negative

Support programming for HIV-negative individuals who are at high risk for HIV was repeatedly identified as a gap in most regions. Many providers feel that there are very few places to refer people who present for an HIV test because they are at ongoing high risk, but then test negative. It was suggested that the model of occupational therapy might be helpful in designing programs focused on goal setting and life skills that would help people get from “I’m doing things that are putting me at risk and am willing to get an HIV test” to looking at their risk behaviours and exploring or modifying their behaviours. Healthcare providers often feel they have no tools to support people in this situation. One organization has

developed a program called “Making the Links” which is designed specifically to make links for people who test negative but are clearly at risk for HIV based on their behaviour. The program involves assessing the factors that put the client at risk and linking them to services that try to help address those factors. It uses a case management approach and helps people to make necessary appointments.

3.2.4 Treatment services with an integrated framework

With an integrated approach to treatment and prevention, there is more emphasis on bringing treatments and treatment discussions to people living with HIV rather than passively waiting for them to approach the health system. In addition to organizations providing HIV treatment services, other health and community-based services may have a greater role to play in informing people living with HIV about treatment and linking them to treatment information and services. There is a need to ensure that community-based organizations are well informed about the basics of HIV treatment, including how to access treatment. Participants felt that there is still considerable misinformation within the community regarding HIV treatment. There is also a need to address structural and institutional barriers to accessing treatment. Some participants felt that a national treatment strategy and treatment access plan would be helpful. This would include examining the payment systems across the country for HIV treatments, including coverage of antiretrovirals for PEP and PrEP.

How people living with HIV are counselled about HIV treatment is an important issue. They need to be given the appropriate information, tools and time to make informed decisions. The rights and well-being of people living with HIV need to come first in treatment counselling. While it is important to discuss the benefits of treatment for reducing HIV transmission, that must be a secondary consideration in relation to the health of the person living with HIV. Some participants feel that we don’t have enough evidence to demonstrate that starting treatment immediately after infection is the best strategy. Likewise they feel that we don’t know enough about long-term side effects. This lack of knowledge should be an important part of the conversation with people living with HIV and is also an important research priority. Recently a great deal of attention has been focussed on issues related to starting HIV treatment. However, there is a need to also consider the needs of those who are treatment experienced. Adherence support may be important, for example, and support with changing treatments might be

needed. Service providers are often not aware of these issues. People on treatment also need the other types of support that they have received in the past.

Many organizations have developed services to support people living with HIV to access care and to improve adherence. Examples include inter-disciplinary collaboratives to improve quality of care; clinical outreach teams; and adherence support programs. These services often involve integration of clinical and community care, which participants have found to be particularly challenging. Peers often play an important role in the circles of care. One northern region found that their adherence program was difficult to sustain because of low enrolment so they are integrating it with other services such as HCV support and wound care. Another region is developing a program for sero-discordant couples in their HIV clinic.

3.3 Other Themes

3.3.1 Legal and Ethical Issues of integrated approaches to HIV treatment and prevention

There are a number of important legal and ethical issues related to frontline work in HIV that need to be addressed in integrated approaches to treatment and prevention. The recent Supreme Court ruling about HIV non-disclosure and the criminal law has made some of these issues even more urgent. A robust ethical analysis of integrated approaches to HIV treatment and prevention would be helpful.

Informed consent to HIV testing is important

It is important that people who are offered an HIV test are given appropriate information about the legal ramifications of testing positive for HIV and that they provide informed consent. Likewise it is important that people living with HIV have appropriate information and access to counselling regarding the legal ramifications of their sero-status. Providers need to understand these legal ramifications and know how to discuss them with their clients. Currently this is often not the case.

In attempts to reduce barriers to HIV testing, such as replacing counselling with pre-test information, it is important that informed consent remain a cornerstone of the testing process. Some participants feel that there is reluctance on the part of healthcare providers to discuss with their clients the criminal issues of testing positive. Educational resources and tools for healthcare providers and other service

providers about the legal aspects of HIV testing are needed. This issue also needs to be addressed in efforts to scale up or routinize the offer of HIV testing.

The Supreme Court Ruling on HIV non-disclosure raises some concerns that should be addressed

Criminal prosecutions of people living with HIV for non-disclosure often involve testimony and records of healthcare providers. As a result, healthcare providers become involved with the legal system and there is currently little support for them in this regard. The legal repercussions of documentation of health records, for example, needs to be examined and guidance provided to physicians, nurses, public health workers and others. For example, healthcare workers may have a responsibility to document the incidence of sexually transmitted infections for the sake of appropriate healthcare for the client. However, because sexually transmitted infections are a marker for unprotected sex, this documentation might be used against a client in a court case. This potential legal use of health records could violate trust and damage the provider-client relationship. Guidance is needed for physicians, nurses, public health workers and others about the legal issues of health record documentation for clients who are HIV-positive.

Some participants felt that the Supreme Court ruling has made the situation worse for people living with HIV. They also felt that it may place legal advice in direct conflict with clinical and public health advice. For example, it may be advisable for legal reasons not to disclose HIV status to healthcare providers, yet this is not in the best interests of the health of someone living with HIV. Some people at high risk may be reluctant to get tested for HIV out of fear of criminal liability without fully understanding that untreated HIV infection can seriously damage their health or be fatal. In some provinces organizations are working towards developing guidelines to help with decisions regarding potential prosecutions. More discussion and guidance is also needed for healthcare providers and other service providers.

Consider other ethical issues related to the use of treatment for prevention purposes

There are some ethical issues about the way treatment as prevention is discussed that must be considered. We have to be conscious about how we talk about the prevention benefits of treatment. Public health messaging about such benefits, for example, may unduly influence the decision-making power of people living with HIV. For example, they may feel obligated to begin treatment. Such messaging can also influence perceptions about criminal liability. It would be helpful to develop consensus about public messaging.

3.3.2 Education and Guidance for Healthcare and Social service Providers

As HIV care becomes integrated with other aspects of health care, there is an increasing need for education and guidance for healthcare providers, particularly those who are not directly involved in specialized HIV care. Many regions are discovering that, as they plan for expanded services, the level of HIV knowledge of physicians, nurses and other healthcare providers is not adequate to meet the needs of people living with or at risk for HIV. This includes knowledge of populations at risk and knowledge of HIV testing and counselling.

Several regions have developed capacity building programs for healthcare providers, including educational sessions, information resources, guidelines, scripts and other tools. Mentorship models have also been developed, including physician mentors, nurse mentors and PHA mentors. Some capacity building topics have included: gay men's sexual health, risk assessment and counselling, and informed consent. Initiatives to improve provider-patient communication have also been developed. Northern BC has developed a successful physician education program with continuing medical education (CME) credits. Program developers have also worked with clinical service providers to help them recognize the importance of community-based services for their clients and to help improve linkages with these services.

In addition to healthcare providers, education and guidance may be needed for other services providers, such as mental health workers or people providing elder care.

3.3.3 Limitations of the dialogue

Participants mentioned several important areas where the dialogue was limited.

There was not enough opportunity to discuss the implications of integrated approaches to treatment and prevention for specific populations. For example, the complex reality of Aboriginal peoples needs further discussion, including consideration of strategies specifically for Aboriginal communities by the Aboriginal communities themselves. HIV is on the rise in African, Caribbean and Black communities; there is a need to have a national discussion about issues impacting these communities that transcend regions. Issues related to integration in rural and remote areas also need further discussion.

The experiences of low and middle income countries (LMICs) have many resonances with the issues that were raised during the dialogue. For example, mobilizing community leadership; providing services in rural and remote areas; implementing health systems change; improving engagement and linkages within the HIV continuum; task shifting and peer-based programming; implementing new testing strategies; and addressing stigma. Sharing of experiences from LMICs might be beneficial to the national dialogue.

4 Evaluation Results

Evaluation forms were distributed to attendees. The response rate was high at 79% (33/42).

The *National Deliberative Dialogue on Integrated Approaches to HIV Treatment and Prevention* was a success. Firstly, it was relevant to all attendees. Relevance was assessed through the following indicators:

- 100% of participants agreed or strongly agreed that the deliberative dialogue was appropriate for them.
- 100% of participants agreed or strongly agreed that the deliberative dialogue was relevant to the work of their organization.
- 97% of participants agreed or strongly agreed that they would recommend CATIE continue to offer this type of event.
- 88% of participants were satisfied or very satisfied with the event, 12% were somewhat satisfied and none were dissatisfied.
- 87% of participants rated the event as useful or very useful; 13% rated it as somewhat useful and none rated it as not useful.

Secondly, the deliberative dialogue met its overall objectives.

1) Increased knowledge:

- 72% of participants agreed or strongly agreed that the first webinar increased their knowledge of the integration of T&P.
- 90% of participants agreed or strongly agreed that the second webinar increased their knowledge of the evidence-base for integrated T&P.
- 97% of participants agreed or strongly agreed that the deliberative dialogue increased their knowledge of strategic regional approaches to integrated T&P.
- 91% of participants agreed or strongly agreed that the deliberative dialogue increased their knowledge of new directions in HIV programming.

2) Increased capacity to respond:

- 91% of participants agreed or strongly agreed that the deliberative dialogue increased their capacity to respond to HIV.
- 100% of participants agreed or strongly agreed that they will use/apply the knowledge gained through this deliberative dialogue in their work.

3) Provided an opportunity to network:

- 97% reported the forum provided an opportunity to network; and

4) Provided an opportunity to explore issues and identify priorities

- 100% of participants agreed or strongly agreed that the deliberative dialogue was effective at exploring the issues related to integrated T&P.
- 88% of participants agreed or strongly agreed that the deliberative dialogue was effective at identifying priorities related to integrated T&P.

Overall, respondents were very enthusiastic with the dialogue and rated it as a very successful event:

- *One of the best meetings I've participated in-very meaningful and important discussion.*
- *....very well planned, ran perfectly and was the most productive HIV meeting I have attended...*

Participants commented on how the dialogue will inform their work:

- *Will provide updated information for clinicians on how it will effect current practice*
- *Will use several of the models used in other jurisdictions for further discussion and consideration within my jurisdiction.*

Some participants raised suggestions and concerns with the content presented and the structure of the dialogue:

- *We need more applied programmatic discussion of on the ground approaches*
- *Still no head-on presentation of the controversies associated with treatment as prevention*
- *The structure of day 2 was not conducive to discussing integration between the 4 areas*
- *Lack of clarity on how the many issues raised/points expressed will be distilled into outcomes*
- *Translation was frustrating, translators not very skilled*

5. Acknowledgements

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Appendix

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