Documenting Lessons Learned and Measuring Progress Towards Global Targets for HIV, Tuberculosis, Viral Hepatitis, and Sexually Transmitted Infections in Indigenous Communities.

Hosted by Canadian Aboriginal AIDS Network

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Table of Contents

Acknowledgements 3
Overview 4
1.0 Introduction 7
   About the Documenting Lessons Learned and Measuring Progress Towards Global HIV, TB, and Hep C Targets in Indigenous Communities Project 7
2.0 The Documenting Lessons Learned and Measuring Progress Towards Global HIV, TB, and Hep C Targets in Indigenous Communities Project 9
   Background 9
   The Health of Indigenous Peoples 9
       HIV 10
       Tuberculosis (TB) 11
       Viral Hepatitis B and C 12
       Sexually Transmitted Infections 13
   Importance and Need for the Project 13
3.0 Methodology 15
   Data Collection Methods 15
   Data Analysis 15
   A Lens for Considering the Findings: Grounding Ourselves 16
4.0 Findings 17
   Wise Practices 18
5.0 Recommendations 29

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(see Appendix 1 and 2)
Acknowledgements

As Indigenous peoples, we acknowledge our ancestors who have gone before us and left us with a long legacy of resilience and traditional knowledge that spans thousands of years. We draw on the inspiration of our ancestors to address challenges to our health and well-being for our benefit and that of generations to come.

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In particular, we thank the Indigenous people from around the world who travelled to Ottawa, Ontario, Canada and shared their knowledge and understanding about how to address the complex challenges to the health and well-being of Indigenous peoples caused by HIV, tuberculosis, viral hepatitis and sexually transmitted infections.

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Finally, we are grateful to the Government of Canada who saw the need to fund this project in the hope that it would lead to an improvement in the health and well-being of Indigenous peoples affected by HIV, tuberculosis (TB), viral hepatitis and sexually transmitted infections (STIs), not only in Canada, but throughout the world.
Overview

The Documenting Lessons Learned and Measuring Progress Towards Global HIV, TB, and Hep C Targets in Indigenous Communities Project (DLL Project) was initiated in response to the disproportionate rates of HIV, Tuberculosis (TB), viral hepatitis (including hepatitis B and C), and sexually transmitted infections (STIs) in Indigenous communities. Indigenous and non-Indigenous experts and leaders from a cross-section of health sectors came together for a three-day meeting hosted by the Canadian Aboriginal AIDS Network (CAAN) in Ottawa, Canada, to share knowledge and insights into prevention, care and support of Indigenous people living with HIV, TB, viral hepatitis, and STIs (collectively referred to as infections throughout the report). Additionally, a literature review of 107 peer-reviewed articles and reports was conducted to identify the global state of infections in Indigenous communities, as well as best and promising practices for effective health initiatives focused on Indigenous populations.

Health in Indigenous communities must be considered from a social determinants of health lens that takes into account the impacts of colonization collectively experienced by Indigenous peoples. An effective response to the disproportionate rates of infections in Indigenous populations needs to be Indigenous-led and take a wholistic approach to addressing the complex health needs of Indigenous peoples. Epidemiological data on infections in Indigenous populations is limited, however the data that we do have suggests that rates of infections are increasing in Indigenous populations, even while they are decreasing in non-Indigenous populations. Data suggests that Indigenous peoples need to be recognized as a key priority population affected by HIV and related infections and that there is a need for robust monitoring and tracking systems to gather data on rates of infections in Indigenous populations.

One of the main contributing factors to the increasing rates of infections in Indigenous communities is the lack of access to equitable health services. Access to health care is inhibited by a prevalence of stigma, racism, and discrimination towards Indigenous people and a lack of respect for the value of Indigenous knowledge. The global targets set by UNAIDS and the World Health Organization (WHO) of eliminating AIDS by 2030 and reaching testing and treatment targets of 90% by 2020 will only be successful if Indigenous peoples are meaningfully engaged in leading a response to addressing the wholistic health needs.

During the three-day meeting approximately 60 delegates from Australia, Canada, Chile, Mexico, New Zealand, Norway, Peru, Uganda, and the USA came together to share wise and promising practices with regard to programs and models of prevention, diagnosis, and tracking data. Delegates shared the following wise practices:

- Operate from a decolonized methodological framework
- Take a person-centered and whanau (family-centered) approach
- Take an integrated, wholistic approach
- Disrupt the status quo: foster a paradigm shift where health care is seen as connected to human rights and social determinants of health
Break down systemic and structural barriers that inhibit access to equitable health care
Build alliances and establish international partnerships and networks
Offer culturally responsive health care guided by Elders and Knowledge Keepers
Share knowledge and build awareness in Indigenous communities to increase prevention outcomes and reduce stigma
Deliver community-based, localized responses
Focus on advocacy work and raising awareness in society at large
Successful programs are Indigenous-led, and adequately and sustainably funded

Delegates also shared wise practices specific to monitoring and tracking data, as there is a need for robust data collection processes in order to track progress towards global targets. Given the history of exploitive research practices in Indigenous communities, before any data is collected, ethical agreements must be developed with stakeholders including consent processes, such as free, prior and informed consent, ownership, access and storage of data. Additionally, the rationale for what data is being collected and why should be made transparent. Delegates suggested specific methods and models for collecting data and noted that more quantitative data is especially needed, however it is important to contextualize numbers as even one life saved in a community is significant. It is recommended that data collection processes take a strength-based, participatory approach with realistic targets and various measures of success.

Recommendations for next steps for this work include:

I. Work collaboratively with key stakeholders to partner with current initiatives and advance the development of a global standard for monitoring and tracking data on HIV, TB, viral hepatitis, and STIs in Indigenous communities.

II. Promote national and international education and advocacy efforts to facilitate the removal of structural barriers that inhibit Indigenous peoples’ access to equitable health care.

III. Promote increased access to culturally relevant awareness-raising, testing, treatment, and continuum of care initiatives related to HIV, TB, viral hepatitis, and STIs in Indigenous communities.

IV. Promote further research and evaluation in Indigenous populations of HIV, TB, viral hepatitis and STI-related initiatives that use Indigenous and decolonizing methodologies.

V. Work collaboratively with stakeholders at the international, national, and community level to develop localized action plans for tracking, monitoring and returning data to support action on HIV, TB, viral hepatitis and STIs in Indigenous communities.
He aha te mea nui o te o
He tangata, he tangata, he tangata

What is the most important thing in the world?
It is the people, it is the people, it is the people

Maori proverb
1.0 Introduction

This section describes the Documenting Lessons Learned and Measuring Progress Towards Global HIV, TB, and Hep C Targets in Indigenous Communities project including the context and rationale for this project. Please consider this document to be a starting point in a larger international journey.

About the Documenting Lessons Learned and Measuring Progress Towards Global HIV, TB, and Hep C Targets in Indigenous Communities Project

Indigenous peoples across the globe share rich cultures with great diversity. A wholistic understanding of the self and the body, informed by ancestral knowledge is a unifying thread of connection. This wholistic understanding frames an approach to health and well being that informs prevention efforts through to end-of-life care and support. Responding to HIV, tuberculosis (TB), viral hepatitis (including hepatitis B and hepatitis C) and sexually transmitted infections (STIs) will be most effective when designed within this cultural context.

As Indigenous peoples, we experience lower health outcomes in comparison to non-Indigenous populations in the same country. This “vulnerability” to infection has not been well tended to despite efforts to address the identified disparities. Indeed, rising rates of HIV, among Indigenous populations have led to calls for innovative approaches to prevention based on Indigenous leadership, community engagement, recognition of the central role of our traditional knowledge, as well as cross-sectoral partnership building with key agencies and stakeholders. The serious challenges to our health and well-being as Indigenous peoples caused by HIV are mirrored in the high rates of TB, viral hepatitis, and STIs within our communities. Furthermore, high rates of infections among Indigenous peoples are exacerbated by higher rates of co-morbid health disparities, including addiction, heart disease, diabetes, and violence within communities.

This complexity can, in part, be understood through a social determinants of health lens. Health outcomes are the result of common drivers and factors, including socio-economic status, engagement in social and financial structures, access to health infrastructure, education and housing, and respect for gender and culture. Within an Indigenous context, the determinants of health must also consider the historic and ongoing impacts of colonization, racism, discrimination, and lack of respect for cultural expression. The “vulnerability” of Indigenous peoples to infections reflects a failure to work wholistically and respectfully with Indigenous peoples towards an adequately funded Indigenous-led response.

At its root, the impact of HIV/AIDS on Indigenous peoples relates to colonization, racism, oppression, resource alienation, and systemic exclusion from research, policy, and program decisions that impact health and well-being.


The UNAIDS and World Health Organization (WHO) have declared global HIV strategies and targets to eliminate AIDS by 2030. Recently, the UNAIDS Fast-Track to End AIDS Strategy calls to action accelerated efforts to end AIDS and reach the 90-90-90 treatment target by 2020 (UNAIDS, 2015):
By 2020, 90% of all people living with HIV will know their HIV status;
By 2020, 90% of all people diagnosed with HIV infection will receive sustained antiretroviral therapy, and;
By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression.

Although current surveillance and epidemiological data with respect to HIV, TB, and Hep C in Indigenous populations is limited, the data that does exist suggests that rates are higher among Indigenous populations compared to non-Indigenous counterparts (PHAC, 2015; PHAC, 2016; Trubnokov, Yan & Archibald, 2014). As such, there is a need to fill gaps in documenting and sharing knowledge regarding global commitments, and to accurately survey and monitor progress towards global targets among Indigenous peoples.

The Documenting Lessons Learned and Measuring Progress Towards Global HIV/TB/Hepatitis C Targets in Indigenous Communities (hereafter referred to as the DLL Project), responds directly to the alarming rates of HIV, TB, viral hepatitis, and STIs among Indigenous peoples in Canada and throughout the world. The DLL Project, hosted by the Canadian Aboriginal AIDS Network (CAAN), began on March 1st, 2017 and brought together international delegates to share wise practices and models, develop recommendations, and brainstorm on evaluative and monitoring systems. The summarized objectives of the project were:

1) To identify and document best and promising approaches and models for a more comprehensive response to HIV, TB, viral hepatitis and STIs amongst Indigenous populations;
2) To foster knowledge transfer between stakeholders through sharing lessons learned for translating promising models into effective policies and programs;
3) To strengthen relationships with key partners and stakeholders to inform and enhance global responses to these infections amongst Indigenous peoples;
4) To identify areas, including concrete recommendations, for advancing work towards global targets on each of these infections, and
5) To include ways of strengthening monitoring and evaluation systems to track results of the global targets.

To meet these objectives, Indigenous and non-Indigenous leaders experienced in health programming shared knowledge and insights on prevention, care and support of people living with these infections. An analysis of the data that emerged from the international Indigenous Policy Dialogue was used to inform the recommendations of this project. These recommendations, which can be found in Section 5, were designed to inform action plans and programs of stakeholders who work with Indigenous peoples affected by HIV, TB, viral hepatitis and STIs.

1 International delegates included Indigenous peoples, policy analysts, program developers and researchers.
2.0 The Documenting Lessons Learned and Measuring Progress Towards Global HIV, TB, and Hep C Targets in Indigenous Communities Project

Background

Indigenous peoples make up a significant portion of the world’s inhabitants, accounting for almost five per cent of the world’s population. We live in 70 different countries, with more than two thirds of Indigenous peoples living in Asia. As Indigenous peoples, we represent a rich tapestry of languages, cultures, and traditions that derive from many generations of strong and enduring attachments to particular geographical locations. Some Indigenous nations have lived for many thousands of years in the same location, such as Indigenous Australians whose origins go back 60,000 years.

While no international definition of “Indigenous” exists, throughout the world, we are identified by a number of common characteristics that include:

- A history that pre-dates colonization
- Strong and enduring attachment to ancestral lands, territories, and resources
- Distinct languages, cultures, and traditions
- Recognition as non-dominant groups within society
- Determination to maintain ancestral knowledge and traditions.

The World Health Organisation’s (WHO) definition of health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity provides an important starting point from which to address and overcome the health disparities experienced by many of the world’s Indigenous peoples.

The United Nations Permanent Forum on Indigenous Issues

Indigenous peoples have sought recognition of their identities, way of life and their right to traditional lands, territories, and natural resources for years, yet throughout history, their rights have always been violated. Indigenous peoples today, are arguably among the most disadvantaged and vulnerable groups of people in the world.

The Health of Indigenous Peoples

For thousands of years, as Indigenous peoples, our health and well-being has depended on traditional methods of care and support. Despite living in harmony with the land and flourishing over thousands of years, today we confront serious challenges to our health and well-being. On almost all health indicators, we experience significant disparities compared to our non-Indigenous counterparts. In response, many of our Indigenous healing systems incorporate western biomedical practices into our systems of care, while continuing to draw on traditional healing practices. The demand to include people living with these infections in decisions and policy that impact their lives and treatment options reflects Indigenous community expectations for self-determination. For some, living with or having lived with these infections became a turning point in their lives for the better, as serious illness helps to push open doors to health services and to cultural care that had not be previously been accessed. The following section describes rates of HIV, TB, viral hepatitis, and STIs in Indigenous populations globally and some successful initiatives used to address the disproportionate rates of infection.
**HIV**

In 2018, almost four decades into the HIV epidemic, it is apparent that we are among those populations that have borne the brunt of HIV and its impact on individuals, families and communities. From the beginning of the AIDS epidemic, Indigenous peoples have been identified as a population group at risk of HIV infection (Te Puni Kokiri, 1994; Orellana et al., 2013). Due to the disproportionate impact of HIV on Indigenous peoples, there have been calls at multiple national and international levels for Indigenous peoples to be recognized as a key priority population group affected by HIV. This recognition leverages increased access to international supports and prioritizes support for the population group as a whole, with emphasis on dialogue between all stakeholders to develop a meaningful and effective response.

In 2010, the Report of the 5th International Policy Dialogue in Canada recommended that Indigenous peoples be recognised as a priority group affected by HIV, while also calling for Indigenous peoples to be integrated into international HIV prevention strategies. The report also called for a better integration of Indigenous peoples into the international response to AIDS as a whole. (Health Canada, 2010). Six years later, this appeal to the international community was reiterated by the United Nations Permanent Forum on Indigenous Issues (UNPFII) in their report to the UN in which they noted that, “[m]any countries have done nothing to specifically address HIV issues in their Indigenous peoples, while a small number of countries have embarked on small-scale initiatives.” (Permanent Forum on Indigenous Issues [PFII], 2006, p.5). The UNPFII report also called on countries to implement robust epidemiological data collection systems to monitor HIV rates among Indigenous populations. In those countries with robust epidemiology collection processes, it is essential and highly beneficial to include ethnic identifiers for Indigenous peoples. However, apart from well-resourced countries, such as Australia, Canada, New Zealand and the US, few countries have systems in place for the collection of Indigenous HIV data. Even within these countries, the quality of the data is not always reliable, and readers are reminded to interpret the findings with caution.

In countries where data are available, distinct and entrenched HIV disparities exist between Indigenous and non-Indigenous peoples. A recent comparative study of HIV data in Australia, Canada, New Zealand showed that Indigenous peoples in the three countries were disproportionately affected by HIV (Shea et al., 2011). Indeed, in some countries, notifications of HIV among Indigenous populations are increasing at an alarming rate, while those of their non-Indigenous peers are decreasing. In Australia, for example, rates of HIV notifications among Aboriginal and Torres Strait Islander people increased by 33% in the five years leading up to 2016 and decreased by 22% among non-Indigenous Australians during the same time period (Kirby Institute, 2017). Given the vulnerabilities to poor health experienced by Indigenous peoples, similar disparities are likely to be experienced by Indigenous peoples in other parts of the world (Gracey & King, 2009).

Research regarding HIV and Indigenous peoples has historically focused on risks and vulnerabilities, rather than exploring our strengths and factors that protect us from HIV and support us to live a good life with the virus. Accordingly, decades of research on Indigenous peoples and HIV has done little to stem the transmission of HIV within our communities. A review of the published literature over the last two decades has highlighted that Indigenous people affected by HIV have built up a distinct distrust of health services, with this being a major contributing factor for poor HIV-related health outcomes among our people in many parts of the world (Negin et al., 2015).
Indigenous people have been the subject of pathologizing research. Looking at our deficits, itemizing our vulnerabilities. Indigenizing research means focusing on our resilience, looking forward. ~ Doris Peltier, National Coordinator of Visioning Health.

Tuberculosis (TB)

TB is one of the top ten leading causes of death in the world. In 2015, more than 10 million new cases of TB were reported, with more than 10% of all cases reporting an HIV co-infection (WHO, 2016). As with many diseases that affect Indigenous peoples, it is difficult to arrive at a complete understanding of the impact of TB on Indigenous populations globally. In many parts of the world, the lack of robust data collection systems means that the true impact of many diseases, including TB, remains unknown. For example, in Asia where an estimated three quarters of the world’s Indigenous people live, only India collects TB data and records Indigeneity (Tollefson et al., 2013).

Tollefson’s (2013) systematic review of the burden of TB among Indigenous peoples globally included 91 articles, with just over a third of which were from Australia, Canada, New Zealand, and the US. From the evidence available, Indigenous peoples have higher rates of TB than their non-Indigenous counterparts in many parts of the world (Tollefson et al., 2013). This systematic review found the highest incidence and prevalence rates in the Amazon region, and among select Indigenous populations in South East Asia and Africa. Incidence rates of TB among Maori and Pasifika people in New Zealand were higher than those of Indigenous Australians. Inuit (Indigenous people in the Northern parts of Canada and Alaska) had the highest rates of TB among all Indigenous peoples in North America. In Canada, the Federal Government and Inuit have launched a task force to examine the TB crisis across Inuit Nunangat (Inuit regions in Canada) as among Inuit the rate of the lung disease in 2015 was more than 270 times higher than the rate among Canadian-born non-Indigenous people. Overall, Indigenous peoples in all countries reviewed were at higher risk of TB, with this indicating an urgent need for the design and implementation of robust TB surveillance systems internationally.

Remote locations provide significant challenges for health service responses to the health and well-being of Indigenous populations. In Australia, the Philippines, and Canada, innovative interventions have been successful in meeting challenges related to TB. In Australia, a centralized reporting system has proven to be successful in identifying Indigenous communities with elevated risk of transmission (Barry et al., 2012). In the Philippines mobile screening for TB has been effective in increasing the number of cases detected among Indigenous peoples (Morishita et al., 2017). And in Canada, where Inuit have the highest reported rates of TB of all Indigenous peoples, information technology involving teleconference has proven highly successful in increasing access to health services for Indigenous people in remote locations, while recording high levels of patient satisfaction (Mashru et al., 2017).

High rates of TB among Indigenous peoples have also been reported in many parts of Latin America and the Caribbean (Tollefson et al., 2013). A study of 26 countries in Latin America and the Caribbean with robust data collection processes demonstrated that higher TB mortality rates were recorded among Indigenous peoples than among non-Indigenous peoples. In order to address these disparities, the study called for the urgent implementation of actions that focus on the determinants of health related to social, economic, environmental, and health services. In particular, policies that address poor sanitation, low literacy rates, poor nutrition, and enhanced access to clean water for Indigenous peoples are likely to lead to an improvement in TB-related health outcomes.
Viral Hepatitis B and C

Viral hepatitis (hepatitis B and C virus) caused the deaths of 1.34 million people in 2015; similar to the number of deaths caused by TB (1.4 million), and more than the number of deaths caused by either HIV or malaria (World Health Organization, 2018). Viral hepatitis contributes to higher rates of liver cancer for anyone currently living with or who has lived experience with the infection (i.e. cured). There is evidence that comprehensive hepatitis management plans can provide a cost-effective means of reducing the incidence of liver cancer (Anderson et al., 2016).

Research has shown that an increase in vaccination rates can contribute to a decline in rates of hepatitis B, with one example of a successful initiative in Australia being the Deadly Liver Mob Project (DLM) (Biggs et al., 2016). While the DLM Project focused on hepatitis C and offering education and screening for STIs and blood-borne viruses (BBV), it also led to an increase in the number of Indigenous Australians who were vaccinated for hepatitis B. Programs such as these illustrate the importance of designing and providing a comprehensive approach to preventing STIs, hepatitis C, and hepatitis B. The DLL project focused specifically on HCV (hepatitis C) and HBV (hepatitis B) in meeting discussions and data gathering.

Hepatitis C

In many parts of the world, Indigenous peoples have higher rates of hepatitis C than non-Indigenous peoples. In North America and Australia, where data is available and efforts are underway to advance access to testing, care, treatment and cure, Indigenous people experience higher rates of hepatitis C, with injecting drug use being a major risk factor for transmission of HCV (Craib et al., 2009; Graham et al., 2016; Hossain et al., 2014; Parmar et al., 2016; Rempel & Uhanova, 2012). In 2016, the rate of HCV diagnoses in Indigenous Australians was almost four times as high as the rate of the non-Indigenous population (Kirby Institute, 2017). Indigenous peoples make up approximately 3% of the population in Australia, yet represent 20% of all HCV notifications, and these rates are rising. Recent research has shown that these high rates of exposure to HCV among Indigenous Australians are likely due to higher rates of incarceration and opioid injection (Doyle et al., 2017).

Internationally, factors that place Indigenous populations at greater risk of HCV infection include unsafe injecting practices among people who inject drugs (PWID), and lack of access to culturally appropriate health services. Measures to prevent the ongoing transmission of HCV within our Indigenous communities include outreach programs, ensuring access to culturally appropriate harm reduction services where PWID are not subjected to stigma and discrimination, and the provision of knowledge about hepatitis C, combined with ensuring easy access to testing and treatment. The advent of new direct-acting antiviral (DAA) therapy for hepatitis C has made it possible to cure as many as 95% of cases and has led policy makers and clinicians to set targets to eliminate viral hepatitis by 2030 (including HBV and HCV).

Despite the availability of a new therapy, however, significant barriers to eliminate HCV continue to exist, with these being particularly pronounced for Indigenous populations. In order to achieve elimination of HCV, there would need to be improved point-of-care diagnosis, better treatment options for children and pregnant women with HCV, improved access to DAAs, increased awareness of and the elimination of stigma, as well as the development of a sustainable financing models as part of universal health coverage (Editorial, The Lancet, 2017). The low rates of treatment uptake by PWID makes elimination of HCV difficult (Iverson et al. 2014). Demonstrating promise however, is the work being done in Australia, a country leading the way to end hepatitis C with their proactive approach. Since March 2016-2017,
Australia has provided low-barrier treatment to approximately 38,470 Australians living with HCV (17%), of which many have been cured (The Kirby Institute, 2017).

**Hepatitis B**

Studies have found that rates of hepatitis B are high among Indigenous populations in geographically distant locations. For instance, in the Republic of Sakha (Yakutia) in the Russian Arctic, Indigenous people experience high rates of hepatitis B (Sleptsova & Borisova, 2015). In the Arctic regions of Canada and Greenland, prevalence rates are especially high among Inuit, although incidence rates have declined due to child HBV vaccination programs. In the southern hemisphere in New Zealand, Maori experience similar disproportionately higher rates of HBV compared to non-Maori (Lim et al., 2015). In Australia, notification rates of HBV were found to be as much as three times higher among Indigenous peoples than non-Indigenous peoples (Wattiaux et al., 2016), however the authors note that a ten-year vaccination program could lead to the prevention of more than 500 cases of hepatitis B in Australia. Additionally, hepatitis B has been found to be the leading cause of chronic liver disease in Latin America. Research into genotypes of hepatitis B has shown that genotype H is prevalent among the Indigenous populations of Mexico, and genotype F is prevalent among the Indigenous peoples of Central and South America; this is particularly important as these two genotypes have been found to cause liver disease, with no additional complications (Roman et al., 2014). These complexities illustrate some of the challenges associated with providing appropriate prevention and clinical responses to the high rates of hepatitis B among Indigenous populations in Latin America.

Indigenous peoples in remote locations are further disadvantaged by the lack of culturally relevant information and access to appropriate health and social services, which consequently exposes our communities to an increased risk of infections such as hepatitis B. In response to these challenges, a study in Northern Australia found that health outcomes of Indigenous people with hepatitis B were enhanced when their Indigenous culture was incorporated into the health information that was disseminated to them (Davies et al., 2014). An additional study from Australia found that Indigenous peoples have high susceptibility to hepatitis B, and that significant benefits would derive from providing access to culturally relevant testing and vaccination (Harrod et al., 2014). Inclusion of culturally relevant information and testing ought to be complemented with a comprehensive public health program, which includes the development of clinical guidelines and workforce training and development (Wallace et al., 2014).

**Sexually Transmitted Infections**

While global data are incomplete or non-existent regarding STIs, available data show that prevalence rates of STIs are increasing and that these rates are higher among Indigenous peoples than non-Indigenous peoples (Kirby Institute, 2017; Minichiello et al., 2013). These disparities, combined with significant gaps in knowledge, indicate the urgent need for the implementation of robust surveillance systems globally to monitor rates of STIs among Indigenous peoples (Ward et al., 2013), and the need to design culturally responsive programs to reduce rates of infections and raise awareness (Ward et al., 2014).

**Importance and Need for the Project**

As Indigenous people, we still share common challenges, including our history of colonialism and neocolonialism that has led to significant inequities for Indigenous people globally. Overwhelmingly, the people who contributed to this DLL Project reported that, more than 30 years into the AIDS epidemic,
Indigenous peoples continue to experience stigma, discrimination and racism from health services and from the people who work in them. A prevailing climate of stigma and discrimination in HIV health services has been identified as a principal cause of poor access to services for Indigenous peoples. As the care continuum begins, access to testing is an important plank in the strategies to prevent the transmission of infections. Testing for infection, and the provision of early access to treatment are essential elements of efforts to bring the AIDS epidemic to an end and to eliminate Hepatitis C. Because of poor access to health services, Indigenous peoples are less likely to know their HIV or HCV status, meaning that they are less likely to receive early and timely treatment for HIV and curative treatment for HCV. Ultimately, poor access to HIV services will serve to undermine international targets to end HIV by 2030. The 90-90-90 targets set by UNAIDS are based on the data of people for whom access to health services exists – a person must be engaged to be counted. If Indigenous peoples do not know their HIV status because of poor access to services they are more likely to fall into the 10-10-10 rather than the 90% targets to end AIDS by 2030. The world will only meet its global targets by 2030 with the meaningful engagement of Indigenous peoples and an Indigenous-led response.

*We need to keep at the forefront, Indigenous people as a priority. We need to have an integrated approach and integrated models of services. It’s about ensuring there is health equity for Indigenous people around the world who are faced with colonial challenges in their own countries.*

Together, with this report, we are working to set the stage for a unified voice and to share practices and learn from each other, so that we are not left behind.

*I think if you are talking about the global targets of 90-90-90, Indigenous people end up being the 10-10-10. There are health equity issues around the world for Indigenous people, and so many levels of barriers. So, these international connections between Indigenous people end up being very powerful. The overall intent of the project is a valuable one—focusing on best practices and approaches, and bringing those voices to decision makers, like UNAIDS.*

**DLL Technical Team Member, 2017**
3.0 Methodology

Data Collection Methods

This report is based on data collected from three principal sources. These include a comprehensive literature review, data collected at a three-day face-to-face International Indigenous Policy Dialogue in Ottawa, Ontario, Canada in July 2017, as well as a number of meetings by teleconference prior to the meeting. Detailed notes were taken at the face-to-face meeting and the teleconferences. As well, the writer conducted interviews with a number of key informants leading up to and following the in-person meeting.

Approximately 60 people participated in the face-to-face meeting which was structured in a way that allowed delegates to contribute in both plenary sessions and small group workshops. The invited delegates at the meeting came from Australia, Canada, Chile, Mexico, New Zealand, Norway, Peru, Uganda and USA. Delegates spoke their Indigenous language in some cases, and the colonial languages Spanish, English, and French. The meeting was conducted in English with interpretation services provided on-site. All printed materials were offered in English, Spanish, and French. A cultural exchange and banquet was hosted to celebrate the work and opportunity to meet together.

International Indigenous and/or allied leaders in the country from which they came, as well as delegates who are seen as content experts that work closely with Indigenous communities were selected and invited to attend the three-day International Indigenous Policy Dialogue. People brought a range of health-related experience gained from working in community health services, community-based organizations, policy agencies, research, as well as government decision-making processes. Many of the delegates at the meeting had strong community affiliations in a range of locations. These included Elders, community-based health professionals, people living with HIV, TB, STIs and viral hepatitis, care and support workers, and youth leaders, each of whom described the key role that they played in providing community-based HIV services and support. This reflects the range of voices that are needed when articulating and implementing the response of communities to targets set by international agencies.

During the course of the three-day meeting, delegates were invited to discuss the following questions:

1. *What practices, programs, models of prevention and diagnosis work?*
2. *What are the key ingredients that make the practice, model, program successful?*
3. *How feasible is it that these models / approaches will work in your region?*
4. *How can they be adapted to fit the needs of your region?*
5. *What are the strengths and areas of weakness in the area of HIV, Hep C, TB, and STI prevention/diagnosis?*
6. *How do you measure and track progress in the work that you are doing?*

Data Analysis

Discourse analysis, using a conceptual framework based on intersectionality, was used to identify key themes that emerged from the meeting’s data sources which informed the findings and recommendations of this report. The application of an intersectional analysis made it possible to take into account variables such as indigeneity, resilience, colonization, racism, access, gender, sexuality, culture, stigma and discrimination, and the impact that these have on our health. While the analysis of the data sought to
understand both the negative and positive impacts of these variables on the lives of Indigenous peoples affected by HIV, TB, viral hepatitis and STIs, greater emphasis was given to the positive factors that contribute to effective prevention, and care and support for people living with these infections. Accordingly, in order to make sense of the qualitative data, the findings are structured in a way that explores the role of community, health systems, Elders, and Indigenous knowledge play in the lives of Indigenous peoples.

A Lens for Considering the Findings: Grounding Ourselves

Participants at the three-day meeting noted that there is a level of anxiety due to being over-researched and having health concerns continuously overlooked, and noted the utmost importance that this report reflect and be grounded in:

- Culture
- Indigenous worldviews
- Indigenous ways of knowing and teachings.

One participant highlighted the importance of grounding this report in Indigenous worldviews and culture by stating that much of the qualitative research that currently exists does not necessarily reflect Indigenous peoples’ stories and knowledge. In fact, oral ancestral knowledge may appear to be unrecognized by western knowledge systems. As such, the importance of including Indigenous ways of knowing shared through oral histories, ceremonies, spiritual experiences, and dreaming for example, as valid knowledge, cannot be understated.

Participants also noted the importance of shifting the focus to a strengths-based model that acknowledges the resilience and strengths of Indigenous peoples living with communicable diseases and away from what has predominantly been a deficit-based model. While the importance of taking a strength-based approach ought to be central to the framework, discourse on communicable diseases among Indigenous peoples internationally cannot occur without contextualizing root causes that have and continue to increase the risks among our people. As such, the importance of contextualizing the current state of communicable diseases among Indigenous peoples internationally by naming colonization is of critical importance. Participants shared that this report reflects our collective relationship with colonization as Indigenous peoples internationally, noting:

- Colonization is a social determinant of disadvantage.
- HIV and AIDS are our second colonizer, so it is important for Indigenous people to unite.
4.0 Findings

Participants at the three-day meeting shared an abundance of wise and promising practices across the continuum of care for those living with HIV, TB, viral hepatitis, and STIs, as well wise and promising practices for tracking and measuring progress.

For the purposes of this report, a wise or promising practice is one that has produced outcomes that are of real benefit to Indigenous peoples and communities affected by HIV, TB, viral hepatitis and sexually transmitted infections. In order to understand the nature of these wise practices, Indigenous experts from Australia, Canada, Chile, Mexico, New Zealand, Norway, Peru, Uganda and USA were invited to provide examples of promising and wise practices from their experiences. The core components of assessing wise practices focused on:

- The elements of the promising or wise practice.
- The impact at the community level.
- The lessons learned from the promising or wise practice.
- The transferability of lessons learned to other locations.

Participants identified a range of key elements that underpin best practices in prevention, care and support of Indigenous peoples affected by the infections relevant to this report. The most important element identified by participants was the Indigenous foundation of the practice. Qualities such as Indigenous leadership, practice and processes based on Indigenous knowledge, and Indigenous culture were considered to be essential elements of an Indigenous-led program. Participants explained that in their experience, Indigenous-led programs were more likely to produce beneficial outcomes.

Other elements included a family-centered approach to the design and delivery of services with a strong focus on the Indigenous social determinants of health and an understanding of how these impact on the lives of Indigenous peoples. Importantly, an understanding of how colonization affected the lives of Indigenous peoples was considered to be fundamental to responding appropriately to the health and social needs of Indigenous peoples.

Increasingly the concept of evidence-based practice and decision making has gained momentum. Evidence-based practices are methods or techniques that have documented outcomes which are readily replicable and transferable to other locations. Community-defined evidence is defined as “a set of practices that communities have used and determined to yield positive results as determined by community consensus over time and which may or may not have been measured empirically but have reached a level of acceptance by the community.” Some communities have deployed practices over a long period of time that have produced positive outcomes as well as a general community support and approval.

The following provides a detailed summary of the key elements of promising and wise practices identified by participants at the three-day meeting in Ottawa, Ontario, Canada in 2017.
Wise Practices

Cultural responsiveness and Elder engagement

Participants shared the importance of culturally responsive practices in the field of HIV, TB, viral hepatitis, and STIs. This includes the involvement of Elders and knowledge keepers, engaging and empowering community leaders and leadership, and working with a cultural framework that embodies Indigenous teachings and values. Some participants noted that wise practices include tailoring messaging such that they are culturally appropriate and geared to the realities of Indigenous communities. For instance, one delegate spoke about condom culture and the importance of focused messaging, explaining that Indigenous men were not receptive to the messaging, and different messaging was needed for gay Indigenous men.

Indigenous knowledge and teachings is an ancestral gift that can be used in a way that generates beneficial outcomes and contributes to the health and well-being of Indigenous communities today. As holders of ancestral stories, Elders are well placed to provide regular and ongoing access to traditional knowledge of Indigenous communities to inform the work of health services and to ensure culturally safe responses to the health needs of Indigenous peoples. Elders are important as they carry with them knowledge of traditional ways, ceremonies, stories, and teachings; they are embody spiritual and cultural leadership and play an active role in supporting community wellness (Stiegelbaur, 1996). Community protocol must be learned regarding customs for how an Elder is asked to share their knowledge and perhaps support a person or group of people. When protocol is respectfully completed, ongoing consultation with Elders should underpin the design and implementation of health services for Indigenous peoples. Participants in this project identified a range of key roles played by Elders within Indigenous communities including:

- Facilitator of cultural ceremonies
- Holders of ancestral knowledge
- Mediators
- Healers
- Activists
- Educators
- Guides
- Health care providers
- Historians

Elders also play an important role in supporting strategies to eliminate infection-related stigma and discrimination in Indigenous communities. One participant spoke about work in their region where female Elders teach youth about the old ways of knowing, de-stigmatizing Indigenous sexuality, and undoing Catholic influences that caused stigma and shame about sexuality. In this region, the Elders and youth worked to take back ancestral culture, based on good living and living in balance. Together, the Elders and youth spoke about awareness, testing, and treatment.

As Indigenous communities strive to confront and overcome the challenges associated with HIV, viral hepatitis, TB and STIs, it is important to ensure that decision-making and strategic direction setting are based on a combination of both ancestral and western knowledge systems. Traditional knowledge must be respected as equally valuable as western knowledge. As one participant stated, “Our Elders are adamant that our Indigenous ways and knowledge must not be subordinated to the dominant knowledge
systems.” The reclamation of ancestral knowledge and traditions is seen as fundamental to overcoming the infection-related health challenges that confront Indigenous communities today.

**Operating from an Indigenous and decolonized methodological framework**

Participants at the three-day meeting identified **centering work in the field of HIV, TB, viral hepatitis, and STIs in Indigeneity** and **recognizing ancestral knowledge and traditional medicines** as a wise practice. One delegate shared that in Africa, they use herbal medicines and spirituality to address concerns, as the soul and community is involved. This delegate explained that there are five plants that have antiviral properties for TB, E-Coli, and Staph infections.

In operating from decolonized lens, an **Indigenous worldview** is paramount; taking an Indigenous approach is a wise practice because the traditional clinical model does not necessarily address individuals holistically. Participants in this project agreed that all health-related programs that target Indigenous peoples must be **informed by Indigenous knowledge and concepts**. In South America, one delegate spoke about metaphors and visual aides for working with clients around sexual health. Another delegate spoke about the spirit of HIV, and the need **nurture it to health** in a wholistic manner. Furthermore, centering health work on Indigenous pedagogical and ontological worldviews involves centering Two-Spirit (and other LGBTQ+ Indigenous) voices to lead the work that needs to be done to address the needs of those affected by HIV and AIDS, TB, viral hepatitis, and STIs. By centering Two-Spirit, and other LGBTQ Indigenous voices, it instills cultural pride, and positive self-esteem.

Participants explained that mainstream models can no longer be the model of choice for Indigenous people, and we need to speak for ourselves, and no longer be spoken about, citing the importance of **“nothing about us, without us.”** As an example, many delegates made reference to the 90-90-90 targets set by UNAIDS, which are intended to bring the AIDS epidemic to an end by 2030. As noted by delegates, the design of these targets occurred without any consideration of the particular health needs of Indigenous peoples. Indigenous delegates recommended more realistic targets that would take into account the complex health concerns of Indigenous communities, adding that this should be done with proper and respectful consultations. Many community members fear that Indigenous peoples will find themselves in the 10-10-10, excluded from achievements the 90-90-90 targets are meant to reach. Indigenous peoples with relevant knowledge and experience must be invited to participate in global consultations by UN agencies and other bodies working internationally to develop recommendations. An **Indigenous-led cultural framework is required** to adequately address the issues. Groupings of national and international Indigenous people must be supported financially and through policy development that engenders a cohesive, culturally respectful response.
Combining a person-centred and Whanau (family-centered) approach

A person-centered approach, in which individuals are encouraged to choose treatment and care options that best suit their needs and preferences, is another wise practice shared by participants. The Greater Involvement of People living with AIDS (GIPA) principles that drive HIV initiatives can be applied to the health services related to TB, viral hepatitis, and STIs. Similarly, the harm reduction movement that introduced the “nothing about us without us” approach (identified above) highlights that it is absolutely imperative that Indigenous key subpopulations are actively engaged in decision-making and the design and delivery of initiatives targeting Indigenous peoples. The lessons learned from the HIV and harm reduction sectors have applicability across multiple domains and efforts must be made to ensure that people affected by these illnesses benefit from the insights of people who are currently living with or have lived experience with these infections. Recognition and engagement of Indigenous people living with infections and their families are essential for enhanced health services that provide ready and regular access to health supports. People with experience have much to offer in relation to infection prevention, care and support. As people who have first-hand living and lived experience of the infections, they bring expertise, skills and personal experiences to program initiatives.

Delegates noted that wise practices include:

⇒ Informing clients about their options beyond western treatment,
⇒ Offering both western and traditional healing options, or a blended model.
⇒ Respecting the individuals’ wishes, and
⇒ Empowering self-determination.

The importance of taking a family-centered approach was identified as a promising practice by delegates; they noted, “there is a failure within the current system. There is a lack of care for those who surround the individual (i.e., immediate caregivers and community). They need support as well.” As such, it was explained that any post-prognosis care and information involves the family, as the whole family is impacted by a diagnosis. The Maori term “Whanau” encompasses family-centered wellness.

Taking an integrated wholistic approach

Participants at the three-day meeting stressed the importance of acknowledging that HIV is not in isolation of the social determinants of health (SDH) or from other infections (i.e., viral hepatitis, TB, STIs). Participants noted that promising practices include integrated and wholistic approaches, whereby the
multitude of needs, and health conditions are addressed together. One delegate explained, “The health concern is complicated; there’s an interconnected nature of communicable diseases, and the root causes are all interrelated. The continuum of care is also complicated; prevention, diagnosis, treatment, and aftercare are all interrelated. We need flexibility, there is no one-size fits all model.”

It was noted that wise practices include creating accessible spaces that are ‘one-stop shops.’ One-stop shops provide information, options, and testing, that is accessible and meets people where they are at. Mobile outreach, in conjunction with one-stop shops were noted as a wise practice. An integrated wholistic approach ensures wholistic care that addresses the complex, interrelated health needs of Indigenous people and is a mechanism to close the loop across the continuum of care.

Given that Indigenous people affected by infections carry a disproportionate burden of chronic diseases, health service providers that provide comprehensive services, including those for HIV, TB, viral hepatitis and STIs, could be well placed to serve the needs of Indigenous communities. Such integrated services are best placed to respond to the multiple and complex demands posed by a range of illnesses, including HIV, TB, viral hepatitis, and STIs.

Disrupting the status quo

Participants noted that Western health systems are often dysfunctional in terms of prevention in Indigenous communities. Participants explained that there is a burden of wellness on those who are ill, and the solution is often to simply take a pill rather than looking at the bigger systemic issues. At the three-day meeting, participants identified the need for a paradigm shift, where a human rights and intersectional approach is taken. This includes:

- No longer focusing solely on conservative medicalization.
- Acknowledging that HIV is connected to human rights and the social determinants of health, and dealing with associated environmental and contextual factors
- Acknowledging the intersectionality of public policy, global engagement, knowledge sharing, and community systems.
- Creating systems of continuity, where the intersectionality between health, sexuality, and human rights are acknowledged (i.e., addressing the sexual life and sexual diversity among Indigenous populations). Historically, trans and two-spirit people have held esteemed positions within Indigenous communities but within contemporary society, this preeminent status has been undermined by colonial efforts to homogenize Indigenous people into a mirror image of settler states from which the colonizers came.

HIV is both a cause and consequence of poverty and stigma. Stigma and discrimination with HIV remain barriers to achieving global targets and testing. There remains institutional racism impacting the HIV disparities. Stigma plays a large role in not accessing and receiving treatment.

DLL Participant, 2017
Breaking down barriers to improve access to testing and treatment

Across the board, there was general agreement that current health services are inadequate and unresponsive to the needs of Indigenous people living with infections and those communities and families affected. Available health services are often beset by systemic problems which expose Indigenous peoples to ongoing stigma and discrimination, with this being exacerbated by staff who are poorly trained in providing appropriate care and support to Indigenous patients. Viewing this context through a colonial lens, the legacy of mistrust of institutions and systematically poor or non-existent access to services are major contributing factors that account for the high rates of late testing and delayed treatment among Indigenous peoples. This in turn contributes to poor health outcomes and higher mortality rates among Indigenous populations compared to their non-Indigenous counterparts. In order to improve access to testing and treatment services for Indigenous peoples, it is essential that:

- Resources are dedicated to the implementation of culturally responsive health services
- Health services are provided in a manner that is culturally responsive and respectful of the particular health and social needs of Indigenous peoples
- Staff are trained to respond appropriately to the multiple health and social needs of Indigenous peoples affected by infection(s)
- Services engage with multiple community stakeholders, including Elders, young people, and community leaders
- Health services provide point-of-care testing
- Health services are aligned with community priorities
- Health services ensure that people who are living with or have lived experience with infection are actively engaged as leaders in the provision of service
- Adequate and dedicated resources are allocated to the provision of accessible services Indigenous people living in remote locations (i.e. mobile clinics)

By working in partnership with health services, Elders can play a key role in disseminating and sharing information about the health and social needs of people affected by infections. Processes such as this also serve to play an important role in prevention programs. In addition to Elder involvement, it is essential that services engage with youth to ensure that their needs and concerns are taken into consideration and factored into programs for youth. Youth must be engaged as leaders and must be provided with mentoring opportunities so that they can participate in the design and implementation of prevention and care programs.

Building alliances and establishing international connections and networking

Since the beginning of the AIDS epidemic, Indigenous peoples have achieved some notable successes in their efforts to build and develop international networks, partnerships and alliances. Participants at the Ottawa meeting described the importance of these alliances, not only internationally, but also in the countries and communities from which they came. Global partnerships have been instrumental in helping to establish and build national initiatives, but delegates agreed that more work needs to be done in this area. Meetings such as the International Indigenous Policy Dialogue were noted as a promising practice, as it provides for opportunities to share wise practices over international borders. What delegates, experts, and leaders share may link to other programs and provide opportunities to work in partnership to leverage strengths and resources. Establishing international connections and utilizing them was noted
as a promising model. For instance, delegates noted the influence Indigenous leaders can have by sitting on international boards, agendas, and groups, such as International AIDS Conference (IAC), UN Permanent Forum, and UNAIDS; these provide a platform for advocating for global forums to focus on Indigenous issues.

Participants also spoke about promising practices in which larger organizations (i.e., UNAIDS, PAHO) support communities and countries to achieve goals at the grassroots level by working together. This would involve working together with leadership and larger organizations acting as motivators, connectors, and conveners who bring people to the table and create space for dialogue to occur.

Again, building on the experience of the HIV community, delegates stated firmly that national governments must continue to support local networks and initiatives that contribute to an enhanced presence of Indigenous peoples within international networks and at international infection-related events. Examples include international conferences, UN sessions specifically regarding AIDS, and more broadly, the Indigenous Peoples Forum, World Health Organization initiatives, and regionally coordinated bodies such as SIPIA and PAHO.

In order to benefit fully from being part of an international network, it is important to know and understand the operational and policy frameworks of international agencies such as WHO, UNAIDS, the Stop TB Partnership, and other international agencies working in the areas of HIV, TB, viral hepatitis and sexually transmitted infections. National Indigenous groups should be kept apprised of the policies and practices promoted by international organizations.

Similarly, several examples of HIV policy documents written by Indigenous peoples were referred to at the face-to-face meeting. These included the Toronto Charter, an Action Plan for Indigenous Peoples and HIV and AIDS (2006), the IIHAC Ten-Point Statement (2017) and the IIWGHA Strategic Plan, 2011 to 2017. Delegates described how important it is to ensure that national and international infection-related strategic documents align closely with the principles of documents such as these. Strategic documents are often produced in tandem, but are not integrated with each other. Delegates agreed that this was an important first step towards working strategically with international agencies.

*Participating in global forums, policy dialogues, and roundtables opens doors and increases the profile of Indigenous people as key affected populations. Success is due to international networking, coalition building and global partnerships. It’s about bringing global and national issues and concern to the table and reciprocal knowledge transmission. Most of the national policies in health are based on international targets. People realized that in order to push the government, it’s important to be at the international platforms where goals are made for countries.*

-- DLL Participant, 2017
Sharing knowledge and increasing awareness within community for prevention and stigma reduction

Community members as individuals and community-driven organizations play a key role in the lives of Indigenous peoples. Overwhelmingly, participants at the Ottawa meeting spoke of the importance of communities and the role that they play in promoting the health and well-being of Indigenous peoples through prevention initiatives and by providing care and support for people living with infection(s). Delegates explained the importance of identifying community members who are deeply invested in community development and well-being since these are the people who are best placed for ensuring the effective provision of community health services. It is vital that people, such as leaders, activists, healers and Elders be provided with comprehensive and culturally relevant infection-related information so that they can contribute to increased capacity of people to lead and guide the implementation of culturally responsive prevention and care programs. Community leaders have a key role to play in mobilizing communities on a number of infection-related issues. One delegate spoke about their program that teaches Chief and Council about what HIV is, prevention, fast testing methods, and treatment options. Many participants referred to the importance of working in partnership with government agencies to design and develop health services that respond appropriately to the needs of Indigenous peoples and communities.

Delegates noted that early prevention for HIV and AIDS, TB, viral hepatitis, and STI’s requires knowledge and awareness, which can be disseminated through a variety of sources, starting with early education in schools to awareness campaigns in the media. Delegates noted a wise practice with campaigns includes centering the campaigns on culturally informed knowledge, which helps to address community-level concerns, and ultimately reduces stigma and tension. Language can be a powerful tool to reduce fear, discrimination, and stigma. It is integral to tailor messaging to certain populations, as this will ensure relevancy and relatability, and contribute to effective campaigns that reduce stigma (i.e., youth, Indigenous men, women, LGBTQ2S+).

Several delegates also noted peer education as an effective way to reduce stigma and to contribute to successful prevention strategies. Delegates noted the importance of prevention through story sharing, where those with lived experience share their experiences so others can learn from them. Effective prevention strategies involve community-wide efforts with involvement from all stakeholders and various methods (e.g., youth and elders, traditional healers, Indigenous women, learning circles, peer-to-peer training).

Community-based response and adapting global targets for community work

Delegates noted that a community-based response is a wise practice as it increases access to health services, particularly community-based responses that include an outreach component (i.e., mobile clinics, one-stop shops). Outreach facilitates increased prevention and treatment by bringing operations to the people, rather than requiring the people to come to the program. Delegates shared that community-level work is essential if the global targets are going to be met. One delegate shared, “We are seeing at the global level, a community response is vital to meeting goals by 2030.” Another delegate shared that community-based responses “are a collective Canadian voice within an international dialogue and we bring knowledge gained within the international venues back to our Canadian partners.” As the 90-90-90 targets have been criticized by mainstream scientists and researchers as unrealistic and unachievable, delegates spoke of the practice of localizing objectives and global targets, such as the 90-
90-90 global targets. They spoke about focusing at the community level on how to increase access to 90% of community members and tailoring the goals so they are contextualized within community.

**Focusing on advocacy and awareness**

Increasing awareness of HIV, TB, viral hepatitis, and STIs and advocacy efforts related to infections was identified as a promising practice. Delegates recommended working to get civil society to partake in dialogues related to infections and noted that advocacy has power: “if you don’t fight, you will go missing.” One participant provided comparisons between HIV and TB, noting that the advocacy efforts for HIV have been strong and has had years of activism, while the advocacy efforts for TB are relatively new, despite TB being around for thousands of years. As a result of the strong advocacy and activism around HIV, testing is rapid, accurate, and many new drugs have emerged for treating HIV. Conversely, testing and diagnostic mechanisms for TB remain out-dated and are not always accurate.

**Sustainability, self-management, and self-determination**

Sustainability, self-management, and self-determination were promising practices identified by delegates for working in the field of HIV, TB, viral hepatitis, and STIs. Delegates spoke about successful programs having long-term funding, and not on a pilot project basis. One delegate shared that, “funding cannot be within the mainstream models. Programs need time.” Other delegates spoke about work being successful when it resolved challenges around jurisdictional and political barriers and agendas. Finally, delegates spoke about their practice in which the community controls healthcare, where Elders in the community serve on an advisory council, and healthcare work is grounded in Indigenous methodologies.

**Wise practices in tracking data and monitoring progress**

“*We have a right to be counted, and a right to know.*”

Participants in this project have called for the uniform design and implementation of robust data collection systems to inform decision-making concerning Indigenous health. These need to be adequately funded and resourced. In many areas of Indigenous health, data are often under-reported, misreported or not reported at all. Because of a lack of robust data collection systems in many parts of the world, existing data related to the health of Indigenous peoples fails to provide a complete and accurate picture of health status. This lack of data means that policy makers lack strategic evidence on which to base policy decisions.
The current lack of accurate Indigenous infection data means that it will be impossible for Indigenous populations to assess progress towards reaching UN, WHO and/or Stop TB goals. Implementing robust data collection processes that include accurate measures of indigeneity is absolutely essential in order to fully understand how countries with Indigenous populations are progressing towards these international measures.

Since data are vital in determining community action related to health strategies, significant efforts and resources need to be devoted to capacity building in data collection, especially at the community level by health care service providers and people currently living with and/or having lived experience with infection. Training is needed regarding Indigenous rights and expectations about the ownership and care of Indigenous data. Community ownership is essential in order to ensure that data are used for the enhancement of Indigenous health and well-being.

The protocol articulated in the Sowing Seeds Research Project (King, King, Montalvo, Stratton, Yac, Moliner, Olivera, Aspin, & Masching, 2017), provides principles and recommendations for undertaking research with Indigenous peoples. The guidelines can be applied to research projects focused on the epidemiology of disease, interventions and implementation of strategies which aim to reduce the impact of HIV specifically among Indigenous peoples. This is also a flexible tool that can be adapted to accommodate the specific needs of research teams and diverse topics in local territories.

The following promising practices were offered by participants in measuring and tracking progress on the global health targets:

⇒ **Use CD4 counts for tracking data**: One delegate explained that they use viral blood work in community to determine if individuals are taking their medications. They cannot rely on tracking data based on how much medication is given out; just because medications were given out, it does not necessarily reflect whether or not medications have been ingested. So viral loads are used instead to track and monitor progress. Furthermore, this delegate spoke about the importance of developing relationships and trusts with individuals, as with relationships built, there is more interest in learning about one’s own viral load and blood count.

⇒ **Consider the European Centre for Disease and Prevention and Control process for modeling estimate incidence**

⇒ **In British Columbia, Canada, the First Nations Health Authority has the Cascade of Care model** that matches data between the health authority and BC Centre of Excellence

⇒ **Consider proxy data**, such as test kits and pharmaceutical sales data (when population numbers are low).

⇒ **Implement the same software system in multiple locations** so data is synchronized (see Telstra Communicare model for integrated health management).

⇒ **Incorporate wellness indicators** in addition to 90-90-90 indicators. One delegate explained, “numbers are fine, but we need to weave stories throughout.”
Consider a variety of indicators to be measured. It is important to recognize that there are different measures of success used, and we ought to look at the pre-requisites or pre-conditions; clean drinking water is a pre-condition of 90-90-90.

Other wise practices related to data collection that were shared by delegates included discussing the rationale for what data is being collected and why. Participants noted that as a field, there is a need to look at the questions being asked and the purpose of the data. Sometimes, there can be hesitancy to self-identify as Indigenous out of fear that care will be impacted; this ultimately has implications for tracking and monitoring progress. With respect to tracking data, participants noted that using electronic medical records often lack robustness and are not systematic (as some clinicians may enter data they perceive to be true, but is biased). Finally, delegates spoke about challenges regarding tracking data for the global targets of 90-90-90, noting that many Indigenous communities face infrastructure challenges that need to be addressed before the 90-90-90 targets can even be considered. One delegate shared, “We can’t achieve a goal that doesn’t talk to the realities as Indigenous peoples.” Furthermore, it was noted that the quantitative numbers do not always reflect the grief and hardship caused by the loss of one person. There needs to be consideration of the proportionality of quantitative data: “an ‘n’ of 1 in statistics is not significant, but in community, and ‘n’ of 1 means the difference between life and death. It is significant.”

A Promising Model
Ahtahkakoop Cree Nation, Canada – Wholistic Supports

Ahtahkakoop reached 90-90-90 in our community. We have wholistic supports in place (i.e., needle exchange program, nurses, counseling, methadone, infectious disease doctor). Our Chief and Council support the initiative, which was driven by a health committee. It’s non-judgmental, has a welcoming environment. We have testing at Treaty Days, and at any community gathering or event. We provide public testing days, with educational opportunities. We’re meeting the community where they’re at.

In the late 1990’s, the goal of our needle exchange program was to connect with high-risk clients to get more testing. It was a way to develop trust and connect with clients. Trust is the KEY to access. So, we offered more services on reserve. We identified more HCV, not HIV. So we started providing more services, as the clients’ grove the demand. We made links with infectious disease doctors.

If I haven’t seen a client in months, I will go see them and I’ll do blood work if needed. Clients want to know what their test results are; they want to know their CD4 count. I do continual follow up with clients. I will go to their house to ensure they’re keeping up with their medications; it’s personalized care.

DLL Participant, 2017
Summary of Lessons Learned

This project has identified a range of practices and lessons learned that provide confidence that the solutions to achieving health and addressing these infections rest firmly within communities. As delegates at the face-to-face meeting in Ottawa stated on numerous occasions, communities are key to identifying culturally responsive solutions to the multitude of illnesses that impact the lives of Indigenous peoples. Stakeholders, including government agencies, community organizations, health service providers, researchers and international partners must engage in a good way with communities with the goal of forming equitable partnerships that confront and overcome contemporary challenges to the good health of Indigenous peoples.

Indigenous peoples have a wealth of experience and skills developed and refined over thousands of years in overcoming challenges to their health and well-being. As people who have lived and flourished in the face of adversity, Indigenous peoples have accumulated and refined practices that provide protection against a multitude of illnesses and infections. Indigenous peoples have had to draw on this experience, wisdom and knowledge to confront modern day challenges to their health, especially in relation to the infections HIV, TB, viral hepatitis, and STIs. Many Indigenous peoples rely on natural remedies and traditional medicines, in part because they do not have ready and regular access to western medicines, and in part trusting in ‘the old ways’ over the new to sustain health.

The history of colonization is replete with examples of external agencies imposing solutions and remedies on Indigenous communities. These have failed to reduce the current disparities related to HIV, TB, viral hepatitis, and STIs, often due to different understandings of health between Indigenous communities and non-Indigenous health practitioners, stigma, and discrimination (Permanent Forum on Indigenous Issues [PFII], 2006).

The importance of the DLL Project is the creation of a platform upon which Indigenous peoples internationally can come together to share their experiences, insights, and knowledge about how best to address these disparities. This project sets an important precedent because it has been Indigenous-led in close partnership with the Government of Canada, has established a model which can be replicated, and has resulted in actionable recommendations that can be implemented internationally across various sectors. As the world moves towards the goals to end AIDS, eliminate hepatitis C, and work toward widespread treatment for infections, it is essential that the voices of Indigenous peoples be heard and acted on as we work together to bring these epidemics to an end for all people.

Indigenous people have been brutalized by institutions that aren’t ours, not created by us. We don’t want our tool to be the same as the colonizers tools. Our tool needs to be indigenous.

DLL Participant, 2017

I come from the end of the world. I live with HIV. I am a native person living with HIV. I belong to the 10% remaining of the 90-90-90 goal. When one speaks of the 90-90-90, I feel excluded because modern society has not included us ... I no longer want to be part of the 10% of the triple 90 objective. Through the support of Health Canada, we shall be able to be part of that 90-90-90 goal.

DLL Participant, 2017
5.0 Recommendations

The Documenting Lessons Learned and Measuring Progress Towards Global HIV/TB/Hepatitis C Targets in Indigenous Communities (DLL) Project was a unique opportunity to bring together Indigenous and non-Indigenous experts and leaders from a cross-section of health sectors to set the stage for a unified voice. Together, Indigenous leaders from countries around the world experienced in health programming, shared knowledge and insights into prevention, care and support of people living with these infections. The following recommendations are based on wise practices shared by international Indigenous and non-Indigenous leaders who attended the three-day meeting in Ottawa, Canada, as well as a literature review of 107 peer reviewed articles and reports. The recommendations resulting from this project are designed to inform action plans and programs of stakeholders who work with Indigenous peoples affected by HIV, TB, viral hepatitis and STIs.

Work collaboratively with key stakeholders to develop a global standard for monitoring and tracking data on HIV, TB, viral hepatitis, and STIs in Indigenous communities

1. Spearhead an Indigenous-led, collaborative approach to developing a global standard for monitoring and tracking data on infections in Indigenous communities that is inclusive of the voice and perspective of all key stakeholders. Key stakeholders include, but are not limited to, those with lived experience, communities, researchers, national and international Indigenous organizations, and governments. Below is a list of key stakeholders and how they may be engaged in this important work.

- **Those with lived experience**: Indigenous people living with HIV, TB, viral hepatitis, and/or STIs and their families must be engaged in policy and decisions that impact their lives and treatment. This is essential not only to gain buy-in for monitoring and tracking initiatives and for the designing and developing of effective programs, but also to promote the self-determination of Indigenous peoples.

- **Communities**: Community-based responses are more effective at accessing Indigenous peoples and will be on the front line of monitoring and tracking data. Communities need to be engaged in determining a realistic global standard for monitoring and tracking data that can be effectively operationalized within each communities’ unique context.

- **Elders**: Elders can help ensure that policies and practices are grounded in Indigenous knowledge and are based on Indigenous values.

- **Indigenous Leaders**: Having buy-in from Indigenous leaders enhances advocacy work and enables change. Indigenous leaders can translate knowledge and awareness of the importance of a global standard for monitoring and tracking data on infections to within their communities, which can facilitate buy-in from community members.

- **Youth**: Engage youth in the development of a global standard and provide them with mentoring opportunities in monitoring and tracking data initiatives. It is imperative to have the buy-in from the next generation of leaders to ensure that this important work continues.

- **Underrepresented Indigenous Communities**: It is important to include the voice of all Indigenous peoples in order for international initiatives to be most effective. Many Indigenous communities in Asia and Africa were either unrepresented or underrepresented in the DLL project. It is important to include their voices in the work of developing a global standard for monitoring and tracking data on infections in Indigenous
communities and to work toward increasing representation of these peoples at future international forums and events.

✓ **Researchers**: Engage researchers in the development of a global standard for monitoring and tracking data on infections in Indigenous communities. Researchers can share best practices in data collection and help ensure that monitoring and data collection initiatives are robust. Indigenous researchers can help design initiatives that are based on decolonizing methodologies.

✓ **Organizations**: National Indigenous organizations should be kept apprised of policies and practices promoted by international organizations. Ensure that the development of any policies and practices is disseminated widely with national and international Indigenous organizations and continue to share best, promising, and wise practices with each other.

✓ **Non-Indigenous Allies**: Ensure that non-Indigenous health agencies and decision makers are kept apprised of international Indigenous health initiatives and informed of the development of policies and practices. Encourage non-Indigenous allies to support a global standard for monitoring and tracking data on infections in Indigenous communities and support the universal recognition of Indigenous peoples as a key population affected by HIV, TB, viral hepatitis, and STIs.

✓ **Governments**: Government buy-in and support for HIV, TB, Viral Hepatitis, and STI initiatives is important to forward this important work. Engage with governments to gain national recognition of Indigenous peoples as key populations affected by HIV, TB, viral Hepatitis, and STIs and gain support for a global standard for monitoring and tracking data on infections in Indigenous communities. Seek fiscal support from governments to increase the presence of Indigenous peoples in international networks and events such as the Indigenous Peoples Forum, and the World Health Organization initiatives in order to share work and disseminate information about the development of any policies or practices. It is also recommended that governments secure adequate, long-term funding for monitoring and tracking initiatives in order to address the disproportionate rates of infections in Indigenous communities.

✓ **Global Leaders**: Global leaders such as the World Health Organization, the UN, and UNAIDS can raise the visibility of issues disproportionately affecting Indigenous populations and create a platform for advocacy. Engage in international forums, boards, groups, and meetings to foster awareness of the intersectionality between public policy, global engagement, knowledge sharing, and community systems; to share the development of policies and practices related to a global standard for monitoring and tracking data on infections in Indigenous communities; and to seek support for developing grassroots initiatives to begin monitoring and tracking efforts. Additionally, engage global leaders to help make international events such as the International AIDS Conference more inclusive of Indigenous peoples.

2. There is a clear need for a unified voice to advocate for Indigenous people living with HIV, TB, viral hepatitis, and STIs. Indigenous leaders in the areas of HIV, TB, viral hepatitis, and STIs and international Indigenous health organizations can spearhead a collaborative effort to work toward better data monitoring and tracking of infections, with the overarching goal of reducing rates of infections in Indigenous communities. Indigenous leaders can help ensure that the principles of MEPA and GIPA are upheld in both policy and practice. Consider partnering with experts in monitoring and systems to gather more robust quantitative data on infections in Indigenous communities.
Promote national and international education and advocacy efforts to address the structural barriers that inhibit Indigenous peoples’ access to equitable health care

3. Advocate for the inclusion of the history and impact of colonization in health care provider curriculum at education institutions and as part of staff training at health care facilities. Promote the development of standards for working with Indigenous populations in a health care setting that includes the voice of those who are most marginalized in the health care system.
   ✓ Underpinning the health inequities and disparities experienced by Indigenous peoples is a history of colonialism, racism, and discrimination. Health service providers need a common understanding of the impact of colonization on Indigenous peoples and how it manifests in stigma, discrimination, and racism in health services.
   ✓ Stigma, discrimination, and racism in health care is a barrier to Indigenous peoples’ accessing adequate and appropriate health care services. This is particularly problematic for individuals who experience multiple, intersecting forms of stigma such as Indigenous people who are experiencing HIV, TB, viral hepatitis, and/or STIs and also engage in sex work, drug use, and/or identify as LGBTQ2S+.

4. There is a need for more resources dedicated toward education regarding the negative impacts of stigma and how it affects equitable access to health care. It is important that the intersectionality between health, sexuality, and human rights is acknowledged and space is made for the voices of those who are most marginalized and stigmatized in the health care system. Information and awareness campaigns in schools and in the media with messaging tailored to specific population can be an effective method of reducing stigma in communities. Peer education is also an effective method of reducing stigma and contributes to successful prevention strategies.
   ✓ Consider creating a community-friendly fact-sheet of the wise practices shared by the delegates on working with Indigenous peoples that can be disseminated and shared widely with health care practitioners and service providers. Promote the development of and support for peer-education initiatives and awareness campaigns on HIV, TB, viral hepatitis, and STIs in communities that are tailored to the culture and local context of each community.

5. Consider advocating for the respectful research of the value and benefits of Indigenous knowledge and medicine in order to incorporate traditional medicine and practices into mainstream healthcare and facilitate access to culturally appropriate health care. It is important to note that traditional knowledge not be exploited, but that there is a process to increase access to traditional knowledge and medicines, and that there is evidence of its effectiveness.
   ✓ One of the damaging impacts of colonization is the devaluation of Indigenous knowledge and Indigenous ways of knowing. With regard to health care for infections, this can be particularly problematic for some Indigenous communities where traditional medicine is devalued and access to Western medicine is limited.

6. There is a clear need to increase access to early testing and treatment for HIV, TB, viral hepatitis, and STIs in Indigenous communities, but many Indigenous communities experience barriers related to infrastructure which inhibits access to testing and treatment. Barriers to accessing health services are reduced when initiatives are culturally responsive, community driven, align with community priorities, have adequate and dedicated resources, and are easy to access. Promote the development of and support for culturally responsive, community-driven testing and treatment programs in Indigenous communities that are adequately funded and have mobile outreach components.
Promote increased access to culturally relevant awareness-raising, testing, treatment, and continuum of care initiatives related to HIV, TB, viral hepatitis, and STIs in Indigenous communities

7. A lack of appropriate, culturally relevant health services is a barrier to Indigenous people accessing health care for infections. Health-related programs focused on Indigenous people must be informed by Indigenous knowledge and concepts, must take into account the history and impacts of colonization, and must have realistic goals and targets. Promote the development of and support for health promotion initiatives that are localized to each Indigenous community and are Indigenous-led.

8. In order for health services focused on Indigenous peoples to be effective, they need to take a wholistic approach to Indigenous peoples’ health and wellness. A wholistic approach considers all aspects of health including mental, physical, emotional, and spiritual wellness, and considers an individual’s family, community, and environment to be part of an individual’s health. Promote the development of and support for health services aimed at addressing HIV, TB, viral hepatitis, and STIs in Indigenous communities that take a “one-stop-shop” approach that addresses all health needs and that are inclusive of the continuum of care.

9. Indigenous knowledge and western knowledge systems should be equally valued and should both be used to inform decision making, and the design and delivery of health services focused on Indigenous peoples. Indigenous peoples affected by HIV, TB, viral hepatitis, and/or STIs should have the option of accessing traditional and western healing options or a blend of both. Elders and traditional knowledge keepers can help ensure culturally safe responses to health needs and, as appropriate, may facilitate ceremonies, engage in traditional healing, and serve as educators, historians, and/or activists. Advocate for equal access and the integration of traditional knowledge and healing into health care systems that is guided by Elders and/or traditional knowledge keepers.

10. Share knowledge of wise practices and promote the inclusion of wise practices into health care systems in order to increase access to culturally appropriate health services. Additional wise practices for health care initiatives aimed at reducing rates of HIV, TB, viral hepatitis, and STIs in Indigenous communities that were identified by delegates included:

- A strength-based approach that celebrates the resiliency of Indigenous peoples
- Acknowledgement that HIV is connected to human rights and social determinants of health
- Community-driven initiatives
- A harm reduction approach
- Partnering with local communities, agencies, and leadership to delivery health services
- Developing realistic goals and targets
- Accessible initiatives (i.e. mobile outreach, free or low-cost services)
- Adequately training health care providers to deliver culturally appropriate health services
- Peer-support initiatives led by those with lived experience
- Awareness-raising initiatives that promote the importance of early testing and treatment for infections
- Initiatives that address the sexual life and diversity amongst Indigenous populations
Promote further research and evaluation in Indigenous populations of HIV, TB, viral hepatitis, and STI-related initiatives that use decolonizing methodologies

11. Currently there continues to be a lack of information and robust data on HIV, TB, viral hepatitis, and STIs in Indigenous communities. There is a need for uniform, robust data collection systems to inform decision-making in Indigenous health. Delegates identified specific suggestions for collecting data on infections in Indigenous communities including using CD4 counts for tracking data, the European Centre for Disease and Prevention and Control process for modeling estimate incidences, the First Nation Health Authority’s Cascade of Fire model, and the Telstra Communicare model for integrated health management. Promote research on infections in Indigenous communities that take a decolonizing, strength-based, and participatory approach to address gaps in research. Gaps in research identified by the DLL project include a lack of data on prevalence of infections in remote Indigenous communities, particularly those located in Asia; a lack of data on STIs in Indigenous communities; research on the effectiveness of traditional medicine; the need for documentation of traditional oral knowledge from Elders and traditional knowledge keepers; and mapping available quantitative data on infections in Indigenous communities by region in order to identify gaps.

12. One of the challenges with gathering data on infections in Indigenous communities is a lack of capacity to collect robust data using culturally appropriate methods. Before any research is conducted, it is important to determine who owns the data, how it will be collected, and where it will be stored. Advocate for resources dedicated toward increasing the capacity of Indigenous communities to collect data and promote responsible research practices such as free, prior and informed consent, and principles that adhere to Indigenous ownership, access and storage of data.

Work collaboratively with stakeholders at the international, national, and community level to develop localized action plans for tracking and monitoring data on HIV, TB, viral hepatitis and STIs in Indigenous communities.

13. Organize a gathering of international Indigenous leaders or establish and maintain a DLL task force to mobilize the work of the DLL project by developing an action plan to begin working with stakeholders to develop a global monitoring and tracking data standard and to develop monitoring and tracking data initiatives. It is recommended that the action plan outline concrete action items relevant to international and national key health organizations, national governments, Indigenous communities, Indigenous leaders, as well as researchers. It is also recommended that the action plan include a strategy on how to translate and share knowledge among key stakeholders.
References


The Kirby Institute. (2017). *From chronic to cured: Could Australia be the first country in the world to eliminate hep c?* Sydney: University of New South Wales.


UNAIDS. (2015). *On the fast-track to end AIDS, 2016-2021 strategy. UNAIDS*


### Appendix 1
**Participants at Ottawa meeting, July 10 to 12, 2017**

<table>
<thead>
<tr>
<th>Name</th>
<th>Affiliation</th>
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<tbody>
<tr>
<td>Marni Amirault</td>
<td>Community-Based Research Manager, AHA Centre/CAAN, Canada</td>
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<tr>
<td>Tihut Asfaw</td>
<td>Senior Policy Analyst, Communicable Disease Control Division, Public Health Agency, Health Canada</td>
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<tr>
<td>Kelly Benning</td>
<td>National Association of Friendship Centres</td>
</tr>
<tr>
<td>Jasine Bernard</td>
<td>Eskasoni First Health Centre, Nova Scotia, Canada</td>
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<tr>
<td>Carrie Bourassa</td>
<td>Canadian Institute of Health Research</td>
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<tr>
<td>Patrick Brownlee</td>
<td>Executive Research Assistant and Project Administrator, Canadian Aboriginal AIDS Network</td>
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<tr>
<td>Richard Burzynski</td>
<td>UNAIDS</td>
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<tr>
<td>Ken Clement</td>
<td>Chief Executive Officer, Canadian Aboriginal AIDS Network</td>
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<tr>
<td>Erin Corston</td>
<td>National Association of Friendship Centres, Canada</td>
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<tr>
<td>Delme Cupido</td>
<td>Senior Program Officer, Indigenous People’s Rights Open Society Initiative, South Africa</td>
</tr>
<tr>
<td>Collene Daniels</td>
<td>Stop TB Partnership</td>
</tr>
<tr>
<td>Rawiri Evans IIWGHA</td>
<td>Ngati Awa ki Kapiti, New Zealand</td>
</tr>
<tr>
<td>Amaranta Gomez</td>
<td>Leader, International Indigenous Working Group on HIV and AIDS, Mexico</td>
</tr>
<tr>
<td>Tanys Isbister</td>
<td>Registered nurse, HIV Program, Ahtahkakoop First Nation</td>
</tr>
<tr>
<td>Gayatri Jayaraman</td>
<td>Acting Director Communicable Disease Control Division, Public Health Agency, Health Canada</td>
</tr>
<tr>
<td>Elena Kanigan</td>
<td>HIV and AIDS Project Manager, First Nations Health Council</td>
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<tr>
<td>Alexandra King</td>
<td>University of British Columbia and Indigenous Physicians Association of Canada</td>
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<tr>
<td>Malcolm King</td>
<td>Health Researcher, Faculty of Health Sciences, Simon Fraser University, Canada</td>
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<tr>
<td>Denise Lambert IIWGHA</td>
<td>Kimamow Ataskanow Foundation and Leader, International Indigenous Working Group on HIV and AIDS, Canada</td>
</tr>
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<td>Name</td>
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<tr>
<td>Marlene Larocque</td>
<td>Health Policy Analyst, Assembly of First Nations, Canada</td>
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<td>Carole McBride</td>
<td>Director of Health, Timiskaming First Nation, Quebec, Canada</td>
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<td>Renee Masching</td>
<td>Manager, Research and Policy, Canadian Aboriginal AIDS Network</td>
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<td>Wilo Muwadda</td>
<td>Leader, International Indigenous Working Group on HIV and AIDS, Australia</td>
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<tr>
<td>Amy Mawdsley</td>
<td>Project Coordinator, Canadian Aboriginal AIDS Network</td>
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<tr>
<td>Dave Miller</td>
<td>Lead Project Coordinator, Canadian Aboriginal AIDS Network</td>
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<tr>
<td>Pilar Montalvo</td>
<td>Social Development Corporation and Leader, International Indigenous Working Group on HIV and AIDS, Peru</td>
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<tr>
<td>Robin Montgomery</td>
<td>Executive Director, Interagency Coalition on AIDS and Development</td>
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<tr>
<td>William Morales</td>
<td>Kelwo Chiloé Organization and Leader, International Indigenous Working Group on HIV and AIDS, Chile</td>
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<tr>
<td>Nnamdi Ndubuka</td>
<td>Medical Health Officer, Northern Inter-Tribal Health Authority Inc, Saskatchewan</td>
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<tr>
<td>Amy Nowahgahbow</td>
<td>Native Women's Association of Canada</td>
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<tr>
<td>Tracey O’Hearn</td>
<td>Executive Director, Pauktuutit Inuit Women of Canada</td>
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<tr>
<td>Nanny Ouellette</td>
<td>Ex-officio membership</td>
</tr>
<tr>
<td>Marama Pala IIWGHA</td>
<td>Executive Director, INA (Māori, Indigenous &amp; South Pacific) HIV/AIDS Foundation and Co-Chair, International Indigenous Working Group on HIV and AIDS, New Zealand</td>
</tr>
<tr>
<td>Emma Palmantier</td>
<td>Northern British Columbia First Nations HIV/AIDS Coalition, Canada</td>
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<td>Adina Popalyar</td>
<td>Nurse Advisor, Sexually Transmitted and Blood Borne Infections Program, Public Health Agency of Canada, Canada</td>
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<tr>
<td>Jeff Potts</td>
<td>Executive Director, Canadian Positive Peoples Network</td>
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<tr>
<td>Harlan Pruden</td>
<td>National Confederacy of Two-Spirit Organizations and Leader, International Indigenous Working Group on HIV and AIDS, Canada</td>
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<td>Norma Rabbitskin</td>
<td>Senior Health Nurse, Sturgeon Lake First Nation Health Centre, Saskatchewan, Canada</td>
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<tr>
<td>Noreen Reed</td>
<td>Ahtahkakoop Cree Nation, Saskatchewan, Canada</td>
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<tr>
<td>Billie Joe Rogers</td>
<td>Reciprocal Consulting, Canada</td>
</tr>
<tr>
<td>Name</td>
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<tr>
<td>Yahaya Sekeagya</td>
<td>Executive Director, PROMETRA and Leader, International Indigenous Working Group on HIV and AIDS, Uganda</td>
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<tr>
<td>Paula Simonsen</td>
<td>Sami Plus Spokesperson and Leader, International Indigenous Working Group on HIV and AIDS, Norway</td>
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<tr>
<td>Marina Smelyanskaya</td>
<td>Stop TB Partnership</td>
</tr>
<tr>
<td>Gregory Springer</td>
<td>National STI Program Coordinator/Manager, Public Health Agency of Canada, Health Canada</td>
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<td>Trevor Stratton</td>
<td>Coordinator, International Indigenous Working Group on HIV and AIDS, Canadian Aboriginal AIDS Network</td>
</tr>
<tr>
<td>Raven Swamp</td>
<td>Miss Indian World, 2017</td>
</tr>
<tr>
<td>Cliff Thomas</td>
<td>Elder, Canada</td>
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<tr>
<td>Merv Thomas</td>
<td>Director of Programs and Communications, Canadian Aboriginal AIDS Network</td>
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<tr>
<td>Mary Ann Torres</td>
<td>Executive Director, International Council of AIDS Service Organizations</td>
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<tr>
<td>Kim van der Woerd</td>
<td>Reciprocal Consulting, Canada</td>
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<tr>
<td>Eduardo Vides</td>
<td>Metis Nation of Canada</td>
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<tr>
<td>Sofia Vitalis</td>
<td>Reciprocal Consulting, Canada</td>
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<tr>
<td>Nick Walsh</td>
<td>Regional Advisor for Viral Hepatitis, Pan American Health Organization, World Health Organization Regional Office for the Americas</td>
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<tr>
<td>Carrie Wapachee</td>
<td>Pauktuutit Inuit Women of Canada, Canada</td>
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<tr>
<td>James Ward</td>
<td>Associate Professor, South Australian Health and Medical Research Institute, Australia</td>
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<tr>
<td>Krysta Williams</td>
<td>Native Youth Sexual Health Network, Canada</td>
</tr>
<tr>
<td>Arlene Wortsman</td>
<td>Canadian Indigenous Nurses Association</td>
</tr>
</tbody>
</table>
Appendix 2
Members of Technical Group

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Tihut Asfaw   Senior Policy Analyst, Communicable Disease Control Division, Public Health Agency, Health Canada
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Robin Montgomery  Executive Director, Interagency Coalition on AIDS and Development
Leticia Rangel Terrazas,  Translator and Interpreter
Merv Thomas,  Director of Programs and Communications, Canadian Aboriginal AIDS Network
Eduardo Vides  Senior Analyst, Metis Nation of Canada
Jose Yac  Leader, International Indigenous Working Group on HIV and AIDS
### Appendix 3
Promising Models and Elements Identified at the Ottawa meeting, July 10 to 12, 2017

<table>
<thead>
<tr>
<th>Key ingredient</th>
<th>Program</th>
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<tr>
<td></td>
<td>Ahtahkakoop Cree Nation (SK, Canada)</td>
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<tr>
<td>Design</td>
<td></td>
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<tr>
<td>Reframed 90-90-90 targets to be community specific</td>
<td>x</td>
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<tr>
<td>Program designed/driven by clients with lived experience</td>
<td>x</td>
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<tr>
<td>Harm reduction model</td>
<td>x</td>
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<tr>
<td>Program driven by community</td>
<td>x</td>
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<tr>
<td>Located in regions where primary users are indigenous</td>
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<tr>
<td>Delivery</td>
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<tr>
<td>Provides wholistic wrap around care and services (prevention, screening, testing, mental health, physical health, substance etc.)</td>
<td>x</td>
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<tr>
<td>Provides training and information regarding infections to clients</td>
<td>x</td>
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<tr>
<td>Needle exchange</td>
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<td>Culturally based</td>
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<tr>
<td>Two-way communication between client and health professionals</td>
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<tr>
<td>Peer mentors with lived experience</td>
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<tr>
<td>Hosts fun public information sessions</td>
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<tr>
<td>Mobile clinic (i.e., testing)</td>
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<tr>
<td>Provided in partnership with communities</td>
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</table>