



# Looking Ahead: Options to Promote Hepatitis C Testing, Treatment, and Prevention for First Nations in B.C.

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B.C. PRIORITIES PROJECT 2019

SIMON FRASER UNIVERSITY SCHOOL OF PUBLIC POLICY

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# Acknowledgement

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We respectfully acknowledge that the research and learning for this report was conducted on the unceded territories of the x̱m̱əθkw̱əy̱əm (Musqueam), Skwxwú7mesh (Squamish), and Səlílwətaʔ/Selilwítlh (Tsleil-Waututh) Nations.

This report acknowledges the following:

- The initial research team was composed of five students, one of whom self-identifies as Indigenous. Since January 2019, the team has been composed of only four students, none of whom are Indigenous.
- This report is a research project undertaken by Simon Fraser University School of Public Policy graduate students and is not the product of the First Nations Health Authority.
- Indigenous-led research on hepatitis C virus currently exists and should continue to be built upon. We gratefully acknowledge this research and its role in guiding our learning.
- Addressing the disproportionate impact of hepatitis C virus on First Nations in British Columbia must uphold the principle of “nothing for us without us.” The findings of this report must be corroborated by Indigenous advice, including Indigenous leaders.

Researchers were required to complete San’yas: Indigenous Cultural Safety Training Program delivered by the Provincial Health Services Authority of British Columbia, and were provided guidance and continuous feedback from the First Nations Health Authority throughout the research period. While the research has the best intentions of informing a made-in-B.C. framework for First Nations populations, the research team stresses the need for Indigenous leadership, collaboration and input prior to any stage of implementation.

While we are proud of the work we have done in completing this report, including the recommendations, we acknowledge the limitations of research undertaken without Indigenous leadership.

*Simon Fraser University School of Public Policy (SFU) graduate students produced Looking Ahead: Options to Promote Hepatitis C Testing, Treatment, and Prevention for First Nations in B.C. for their 2019 BC Priorities Project. The research team conducted a comprehensive review of hepatitis C virus (HCV) literature for First Nations populations, an overview of key players involved in the HCV ecosystem, and identified short- and long-term opportunities to strategically address the high incidence rate of HCV among B.C. First Nations. The team was supported and guided by the First Nations Health Authority (FNHA), though this report is not the product of FNHA.*

# Executive Summary

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Hepatitis C virus (HCV) infection in Canada exemplifies the widening gap between Indigenous and non-Indigenous health outcomes. Approximately 250,000 to 275,000 Canadians are living with HCV, with Indigenous peoples being disproportionately affected (CATIE, 2018). Although HCV demographic information is limited, current evidence demonstrates that the rate of HCV infection among Indigenous peoples is at least five times higher than that of the rest of Canada (Fayed et al., 2018). This sharp disparity encompasses many HCV-related epidemiological statistics, including incidence, prevalence, and health outcomes, and reflects a history of colonialism in Canada where the health and wellness of Indigenous peoples has not been prioritized.

The disproportionate incidence rate of HCV among Indigenous peoples in Canada mirrors a myriad of social and health factors. Many experts have pointed to the social determinants of health, lack of culturally relevant care, and health gaps resulting directly or indirectly from colonization and its aftermath, to help explain the overrepresentation of HCV within Canadian Indigenous populations.

In B.C., this inequity is especially prominent, as First Nations peoples in the province have one of the highest rates of HCV infection in Canada. To address this issue, community leaders, researchers, and health professionals suggest utilizing Indigenous perspectives on wellness in developing a holistic healthcare model. The Federal government has also committed to improving the health outcomes within Indigenous communities through the implementation of the Calls to Action put forward by the Truth and Reconciliation Commission of Canada. 7 of the 94 Calls to Action relate directly to health and include, increasing access to Indigenous-led and culturally-specific care, recognizing the relationship between colonization and health, and improving the health access and care offered to on-and-off reserve communities.

This SFU-led research project is intended to help provide FNHA with critical insight into the challenges and opportunities of a made-in-B.C. HCV testing, treatment, and prevention model that reflects and supports the First Nations perspective of wellness. Research, learnings, and outcomes are rooted in FNHA's Directives and its visual representation of the First Nations perspective on health and wellness, as well as principles of the Truth and Reconciliation Commission of Canada's Calls to Action.

The key policy recommendations to promote testing, treatment, and prevention of HCV for First Nations in B.C. include:

- Encourage the adoption of a formal HCV strategy by the provincial government
- Expanded use of dried blood spot-testing through mobile clinics
- Increase Indigenous focused education and engagement to reduce stigma and promote testing, treatment, and prevention of HCV

# Key Terms

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**HCV** - Hepatitis C virus is a bloodborne virus impacting the liver. The virus can go undetected for 20-30 years and may lead to severe liver damage (cirrhosis), liver cancer and liver failure. Currently, HCV is most commonly transferred through the sharing or reusing of drug equipment (needles, syringes, pipes for smoking crack or crystal meth, etc.). Infection can also occur from shared use of tattoo equipment, blood-to-blood contact through intercourse or personal items, and unscreened blood transfusions, though Canada has been screening since 1990.

**Eradication** - Reduction of the worldwide incidence of a disease to zero as a result of deliberate efforts, obviating the necessity for further control measures.

**Cured of HCV** - The goal of hepatitis C treatment is sustained virologic response (SVR) through the use of protease inhibitor drugs. SVR means that the amount of hepatitis virus in your system is so low that it cannot be detected 12 weeks after treatment. If you achieve SVR after treatment, you can say that HCV is cured.

**Sexually transmissible and blood-borne infections (STBBI)** - The term used to designate infections that are sexually transmitted or transmitted through the blood, such as HCV and HIV, among others.

**Harm Reduction** - Harm reduction refers to policies, programs and projects that aim to reduce the health, social and economic harms associated with the use of drugs. Harm reduction practices include, but are not limited to, safe consumption/injection sites, needle and syringe distribution, opioid substitution therapy, and the distribution of Naloxone. (CATIE, 2018).

**Dried Blood Spot-Testing** - Dried blood spot-testing is a testing process that uses drops of dried blood on a piece of filter paper. It is a simpler process than testing using blood plasma or serum drawn from a vein by a needle in a number of ways. With dried blood spot-testing, blood is collected through a finger prick, or a heel prick in infants. A lower volume of blood is needed, blood transport and storage are simpler, less equipment is required, and finger prick blood collection does not need to be administered by a trained healthcare worker (CATIE, 2018).

**Two-Eyed Seeing** - Developed by Mi'kmaw Elders Albert and Murdena Marshall from Eskasoni, two-eyed seeing or Etuaptmuk is a guiding principle that encourages seeing the strengths of Western knowledges and ways of knowing from one eye and the strengths of Indigenous knowledge and ways of knowing from the other. This principle calls for cross-cultural collaboration wherein neither eye dominates the other (Martin, 2012).

**Direct-Acting Antivirals (DAAs)** - DAAs are a relatively new group of oral medications that directly block the ability of the hepatitis C virus to make copies of itself. DAA HCV can clear a person's HCV infection, however, a person can become reinfected (CATIE, 2018).

**Naloxone** - Naloxone is an opioid antagonist medication used to block or reverse the effects of opioid drugs, particularly within the setting of drug overdoses. It is sold under the brand name Narcan.

**Opioid Substitution Therapy** - Opioid substitution therapy is an effective treatment for addiction to opioid drugs such as heroin, oxycodone, hydromorphone (Dilaudid), fentanyl and Percocet. The therapy involves taking the opioid agonists methadone (Methadose) or buprenorphine (Suboxone). These medications work to prevent withdrawal and reduce cravings for opioid drugs.

# 1. Introduction

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For decades, hepatitis C virus (HCV) has impacted the health outcomes and lives of many British Columbians. With recent advances in treatment and a subsequent global strategy to eliminate viral hepatitis by 2030, British Columbia is well-positioned to eradicate the virus. However, in order to accomplish these goals, First Nations' health inequities must be considered and separately addressed with Indigenous perspectives on wellness.

While HCV treatment is more accessible than ever, legacies of colonialism continue to pose major barriers to British Columbia's First Nations communities such as stigma and discrimination within the healthcare system. These barriers have led to poor health outcomes for this population that are disproportionate to the rest of British Columbians. British Columbia's health authorities and providers can continue to test, treat and educate populations to no avail if a holistic understanding and approach of the issue is not taken.

Although there have been advances in treatments options, B.C. does not currently have a strategy that holistically supports the eradication of HCV among its First Nations populations. The current landscape is composed of researchers, non-profit organizations and independent healthcare clinics/treatment centres. By learning from their effective approaches, the impact can be scaled up and across the province.

Health authorities, governments and nations across the world have approached HCV eradication in unique ways. The intention of this research is to build off of successes and lessons learned from across jurisdictions and within the province to inform the creation of a made-in-B.C. framework to promote testing, treatment, and prevention of HCV for First Nations populations in British Columbia.

This report provides recommendations for a holistic policy package that seeks to provide effective and culturally safe options for HCV testing, treatment, and prevention.

## 2. Background

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In 2016, along with member states of the World Health Organization, Canada adopted the first global strategy on viral hepatitis with a goal to eliminate viral hepatitis as a major public health threat by 2030. This requires everyone living with viral hepatitis in Canada to have access to safe, affordable and effective treatment. In 2011, it was estimated that 44% of people who were living with hepatitis C virus (HCV) were unaware of their infection, and approximately 250,000 individuals across Canada are living with the infection (CATIE, 2018). As the treatments for HCV have transformed the infection into an easily curable disease, the impetus to eradicate HCV has grown.

The rate of HCV incidence is particularly high in B.C., with approximately 80,000 British Columbians living with the infection, and the number growing by up to 2,500 new infections annually. Within the province, it was estimated that the incidence of HCV is twice as high among Indigenous peoples compared to non-Indigenous peoples (Uhanova et al., 2013). HCV is contracted through blood-to-blood contact which may occur with sharing syringes and crack pipes, as well as tattoo and piercing equipment. However, the rates of HCV incidence disproportionately impacts marginalized groups due to the complex needs of the underserved and the inability of Eurocentric interventions to address the barriers faced. This aligns with the notion that meaningful engagement and collaboration is needed when considering program delivery options in partnership with marginalized populations.

As a result, HCV remains a major concern amongst Indigenous peoples throughout Canada. While it is difficult to estimate the number of Indigenous people infected with HCV, Indigenous groups are 7 times more likely to be HCV positive than non-Indigenous populations. First Nations people make up approximately 4% of the Canadian population, but in 2001 were estimated to represent more than 20% of all cases of HCV (CATIE, 2017).

The legacy of colonialism and intergenerational trauma continue to entrench health inequities amongst Indigenous peoples. The intersectionality and compounding effects of social determinants of health such as poverty, limited access to healthcare, unemployment, homelessness, and discrimination impact the ability and willingness of Indigenous populations to access available HCV interventions. Additionally, the inequities faced are linked to the overrepresentation of Indigenous peoples in many groups considered at increased risk for HCV transmission, such as those in unstable housing situations and engaging in injection drug use, involvement in other high-risk activities at an early age, and incarceration.

While British Columbia has yet to adopt a comprehensive framework for eradication, Canada saw three major changes to its HCV approach throughout 2018. First, three new strategies were launched to address both HCV and HIV in Canada. The Canadian Foundation for AIDS Research (CANFAR), the Canadian Network on Hepatitis C (CanHepC), and the Public Health Agency of Canada produced independent reports and strategies outlining goals and steps to address the high rates of blood-borne illnesses. For its part, CANFAR published a report detailing goals and practical applications targeted at ending the HIV epidemic in Canada in five years (CANFAR, 2018). Similarly, CanHepC began the development of a “blue print” for HCV elimination by 2030. Additionally, the Public Health Agency of Canada created the pan-canadian sexually transmitted and blood-borne illnesses (STBBI) framework for action to address and reduce the health impacts of the sexually transmitted and blood-borne illnesses. With the goal of reducing the health impacts of STBBI by 2030, the Federal framework specifies five areas for change: 1) Reviewing and revising policy/law, 2) Facilitating access to basic needs, 3) Data collection and analysis, 4) Access to harm reduction and mental health resources, and 5) Strategies to address stigma and discrimination (CATIE, 2018).

Beyond the adoption of targeted strategies by health agencies and leaders in HCV advocacy, Canada also saw changes to testing guidelines and treatment eligibility. As of 2018, the Canadian Association for the Study of the Liver changed its recommendation for screening criteria. Previously, it was recommended for those engaged in behaviours that may increase the risk of HCV transmission, irrespective of age. Testing is now recommended for all Canadians born between 1945–1975, as well as those engaged in behaviours that may make them more susceptible to HCV infection (CATIE, 2018). As HCV advocates had long-pushed for broader testing recommendation, the change to a universal age-based testing recommendation was welcomed, especially given HCV’s extended latency period of 20–30 years.

In line with the changes to screening recommendations, HCV treatment guidelines also saw a shift in 2018. The successful negotiations between major pharmaceutical firms and Canadian governments helped to reduce the price of HCV drugs. This change in pricing helped to shift policy, making treatment available through Canadian health plans, regardless of the severity of liver injury. Previously, restrictions had been put in place to limit the availability of treatment, partially due to its high costs. The adoption of universal treatment plans now allow Canadians living with HCV access to safe and efficient treatment, thereby reducing the impacts of liver injury, long term damage, and the risk of transmission to other people.

Canada is currently experiencing broad changes to HCV and other STBBI. These changes signal a broader shift in Canada’s approach to testing, treatment and education with regard to HCV. Given the momentum and strides being made at national levels, British Columbia is currently in a position well-suited to the adoption of a comprehensive HCV eradication framework.

# 3. Methodology

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## 3.1 SAN'YAS INDIGENOUS CULTURAL SAFETY TRAINING

Prior to undertaking any research, the research team was required to complete Provincial Health Services Authority's (PHSA) San'yas Indigenous Cultural Safety Training from October to December 2018. The online training is a unique training program designed to enhance self-awareness and strengthen the skills of those who work both directly and indirectly with Indigenous communities. The training is aimed to develop understanding and promote positive partnerships between service providers and Indigenous people.

The San'yas training involves skilled facilitators who guide and support each learner through interactive course materials. Researchers examined culture, stereotyping, and the consequences and legacies of colonization. Researchers learned about terminology, diversity, aspects of colonial history such as Indian residential schools and Indian Hospitals, and a timeline of their events.

The course took approximately ten hours of online training. All researchers were required to present a certificate to FNHA upon completion of the course.

## 3.2 LITERATURE REVIEW

With guidance and direction from FNHA, a literature review was conducted in December 2018 to understand current best practices in Indigenous wellness interventions, gaps in HCV testing, treatment, and prevention, harm reduction and the successes or lessons learned from analogous interventions/research.

Themes that emerged from the literature review include:

- The need for culturally sensitive and relevant practices
- Continued barriers in HCV prevention, testing and treatment
- Lessons learned in addressing HCV prevention, testing and treatment

Research specific to British Columbia and the province's First Nations communities were consulted with the intention of building off their findings and weaving their recommendations into proposed policy options.

The literature review framed the context of the issue and offered relevant areas of research to consider within the context of British Columbia and First Nations communities in the province. The themes from the literature review informed the development of the interview guide and jurisdictional scan to consider as potential policy options.

### 3.3 JURISDICTIONAL SCAN

Following the completion of the literature review, a jurisdictional scan was conducted in tandem with qualitative interviews in January 2019. Cases were chosen through the literature review and as new cases were brought to attention via the interview process.

The jurisdictions that were selected for the report were due to their successes or learnings with HCV testing, treatment, and prevention for First Nations communities. Jurisdictions were selected based on their current initiatives and commitment to HCV eradication, especially those which have a similar history to British Columbia's colonization of Indigenous populations.

The following jurisdictions and their policies were considered:

- British Columbia
- Saskatchewan
- Australia
- Cherokee Nation, USA

Further jurisdictional research examined British Columbia and Canada's policies as they relate to HCV and First Nations. Government policies at the federal, provincial and municipal level were analyzed to understand recent changes to, or gaps in, pharmaceutical/treatment coverage. Further, the scan attempted to identify research or interventions that have been used to understand their successes or lessons learned.

Demographics of HCV infected populations in British Columbia were considered to understand implications of age, geography or behaviours that current interventions may not be adequately addressing.

### 3.4 INTERVIEWS

11 structured qualitative interviews were conducted from January–February 2019 with experts in the field of Indigenous wellness, HCV support and/or treatment, and harm reduction. Many interviewees had intersectional viewpoints of Indigenous health inequities as it relates to HCV. The interviewees worked in fields that range from academia, frontline healthcare provider, non-profit organization to health authority.

The preliminary interview candidates were selected with guidance and direction from FNHA. As the interview process continued, the researchers identified areas which required further analysis and connected with appropriate contacts to gain additional insight.

Nine interviews were conducted over the phone, one via skype, and one in-person interview. Interview lengths ranged from 25 minutes to 1.5 hours.

The interview guide was developed following the completion of the literature review and jurisdictional scan, and was broken into the following themes:

- Background
- Colonialism and healthcare
- Co-infection with HIV/AIDS
- Urban vs rural/geographic equity lens
- Indigenous healthcare/wellness
- Western models
- Harm reduction
- B.C. & HCV
- Conclusion

The interviewees were provided the interview guide and a consent script in advance of their scheduled interview to prepare their answers. The interview guide allowed for the interviews to remain structured if necessary, however the initial introduction provided both researchers and interviewees opportunity to have flowing conversation. Every interview was led by one researcher with a second researcher recording and taking notes.

Participants who did not consent to their name and/or quotes being shared have been made anonymous within the report. Those who consented to being quoted also had the opportunity to review their quotes prior to the report being finalized. A list of interviewees can be found on the following page.

As the research project was conducted by graduate students, limitations were in place to ensure that all activities adhered to ethics standards while also being cognizant of the sensitive nature of the topic. As such, those who were selected for interviews were primarily from HCV-related organizations and/or service providers. In order to abide by ethics standards, the interview process did not intentionally seek out those with lived HCV experience or vulnerable populations.

While some interviewees self-selected to disclose their lived-experience with HCV, at no point during the interviews were participants asked to disclose their health status. The team did, however, seek out the express input of an Indigenous Elder. With guidance from FNHA, the research team conducted an in-person interview and review session with Elder Sandy Laframboise (Sandy Leo). We sincerely thank her for her time, knowledge, and critical feedback, as noted in the report's acknowledgement section.

## LIST OF INTERVIEWEES

NAME	TITLE	ORGANIZATION
Anonymous	Healthcare Provider	Vancouver Native Health Society
Greta Pauls	Registered Nurse (HCV Clinic)	Urban Indigenous Health and Healing Cooperative
Sarah Chown	Executive Director	Youth Co
Anonymous	Community Based Research Assistants	Pacific AIDS Network
Andrea Medley	Research Coordinator	First Nations Health Authority
Cheryl Reitz	Board Member	HepCBC
Anonymous	Program Manager	Provincial Hepatitis C Organization
Daryl Luster	President	Pacific Hepatitis C Network
Sandra Laframboise (Sandy Leo)	Algonquin Métis	Chief, Dancing To Eagle Spirit society
Anonymous	Researcher	Public Health
Jennifer Hawkes	Pharmacist	Northern Health

### 3.5 CHALLENGES

The research conducted faces limitations; namely, the research was not done in collaboration with or by First Nations communities. Further, the number of self-identified Indigenous interviewees was limited.

The identified limitations include:

- Limited scope of research
- Lack of Indigenous perspectives on the research team
- Lack of Indigenous interviewees
- Lack of rural representation
- Lack of published information in other jurisdictions
- Lack of data
- Limited capacity
- Time constraints

A research project of this scope does not allow the researchers to adequately address long-lasting legacies of colonization. Further, time constraints and limited team capacity presented challenges to the number of interviews possible, resulting in a Vancouver/Lower Mainland bias to interview results.

# 4. Literature Review

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For the purpose of the literature review, we explored a variety of different sources to better understand the growing health inequities and high rates of HCV among First Nations communities within B.C., and consider approaches that may work to mitigate these high rates through culturally competent approaches to testing, treatment, and prevention.

This literature review encompasses advances made in HCV testing, treatment, and prevention in Western epidemiology and best practices in service delivery that supports Indigenous perspectives on health and wellness. The existing literature contributes to informing the current needs of First Nations people in British Columbia, as well as highlighting opportunities for culturally safe practices and programming options. The review seeks to add to the understanding of HCV- and Indigenous-specific best practices with the goal of contributing to a made-in-B.C. model for HCV testing, treatment, and prevention for First Nations in B.C.

## 4.1 THE NEED FOR CULTURALLY SENSITIVE AND RELEVANT PRACTICES

A key theme that emerged from the literature review was the need for culturally safe and holistic healthcare options for Indigenous peoples in Canada. A legacy of discrimination within the healthcare system, coupled with a lack of culturally relevant modes of healing, has made many Indigenous people hesitant to access care when needed (Barney, 2005). The importance of integrating Indigenous understandings of health and wellness into Western models of care is exemplified through the high incidence of HCV among First Nations peoples in B.C. Placing Indigenous peoples and Indigenous ways of knowing at the forefront of HCV research, policy, and prevention programs may lead to improved health outcomes for Indigenous peoples throughout Canada (Fayed et al., 2018).

Increasing health practitioners' understanding of Canada's ongoing colonial history and embedding culturally safe practices within the healthcare system has been repeatedly identified as being critical to mitigating the high rates of HCV seen in First Nations populations in B.C. Researcher Gertrude Barney (2005) highlighted this in her paper, *First Nation Perspectives on Why First Nation Youth Are At Risk for Hepatitis C*. Here, Barney recommends that, in order to reduce these high rates, it is necessary to make cultural competency training mandatory for all healthcare providers, ensure that medical spaces are culturally accessible, and increase HCV awareness. She emphasizes the role of Elders and community in implementing these processes. Barney also stresses the need for cultural rehabilitation, whereby Indigenous peoples can connect with cultural practices that support self-respect and positivity, while also ensuring the presence of cultural role models and ceremony.

Barney's desire to expand Indigenous ways of knowing within Canada's healthcare system is echoed in Kallos et al.'s (2016) Water Journey project. Within this work, researchers explored the culturally resonant ways to aid and support Indigenous peoples who have been impacted by HCV. They found that legacies of colonialism and racist health policies left many Indigenous individuals with a deep mistrust of the healthcare system. In particular, historical traumas, compounded with the complex systemic injustices that many Indigenous people face in Canada, continue to shape the realities of people living with HCV. To lessen these barriers, the study identified the need for greater involvement of Indigenous peoples in advancing HCV research and stressed the importance of ensuring that health programming is community-led and guided by the strengths and expertise of Elders.

The profound link between colonialism and adverse health outcomes is further explored by The Cedar Project, a longitudinal health research study based out of Vancouver and Prince George. The researchers here highlight the impact of trauma on individuals, families, and communities, and underscore the importance of addressing the cumulative effects of historical and current trauma through client-driven, culturally safe programming. Similarly to the findings put forward by Kallos et al. and Barney, The Cedar Project identifies the importance of developing programs that address the relationship between unresolved emotional trauma, and stresses the importance of creating increased involvement of Indigenous peoples in the design of health programming.

Comparable themes emerge in Fayed et al.'s (2018) paper, which considers how anti-colonial and trauma-informed approaches need to be applied in order to meaningfully respond to historical trauma and its impact on health. More specifically, the authors highlight the importance of anti-colonial approaches to supporting Indigenous health and wellness.

Research offers strong evidence for the need to incorporate health practices that are rooted in traditional ways of knowing, healing and wellness, in order to address the high rates of HCV infections amongst First Nations populations in B.C. In order to do this, it is necessary to involve First Nations peoples and communities in every stage of the conceptualization of health programming and research priorities; promote cultural safety and culturally appropriate care; and incorporate community-led approaches to wellness within the healthcare system.

## 4.2 CONTINUED BARRIERS IN HCV TESTING, TREATMENT, AND PREVENTION

Indigenous peoples within B.C. continue to face a myriad of barriers in relation to HCV prevention, testing, and treatment. Many of these barriers are linked to issues such as a lack of cultural safety, stigma, and a legacy of discrimination within healthcare settings which may affect access to health services or HCV treatment. Beyond this, geography and a lack of confidential care in remote communities may also add to the barriers faced by First Nations peoples living with HCV in B.C.

Practitioners also face a unique set of challenges when providing HCV prevention, testing, and treatment. Barriers include the lack of a vaccine, treatment failure or resistance, post-cure health issues, stigma, the complex needs of those engaged in behaviours that make them more susceptible to HCV transmission, and the limitations of treatment access (Khan et al., 2018).

Shehata et al. (2018) add to this list of barriers by noting that, although the effectiveness and availability of treatment for HCV have improved, there are still a number of systemic issues making HCV challenging to treat. For example, B.C.'s fee for service (FFS) remuneration model incentivizes shortened physician-patient appointments and disincentivizes the treatment of complex and time-consuming conditions. Compounding these effects is the limited HCV-knowledge on the part of both providers and individuals. Patients typically have little understanding of HCV transmission or symptoms, have a low perceived risk of infection, fear the stigma and discrimination around testing, and may have limited access to healthcare services. To address these barriers, Shehata et al. recommend healthcare providers gain increased awareness of HCV risk factors and developments in treatment options, and actively work to share this information with their patients.

In addition to this, Khan et al. (2018) note that healthcare providers must also adopt holistic programs that incorporate meaningful involvement with the community at every step of the process. Examples of applications include the inclusion of Elders and traditional healers, and community-led ceremony. This, they suggest, will help achieve better health outcomes and reduce barriers for Indigenous peoples living with HCV in Canada.

To to reduce stigma, increase knowledge and prevention, and ensure that all Canadians are receiving adequate HCV care, experts at the Centre for Communicable Disease and Infection Control (2018) suggest that practitioners must ensure that testing is a routine part of care. Blanket testing, in tandem with patient follow-up and discreet and accessible HCV information, may work to ensure that healthcare providers are better supporting HCV prevention, testing, and treatment, while simultaneously working to limit the stigma associated with HCV screening and disclosures.

The importance of screening is echoed by Ha et al. (2016), who suggest that implementing regular testing may help to reduce transmission and infection of the general population. While the authors note cost as a potential barrier, they highlight the option of prioritizing those individuals who are especially susceptible to HCV infection, including: injection drug users, those who have had a blood transfusion or organ transplant, individuals whose mothers are infected with HCV, men who have sex with men, incarcerated individuals, and Indigenous peoples. Although screening is certainly important, others have argued that focusing testing on those groups deemed to be at higher risks of infection may serve to reinforce stigma, discourage individuals from seeking support, and lead to many infected persons remaining undiagnosed (Kallos, 2016).

While barriers to testing and treatment continue to pose challenges to HCV in B.C., advances in treatment provide new opportunities for addressing the issue. The BC Centre for Excellence in HIV/AIDS (2018) has worked to help develop directly acting antivirals (DAAs); drugs that help to eliminate transmission of HCV. DAAs are medications that target specific steps within the HCV lifecycle and cure infected populations in 12 weeks or less through regular treatment. Now that DAAs are more widely available, the BC Centre for Excellence in HIV/AIDS charges that targeting the core transmitters will be essential in helping to eliminate hepatitis C in Canada.

Overall, the effectiveness and availability of treatment for HCV have continued to improve. Moreover, testing and prevention continue to be fundamental components of eradicating HCV amongst Indigenous populations, as cultural, social, educational constraints continue to be a barrier for both service providers and individuals in Canada.

### 4.3 LESSONS LEARNED IN ADDRESSING HCV TESTING, TREATMENT, AND PREVENTION

Reducing community gaps in HCV knowledge requires multiple approaches and perspectives. In one approach, Buller-Taylor et al. developed a free, one-hour, online course for patients and providers in an attempt to increase understandings of HCV, raise levels of engagement for those who require care and heighten the sense of need for follow-ups for those at risk of reinfection. The intentions were to reduce stigma, foster dialogue, and provide alternative, culturally sensitive approaches that build the capacity of both providers and patients. In another approach, Alimohammadi et al. offered a community pop-up clinic to engage with residents of Vancouver's Downtown Eastside (DTES) who use injection drugs. Using OraQuick saliva assay, a rapid HCV test, this method was successful in increasing testing, with 1,283 tests completed and care offered to 50% of those who tested positive – though the approach did not address prevention or social determinants of health as a significant portion of the homeless population lacked engagement and willingness to get tested and/or acquire treatment (Alimohammadi et al., 2018).

At a provincial level, strategic approaches in B.C. and Saskatchewan through the healthcare system saw positive results. As Saskatchewan has been challenged with program delivery in rural areas, the province's intervention has been in the form of mobile clinics that have found innovative ways of delivering information and services. The lack of continuity in care and communication with rural communities, especially those that are First Nations, was identified as a key challenge in this approach. In B.C., the Ministry of Health has made revisions to its strategic policy for viral hepatitis through a series of engagement sessions involving the Ministry of Health, the BC Centre for Disease Control, the BC Centre for Excellence in HIV/AIDS, six regional health authorities, as well as organizations and partners with provincial mandates. The discussions were framed within a syndemic, community-driven approach that focused on social determinants of health, equity, cultural safety, and harm reduction. Eligibility criteria for accessing treatment were identified as non-inclusive, insufficient, and created confusion for providers (BC Ministry of Health, 2016). The participants largely suggested integration of hepatitis prevention, testing, and care, as well as mental health supports with opioid substitution therapy, supervised consumption facilities, and other harm reduction measures to help prevent infection and oversee treatment adherence. Focusing further on Indigenous health, the discussions centred on the need for community-driven and trauma-informed practices that also considered the burden of compounding inequities related to increased predisposition to HCV among some Indigenous groups.

Looking more broadly at Canadian institutions, corrections facilities are particularly overburdened with HCV. A recent analysis from the Public Health Agency of Canada determined that 24% of inmates in federal custody and 23.3% of inmates in provincial or territorial custody are living with HCV (Kouyoumdjian and McIsaac, 2015). With a high incidence rate and limited access to preventative tools, many incarcerated people face the possibility of being infected while in prison. Indigenous prisoners are particularly affected, with roughly one in two Indigenous individuals in prison being infected with HCV. McLay and Silverside (2011) suggest that it is no surprise that rates of HCV in prison are so much higher than those in the general population because there is no official access to sterile syringes, so inmates often resort to sharing drug use supplies. To reduce the prevalence of HCV in prisons, McLay and Silverside argue that there needs to be a shift away from an abstinence approach to stronger harm reduction and education programs, as well as regular HCV testing and treatment provided in corrections facilities or directly upon release.

Among illicit drug users, HCV is one of the strongest predictors of mortality within Vancouver's DTES. Jongbloed et al. (2017) found that those who joined their study with HCV at baseline were three times more likely to die prematurely than other participants. They suggest that the impact of colonization – including intergenerational trauma, systemic racism, a lack of culturally competent care – has led to increased rates of substance use and addiction amongst Indigenous youth, which in turn places these youth at a higher risk of contracting HCV.

Suggestions for mitigating the HCV risk for Indigenous youth include support and counselling, cultural connectivity, education for youth in care, ensuring that youth have options for safe, culturally competent, and non-judgemental health services, implementing harm reduction services, and decolonizing health policy. During the 67th World Health Assembly, the communities identified as being at greater risk of HCV infection are injection drug users, people who are co-infected with HIV, Indigenous persons, and baby-boomers. It is, however, critical that these groups are tested, informed, and treated without added stigma attached to their entire group or the activities they are engaged in.

## 5. Jurisdictional Scan

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Indigenous healthcare in Canada falls under federal jurisdiction but has been delivered in collaboration with First Nations Health Authority since the authority's assumption of Health Canada's programs, services and responsibilities in 2013. The work done by FNHA does not replace the Ministry of Health or Regional Health Authorities. To continue to better support health outcomes of First Nations in B.C., learning can be extracted from the federal government's 2018 launch of the pan-Canadian STBBI framework for action. The federal government's adoption of the STBBI framework focuses on four pillars of care: prevention, testing, initiation of care and treatment, and ongoing care and support (Public Health Agency of Canada, 2018). The framework was developed in consultation with Indigenous organizations, provinces, and clinicians. Provinces can choose to customize the framework in prioritizing STBBI, including HCV and its disproportionate impact on First Nations people. B.C. has not yet adopted the framework, and its current patchwork of HCV-related services would greatly benefit from an overarching directive that guides a united front and streamlining of services that support the eradication of HCV.

Additionally, the federal government has committed to implementing the Truth and Reconciliation Commission's (TRC) Calls to Action. Of the 94 Calls to Action, there are seven that pertain specifically to health. These recommendations focus on the need to address the history of colonization as it relates to health outcomes, provide better healthcare for on-and-off reserve Indigenous communities, create more holistic and culturally-specific health and wellness options, increase the number of Indigenous peoples within the health field, and improve cultural competency training amongst health professionals. It is important to note that progress in implementing these principles has been slow, however, in making a commitment to the TRC Calls to Action, the federal government may help to reduce some of the health barriers facing Indigenous peoples in Canada.

## 5.1 BRITISH COLUMBIA

British Columbia has one of the highest rates of HCV infection in Canada. The following are demographics of those who are infected with HCV:

- The odds of new infection are highest for those born between 1975 and 1984
- 75% are baby boomers (born between 1945 and 1975)
- 35% are born outside of Canada
- 23% formerly used intravenous drugs one or more times
- 20% currently use intravenous drugs
- 4% are incarcerated (28% of incarcerated persons have HCV)
- 3% are in a long-term nursing home
- Behaviours that have the highest risk of infecting others include: tattoo/piercing, men who have sex with men, and users of injection drugs, inhaled drugs, injection steroids and/or crack pipes
- Infected but low risk of infecting others: engaged in behaviours that increase STBBI risks in the past, victims of tainted blood
- Indigenous populations are five times more likely to be infected
- Youth are at the highest risk to adopt behaviours that may increase their risk of contracting HCV if not educated at an early age
- Remote, Northern, and First Nations communities have limited access to testing, treatment and support and the lowest levels of confidentiality
- Newcomers are more likely to be infected with HCV (common practices in their home country, traditional culture, passed onto child via childbirth)
- Those who received blood transfusions from the Canadian blood supply between January 1, 1986 – July 1, 1990

In March 2018, British Columbia's Ministry of Health announced that chronic HCV medication would become available for all through PharmaCare, regardless of the severity of the disease. The government recognizes that HCV is the most frequent cause of premature death among reportable infectious diseases in North America and that it has become the most frequent cause of premature death among people living with both HCV and HIV.

The BC Government reports that in 2017, 2,657 people in B.C. used PharmaCare coverage for medication to treat chronic HCV. These individuals may have had varying levels of coverage due to the severity of their disease and/or their ability to afford treatment. However, while several treatment options were added to the PharmaCare formulary at this time, the PharmaCare payment structure was not updated until January 2019, when it removed the \$200-\$600 deductible required to initiate coverage. This deductible significantly impacted the level of access for low-income and senior users whose incomes fell under \$30,000/year.

Other forms of funding have existed in B.C. People who contracted HCV from a blood transfusion between 1986 and 1990 may have been eligible to have HCV treatment expenses covered by the HCV January 1, 1986 - July 1, 1990 Class Actions Settlement. Individuals who receive income assistance from the Ministry of Housing and Social Development automatically receive health benefits and coverage for prescription drugs through Plan C. Status First Nations and recognized Inuit people can access coverage for their HCV medications through the Non-Insured Health Benefits (NIHB) program.

While HCV has taken the forefront in health priorities since 2015, there are few direct interventions delivered, especially Indigenous-specific interventions or programs targeting those who engage in behaviours that may increase their risk of contracting HCV. Several HCV clinics exist throughout the province, including those that are community-based organizations and those led through health authorities. However, most, if not all, require self-identifying as an individual with HCV and require the individual to attend regular treatment at an office, which may pose a problem for those with limited mobility or fear of a lack of confidentiality.

The BC Government has provided online guidelines for practitioners from 2012, and it is reported that medical schools provide little training on the topic. In recent years, PHSA has provided funding to local non-profit organizations through an Innovation Fund, however, these programs focus on support versus direct treatment. The projects include:

- HIV Stigma and Discrimination within Indigenous Communities
- On the Ground: Laying the Foundation for Hep C Peer Navigation in B.C.
- HIV and Hep C Prevention & Care for Trans, Non-Binary, and Two-Spirit Youth

Other projects, such as Chee Mamuk, an Indigenous program of PHSA that provides innovative and culturally appropriate training, educational resources and wise practice models in STIs, hepatitis and HIV, have helped to deliver culturally appropriate care and resources. Research has been piloted in the way of testing and prevention education, such as OraQuick HCV and an online patient education course led by BCCDC. However, these interventions have not addressed the social determinants of health and the uptake in referrals to treatment has been low.

While changes to pharmaceutical coverage have better positioned B.C. to treat HCV infections, physician and specialist remuneration models continue to present barriers to HCV testing and treatment, as well as complex cases that involve mental health, addictions and co-infection. Pharmacare coverage has resulted in long wait lists for physicians and specialists due to the need for a referral. Further, physicians and specialists are paid on a per-patient basis, which does not address the social inequities of health. While these treatments could be administered by nurse practitioners and nurses, provincial policy would have to expand their scope of practice and adapt existing funding models.

Ultimately, British Columbia does not have a clear strategy on how it will meet the World Health Organization’s goal to eradicate HCV by 2030. British Columbia currently has a patchwork of community-based or non-profit delivery of services and programs which leads to a competition for funding and resources. Very few organizations are focused on delivering culturally appropriate services to B.C.’s First Nations.

## 5.2 SASKATCHEWAN

As per 2016 data, First Nations communities in Saskatchewan had the highest rates of HIV infections in Canada, in addition to carrying the greatest burden of HCV infections. However, through a trio of innovations in community-led approaches, the province is seeing positive results in improving both rates of HCV infections and outcomes, with some First Nations communities having achieved the United Nations’ 90/90/90 goal (Skinner, 2018). The success of these communities’ combined HIV/HCV approach is linked to three innovations: Preventative services (Know Your Status), mobile HCV clinics, and determinants of health associated with behaviours with increased risk of infection.

Grounded in respect for, and integration of, Indigenous ways of knowing, the “Know Your Status” model involves community engagement through education, harm reduction, and prevention, as well as evaluation and surveillance through clinical management (Skinner, 2018). This preventative service approach includes collaboration with lab services, primary care teams, community health partners, as well as harm reduction and education outreach services. Following the allocation of a \$2 million research grant from Canadian Institutes of Health Research, Dr. Skinner has been working in partnership with Big River First Nation to implement the model with communities. Based on an approach that combines Western medicine and traditional Indigenous knowledge, the program seeks to develop community-based and local practitioners’ ability to treat blood-borne diseases, such as HIV and HCV, while enhancing the availability and quality of primary care.

Saskatchewan has also seen success in HCV interventions in the form of mobile clinics. Partnerships between public health agencies, labs, clinic providers, and First Nations communities have served to expand these clinics to more remote regions, with an emphasis on educating and engaging with those who have HCV or who are engaging in behaviours with an increased risk of infection. The services are grounded in culturally safe methods of care with an emphasis on community-led education and prevention. Lastly, the province has acknowledged the role of social determinants of health and the ongoing legacy of colonialism on HCV rates among First Nations people. In addition to providing community-based HCV services, recognition of “factors that promote resilience” are seen as a critical tool to increase the accessibility of health care services among First Nations people (Skinner, 2018). Specifically, garnering the interest of communities and support of its leaders is imperative to increasing the accessibility of services and overcoming HCV-related stigma.

## 5.3 AUSTRALIA

Australia is leading the way in HCV eradication and is on track to meet the World Health Organization's targets by 2026; three years ahead of schedule. The number of Australians dying from liver failure and liver cancer related to HCV has dropped by 20% in the two years since introducing the low-cost medication to the Pharmaceutical Benefits Scheme (PBS) in 2016. Since March 2016, 40,000 people with HCV have had treatment with approximately 95% cured.

Australia implemented HCV treatment with no restrictions based on the individual's stage of liver disease or behaviours such as drug use. Further, there were no caps placed on treatment. Australia is proactive in treating those in corrections facilities and making use of harm reduction interventions. Australia has been efficient in creating health policy that recognizes the necessity of HCV testing, treatment, and prevention, and considers testing to be a priority. The eight basic principles that guide HCV testing in Australia are:

- Confidential, voluntary testing with informed consent and post-test discussion as fundamental to Australia's response to HCV;
- Testing is critical to understanding the epidemiology of HCV infection in the community;
- Testing must be accessible to all those who are or have been at risk of HCV infection;
- Testing will be of the highest possible standard and provided in a timely manner;
- Testing is of benefit to the person being tested;
- Testing can be critical to interruption of transmission and can support harm minimization;
- Testing to monitor people with HCV before, during and after treatment is an integral part of their care; and
- People should not be denied testing because of fear of having their name associated with an HCV test (e.g. in a small community where confidentiality is harder to maintain). De-identified testing should be provided to protect privacy where relevant.

Australia has created a national strategy to reach groups that have higher rates of HCV infection per capita, such as Aboriginal and Torres Strait Islander peoples. Australia's Aboriginal populations are approximately five times more likely to be infected with HCV than non-Aboriginal populations. This stresses the need for culturally appropriate care, education, prevention, testing and treatment to be delivered by Aboriginal Community Controlled Health Services and Aboriginal Medical Services.

Organizations like Hepatitis New South Wales and Lowitja are leading the development of policies, programs and resources that are specifically targeted to support Aboriginal populations in screening, treatment and understanding the disease. Success stories include the Deadly Liver Mob which emphasizes conversation and storytelling and acts as a referral/entry point into treatment if the individual is interested. Peer-led support, storytelling, incentives and curated resources have proven successful in ensuring that HCV resources are utilized and trusted, as many Australian Aboriginals have a deep distrust of the healthcare system.

As the initial uptake for treatment was much higher than expected, Australia is looking to sustain momentum and scale deeper into priority communities through community-led initiatives, and communications strategies that minimize stigma and promote education.

The Australian Government invested \$1 billion over five years to treat the 230,000 Australians living with the disease. Further, the government has committed an additional \$1 million in 2018 to continue education and awareness activities to promote HCV testing and treatment.

Australia's success rates are supported by:

- Consistent federal funding to promote testing, treatment, and prevention
- Widespread harm reduction strategies
- Low barriers and costs for treatment
- Low drug prices from pharmaceutical companies
- Non-specialists may prescribe and administer treatments
- Previously established HIV treatment/drug dependency model support HCV practitioner training

## 5.4 CHEROKEE NATION, USA

Since 2013, Cherokee Nation Health Services (CNHS) has adopted an aggressive HCV elimination strategy to address the disproportionate burden of HCV infections among its members. As the second largest Indian Nation in the United States, CNHS has partnered with the University of Oklahoma and state and federal health officials to develop an innovative strategy built upon strengths of the Cherokee Nation's existing health structures. A key piece of the model is expanded age-based testing for all community members, regardless of risk factors. Counter to the national model that advocates for testing for those in the baby boomer generation, CNHS has adopted blanket screening for community members aged 20-69 based on infection rates and disclosure barriers (Ward et al., 2018). Further to this, they have increased access to testing by adopting "non-conventional" testing clinics within existing care centres, including dental offices, emergency departments, OBGYN clinics, and other health service locations. Of those new HCV cases, 67% were detected in emergency rooms or urgent care clinics (CNHS, 2018).

In addition to increasing screening at both a service and target population level, CNHS leveraged community members' expanded health coverage. This also included financing through the Cherokee Nation itself and a partner university, as well as a pharmaceutical company that subsidized treatment costs throughout the study following the 2014 FDA approval of DAAs (Ward et al., 2018). The availability of new treatment options served as a communications tool in the CNHS education campaign, a key piece of promoting testing and treatment options within the Nation.

Beyond advertising the availability of new treatment plans, the Nation also relied upon community buy-in and promotion from its leaders, including Principal Chief Bill John Baker. The community-based messaging and promotion of testing and treatment options served to reduce stigma and foster trust within the system.

CNHS also implemented harm reduction strategies as well as HCV training programs for local primary care providers. This training followed the ECHO model (Extension for Community Healthcare Outcomes) of “moving knowledge, not people,” whereby specialists train and support community-based providers with the tools to test and treat for HCV. Preliminary results of this approach indicated no difference in HCV cure rates in patients who received treatment from community providers versus those who received treatment from HCV specialists (CNHS, 2018). The approach also includes harm reduction strategies, including opioid substitution therapy and needle and syringe exchange programs. This holistic approach has served the community well thus far, with CNHS having tested more than half of the target population, and of those who have started treatment, 90% have been cured (Ward et al., 2018).

## 6. Interview Results

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To further understand and assess the landscape in British Columbia, eleven in-depth interviews with HCV experts, health professionals, and an Indigenous Elder from B.C. were conducted. Interviewees represented a diverse set of organizations and backgrounds, and each provided a unique perspective related to improving Indigenous health outcomes and mitigating HCV inequities within the province.

Several key themes emerged from the interviews which provided insight into options to increase access to HCV testing, treatment, and prevention for First Nations in B.C. Some of these themes included the need for community-led, culturally safe, and holistic care for First Nations peoples, addressing the specific health needs of rural areas, minimizing stigma through training and peer-support, ensuring patient confidentiality, integrating Elders, Indigenous ways of knowing, tradition and ceremony into health practice, and improving HCV education and treatment efforts.

Although overarching themes did emerge, it is important to note that there is no one Indigenous perspective related to improving health and lessening the impact of HCV. Further, during the interviews, we encountered several conflicting opinions regarding the best ways to reduce HCV transmission and improve treatment and prevention efforts and found that each area of the province is confronted with a unique set of challenges that impact health outcomes.

The knowledge offered by each interviewee provided invaluable insight into the topic. Below is a detailed overview of each interviewee, their field of expertise, and opinions offered during their interview.

## 6.1 INDIGENOUS ELDER

### **Sandy Laframboise aka Sandy Leo - Algonquin Métis, Chief of Dancing to Eagle Spirit Society**

Sandy Laframboise is an Indigenous and Métis Elder adopted by the Tsleil-Waututh nation, prominent HIV/HCV researcher, advocate, and psychiatric nurse. Elder Sandy Leo feels that for the healthcare system to better support Indigenous peoples living with HCV, it is imperative to incorporate Indigenous approaches to healing and wellness into general practice. One framework she feels is important for Canadian health professionals to adopt is the Two-Eyed seeing approach, which draws from both Western and Indigenous health traditions and finds an ethical space in the middle. Importantly, this approach must be adaptable and flexible for each First Nations community. Beyond this, Elder Sandy Leo notes that making space for culturally appropriate care, incorporating widespread harm reduction initiatives (such as a mobile harm reduction van), making dried blood spot-testing more readily available, and training Elders to work alongside health professionals may work to increase the effectiveness HCV of testing, treatment, and prevention within First Nations communities in B.C. Elder Sandy Leo also highlights the importance of treating each person holistically, incorporating ceremony to treat the spiritual and cultural needs of people, suggesting that unless we as a society begin dealing with these root causes from a spiritual and cultural perspective, we will only be providing band-aid solutions. Lastly, Elder Sandy Leo spoke to the importance of making healthcare more accessible by incorporating and facilitating traditional cultural practices and healing more widely within the healthcare system (e.g. through sweat lodges, traditional medicines, etc.), incorporating Indigenous specific approaches to health education through storytelling or puppets, and leaning more on Elders to inform communities about health options.

## 6.2 ADVOCATES

### **Cheryl Reitz - Board Member and Volunteer at HepCBC**

Cheryl Reitz has been involved with HCV advocacy for over 10 years. She began volunteering at HepCBC (Incorporated 1999) in a support role by providing an empathic ear to others living with HCV but later became involved with policy and advocacy efforts. In her role, she has also traveled to First Nations communities throughout the province to provide educational materials and advocacy to others living with HCV. During the interview, she identified several key barriers that affect First Nations peoples' access to testing, treatment, and prevention in rural communities, including distance to healthcare facilities, inadequate infrastructure, and lack of confidential care.

She highlighted stigma and confidentiality as being the issues that most need to be addressed. From a patient perspective, this interviewee also acknowledged the need for increased post-treatment monitoring and follow-up care, and expansion of testing models and approaches. She feels that the healthcare system could work to better support Indigenous peoples living with HCV by training more nurse practitioners and nurses to administer testing and 'specialist-supported' treatment, increasing communication between rural communities and various health authorities, providing better access to DAAs, allowing for more consistent testing and HCV education, and increasing the availability of Telehealth services in rural communities. Moving forward, this interviewee points to successful elimination projects in the United States, such as the Cherokee Nation, as a model for B.C. to mirror.

### **Daryl Luster - Board President at Pacific Hepatitis C Network**

Through his work at Pacific Hepatitis C Network, Daryl Luster focuses on advocacy efforts to shed light on the need for equitable access to HCV care and treatment. He notes that HCV carries a considerable amount of stigma, manifested as discrimination, which has huge ripple effects within HCV communities, impacting the self-esteem and sociability of those living with HCV, affecting HCV specific program development and implementation, and limiting the availability of testing, treatment, and prevention options. In order to meaningfully address high HCV rates within First Nations populations in B.C., he suggests that we must first address the damage and destruction caused by stigma. Beyond this, Luster feels that holistic approaches to healing and wellness that incorporate Indigenous ways of knowing may be helpful in making healthcare more equitable. He also notes that there needs to be more meaningful consultation between Indigenous peoples and care providers. There is no single template that can be used within every Indigenous community, therefore, communication is a key part of ensuring a safe approach to HCV care that recognizes the unique experiences of Indigenous communities. Lastly, Luster highlights that there are gaps in Western approaches to HCV testing, treatment, and prevention. For example, primary caregivers tend to have a limited understanding of HCV and its signs and symptoms, and there are few peer programs to support HCV patients.

### **Anonymous - Public Health Researcher**

According to one researcher, some of the main barriers Indigenous peoples in B.C. face when accessing HCV testing, treatment, and prevention include ongoing racism and colonial practices within the healthcare system, intense stigma related to the diagnosis (due to the perceived relationship between HCV and injection drug use), and the ways in which treatment is offered (e.g. new DAAs are expensive and difficult to access, there are long waitlists to be seen by a specialist, and many people outside of urban centres have difficulty being seen by a doctor they trust). This researcher notes that, in order to improve the health and well-being of First Nations communities in B.C., it is necessary to address the health impacts of colonialism. Beyond this, in order to mitigate the effects of HCV, this researcher highlights the importance of meaningfully engaging with Indigenous communities to ensure that community-led testing, treatment, and prevention options are available.

Notably, this ensures that the HCV approaches being adopted by care providers are culturally resonate and appropriate, and necessarily incorporate the knowledge held by First Nations peoples. Finally, the researcher feels it is imperative to incorporate holistic approaches to health and wellness more widely within the healthcare system, otherwise it is a missed opportunity to address the disproportionate impact that HCV has on Indigenous peoples.

#### **Anonymous - Community Based Research Assistants at Pacific AIDS Network**

According to this team, some of the main reasons why Indigenous peoples in B.C. are disproportionately affected by HCV include the ongoing impacts of intergenerational trauma in tandem with a lack of culturally safe or relevant spaces, widespread stigma and discrimination within the healthcare system (and interconnected institutions), a lack of adequate and safe transportation options, and limited access to confidential care in rural communities. They feel that in order to address these issues, it is imperative that health providers focus on client-centred care. This model recognizes that clients and communities know best, and works to ensure that health policy and programs are community-led. Beyond this, the team stresses the need to better incorporate peer training and peer-led initiatives into the health system in order to lessen the stigma felt by people living with HCV, and prioritize culturally safe care options. Lastly, the interviewees highlight that peer support is absolutely crucial in conceptualizing a better framework for HCV care.

#### **Anonymous - HCV Advocate**

The advocate identified several reasons why Indigenous groups in B.C. are disproportionately impacted by HCV. For example, they point to the lack of Indigenous sovereignty in making decisions around healthcare, challenges in accessing land, culture, food and community, and use of substances to cope with challenging realities, which may lead to HCV transmission or re-infection. This advocate suggests that some of the main barriers Indigenous youth face in accessing HCV testing, treatment, and prevention, include a lack of free transportation to access care, a lack of Elder representation within the healthcare system, and insufficient knowledge sharing.

On a more structural level, they also note that stigma related to harm reduction, increased surveillance of people who use drugs, a lack of education from health providers, and a lack of culturally safe models within the healthcare system may also lead to high levels of HCV transmission. They suggest that better integration of Indigenous models of care, such as being able to access food, culture, and medicine in the same space would have a positive impact on the relationship between Indigenous youth and the healthcare system. In addition, she notes that providing services such as childcare, safe transportation to and from appointments, not giving up on people (within our colonial, capitalist healthcare system), and supporting individuals through integrated support systems, would all lessen the burden many Indigenous youth experience when accessing healthcare. Lastly, this advocate speaks to the need to educate people about HCV at a younger age, in order to better develop skills to talk about these issues, and de-stigmatize HCV.

## 6.3 HEALTH PROFESSIONALS

### **Greta Pauls - Registered Nurse at Urban Indigenous Health and Healing Cooperative**

Greta Pauls is a registered nurse specializing in HCV care. Currently, Pauls works with the Urban Indigenous Health and Healing Cooperative, which is a primary care clinic in Vancouver's Downtown Eastside (DTES). Based on her experience, Pauls attributes the high incidence of HCV within Indigenous communities to a number of intersecting factors. Some examples include historical trauma, poverty, cultural stigma related to HCV, systemic and structural racism within the healthcare system, and a lack of clarity or lay-language used within healthcare settings. In order to mitigate high rates of transmission, Pauls points to harm reduction efforts within the Downtown Eastside. She suggests that harm reduction needs to begin with educating folks about various routes of transmission other than sharing injection drug use supplies, such as sharing pipes or engaging in unprotected sex. She also feels that special care needs to be made for those transitioning out of prisons, as they are especially susceptible to contracting HCV. In order to make HCV care more accessible for Indigenous patients, Pauls suggests that it is important to listen to each client's unique needs, and support them in accessing healthcare the way that they want to access it, integrate Elders, culture and ceremony into the healing process, utilize pre-existing and trusted patient-client relationships, and use non-stigmatizing language to minimize the shame associated with HCV, as stigma and shame deters people from testing, and/or following through with treatment.

### **Jennifer Hawkes - Pharmacist at Northern Health**

As part of the regional care team for Northern Health, Jennifer Hawkes provides support to patients and health providers in Northern B.C. Operating mainly out of Prince George, Hawkes interacts with many individuals from remote communities across northern B.C. and has noticed several discrepancies in relation to rural First Nations' access to healthcare. For example, she highlights the need for outreach health professionals that meet rural community members where they are at, increased harm reduction services and education within rural areas, more straightforward testing options (that can be implemented by non-healthcare providers) and treatment (that can be prescribed by general practitioners and nurse practitioners), and increased access to testing for those who have had blood-to-blood contact with someone infected with HCV.

Hawkes also echoes other health experts by pointing to the historical impacts of intergenerational trauma, the overrepresentation of First Nations peoples in prisons, and systemic racism and stigma within the healthcare system as being key factors that may lead to higher rates of HCV within Indigenous populations. In order to lessen HCV transmission within rural communities, Hawkes feels that there is a need for better transportation networks, which would allow rural community members to more easily travel to Prince George or other central locations to access confidential testing and treatment, more health supports for incarcerated populations, and increased availability of opioid substitution therapies such as suboxone (which many rural B.C. communities are still struggling to get access to) and detox centres.

### **Andrea Medley - Harm Reduction and Special Education Coordinator at First Nations Health Authority**

As a Harm Reduction and Special Education Coordinator with the First Nations Health Authority, Andrea Medley feels it is imperative to incorporate holistic approaches in relation to HCV testing, treatment, and prevention, and follow the lead of community. Medley notes that there are several gaps to care that disproportionately impact Indigenous peoples in B.C., including a lack of meaningful engagement or consultation between health authorities and Indigenous communities, too much of a focus primarily on testing rather than education and after-care supports, lack of Indigenous representation within the health system, and stigma towards people who use substances. Medley also highlights key barriers that are specific to HCV testing, treatment, and prevention within First Nations communities in B.C. She first points to the time people often have to wait for testing, lack of access to community-based care, and stigma around testing due to a lack of confidentiality. Further, she notes that racism and assumptions within the healthcare system and misinformation around treatment pose barriers. Medley suggests that in order to better support access to HCV care, it is necessary to ensure that there is more Indigenous representation within the healthcare system (through hiring and consultation with Indigenous communities), holistic, culturally safe practices are more readily incorporated, testing and treatment are better integrated with Indigenous models, and more people with lived experience are included into health and policy discussions.

### **Anonymous - Healthcare Provider at Vancouver Native Health Society**

According to the healthcare provider, a lack of trust or rapport between the practitioner and patient, widespread stigma and misinformation about HCV, past trauma, and shame or stigma around drug use are some of the main factors that lead to higher rates of HCV amongst Indigenous groups in B.C. In order to mitigate these heightened rates, this healthcare provider feels that it is the responsibility of care providers to decolonize their practice by offering consistent and regular support, meeting clients where they are at, and integrating Elders and holistic approaches to health and wellness into the kinds of care they provide. They suggest that one way to address the stigma attached to blood-borne illnesses such as HCV is to provide birth cohort screening as per CDC guidelines, regardless of lived-experiences. While the screening is not intended to reduce stigma in and of itself, it is a byproduct of identifying new diagnoses through birth date versus behaviours that increase the risk of infection. Lastly, they note that it is imperative to focus on addiction when considering testing, treatment, and prevention options for people living with HCV. This might mean incorporating the entire community as part of one's healing, offering opioid replacement therapies or other addiction supports, as well as building relationships and being consistent with patients so they feel comfortable opening up about their experiences.

# 7. Criteria and Measures

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The criteria and measures were developed and selected to assess policy options based on the findings from the literature review, jurisdictional scan and expert interviews. The research identified key challenges and desired outcomes in the context of HCV testing, treatment, and prevention for First Nations in B.C. Many of the criteria and measures apply to the broader Indigenous population and non-Indigenous populations as HCV remains a public health issue in B.C.

Security and protection is a key objective as the lives of individuals are at stake if action is not taken to reduce the incidence rate of and lack of awareness surrounding HCV. The criteria is divided into testing and treatment sub-criterion and outline the key outcomes the policy options should aim to achieve (as outlined in the next section). One important note on the numerical value of the prevalence of HCV among First Nations peoples is to consider that as testing increases, a greater number of cases will be identified which may appear as a growing incidence of HCV; however, these values will shine light on existing cases alone and will enable more HCV infected individuals to be treated. In the long-term, prevention is key to reducing the number of new infections; however, in the short-term, treatment as prevention will be key to reducing the number of infections.

Equity was selected as another key objective. A barrier identified for First Nations in B.C. is the lack of culturally safe and appropriate care options within the current healthcare system. Systemic discrimination against Indigenous peoples has resulted in a lack of trust and engagement with the healthcare system. As such, equity is to be addressed with efforts to increase cultural safety by integrating Indigenous perspectives into services and the practice of healthcare providers. Increasing cultural safety is a key theme that emerged from all interviews and is therefore a central component of the analysis.

The secondary objectives identified were to achieve manageable administrative complexity; maintain reasonable cost; and maximize stakeholder acceptance across organizations and authorities to the highest extent. Administrative complexity is a measure of the inter-institutional collaboration in implementing policy recommendations. It is critical that the relevant health authorities and organizations are one in mind and action, which also directly impacts the issue of equity. The greater the collaboration, the greater the understanding of best steps forward, considering all perspectives. Stakeholder acceptance is also important in ensuring the policy moves forward as planned. The acceptance from First Nations communities, HCV advocacy groups, public health organizations, healthcare professionals and educators will allow for the recommendations to be implemented with support, furthering the potential for success. Lastly, cost is an important objective to consider, as the budget will influence the feasibility of the recommended options and therefore must be considered as a key part of the analysis process. The secondary objectives will require internal analysis by FNHA to access the specific details and requirements of the criteria.

## CRITERIA AND MEASURES

OBJECTIVE	CRITERION	MEASURE
Key Objective 1: Security & Protection	Increase in testing for HCV among First Nations in British Columbia	Projected increase in the portion of the First Nations population in B.C. that is tested for HCV
	Increase treatment for those First Nations in B.C. infected with HCV	Projected increase in the portion of those First Nations infected with HCV who access treatment
Key Objective 2: Equity	Integration of First Nations perspective on health wellness (FNHA wheel)	Degree to which First Nations perspective on health and wellness is integrated into policy
Administrative Complexity	Increase inter-institutional collaboration	Number of relevant health authorities and agencies required in the implementation of the policy
Stakeholder Acceptance	Stakeholders accepting and engaging in policy options	Degree to which stakeholders communicate acceptance of policies (First Nations communities, HCV advocacy groups, public health organization, health care professionals, educators)
Cost	Cost to FNHA and potential costs to stakeholders	Projected budget of policy option
Key Objective 1: Security & Protection	Increase in testing for HCV among First Nations in British Columbia	Projected increase in the portion of the First Nations population in B.C. that is tested for HCV
	Increase treatment for those First Nations in B.C. infected with HCV	Projected increase in the portion of those First Nations infected with HCV who access treatment
Key Objective 2: Equity	Integration of First Nations perspective on health wellness (FNHA wheel)	Degree to which First Nations perspective on health and wellness is integrated into policy
Administrative Complexity	Increase inter-institutional collaboration	Number of relevant health authorities and agencies required in the implementation of the policy
Stakeholder Acceptance	Stakeholders accepting and engaging in policy options	Degree to which stakeholders communicate acceptance of policies (First Nations communities, HCV advocacy groups, public health organization, health care professionals, educators)

# 8. Policy Framework - Three Levels of Intervention

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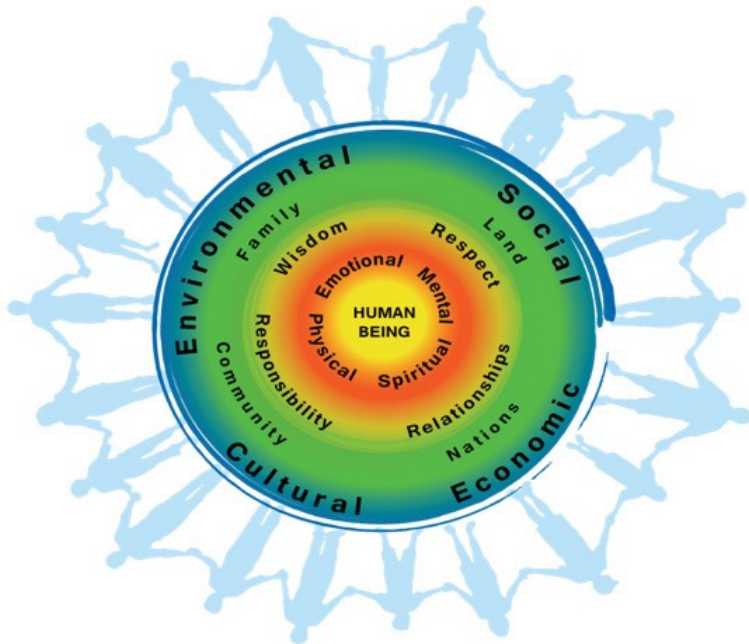


Figure 1: First Nations perspective on health and wellness



Figure 2: Levels of Intervention

Throughout the research, it became evident that given the scope and nature of the policy problem, singular policy interventions would not effectively contribute to the goal of increasing HCV testing, treatment, and prevention for First Nations in B.C. The challenges identified by interviewees highlighted that beyond addressing testing and treatment needs of the individual, a made-in-B.C. HCV model should advance streamlined approaches at both the provincial and service provider level.

As the prevalence of HCV among First Nations in B.C. is compounded by historical trauma and ongoing legacies of colonialism, policy options must be supported through a holistic approach that upholds Indigenous perspectives on health and wellness at every level of intervention. In response to this, the development of policy options was undertaken with two considerations in mind. First, options must account for both Western epidemiological understandings of HCV as well as Indigenous perspectives on health and wellness as per the Two-Eyed Seeing method. Second, policy options must attempt to address the systemic barriers related to HCV prevention, testing and treatment, and should therefore approach the problem at three levels of intervention: provincial policy, service providers, and the individual. A visual representation of this approach can be seen above (right), alongside the First Nations perspectives on wellness (left).

As suggested by the research, addressing only one of these three areas will limit the successful eradication of HCV and long-term outcomes of other intervention methods. The following subsections highlight the need for each of the three levels of intervention.

## 8.1 INTERVENTION LEVEL I - PROVINCIAL POLICY

The provincial policy level of intervention seeks to address the systemic issues that limit HCV testing, treatment, and prevention, as well as to unify the efforts of existing groups and healthcare providers with streamlined support and guidelines. The literature and interviews noted that the opioid crisis has taken precedence within the province, and as such, B.C.'s HCV approach has not been given priority. This has resulted in siloed care, with health agencies and service providers working without an overarching framework. Therefore, policy options designed to promote the testing, treatment, and prevention of HCV amongst First Nations in B.C. should aim to address these service gaps. Supported by the jurisdictional scan, formal, overarching eradication strategies streamline services and offer guidance and clear priorities to service providers and the public. In looking to jurisdictions with eradication strategies and the recent launch of the federal government's sexually transmitted and blood-borne illnesses framework (STBBI), it is clear that advocacy needs to be undertaken to encourage the provincial government to adopt a similar path.who have had blood-to-blood contact with someone infected with HCV.

## 8.2 INTERVENTION LEVEL II - SERVICE PROVIDERS

Service providers are a key level of intervention when considering testing, treatment, and prevention of HCV. The findings pointed to opportunities and limitations of leveraging service providers, and also indicated the importance of shifting away from HCV models that rely heavily on specialists. Given the advances in testing and treatment options, service providers are more capable than ever to identify, treat and support those with HCV. However, there are many systemic factors that continue to pose barriers. For example, a general lack of clinical education, the appropriate means to identify and treat HCV, personal biases and institutional discrimination. This intervention level is largely intended to account for the short- and medium-term opportunity to increase HCV testing and treatment while also seeking to embed Indigenous perspectives on health and wellness into the healthcare system.

To support a suitable intervention at this level, organizations and practitioners that interact with First Nations living with HCV via primary care, support services or harm reduction need options for testing, treatment, and prevention that utilize existing channels of HCV care and incorporate Indigenous perspectives on wellness. Beyond expanding on existing structures that facilitate HCV testing and treatment, the analysis sought to address challenges such as accessibility, confidentiality, community relevant and culturally safe initiatives.

## 8.3 INTERVENTION LEVEL III - INDIVIDUAL

First Nations in B.C. who are currently infected with HCV, and those who may become infected with HCV, are the final level of intervention. Many of the barriers to testing, treatment, and prevention of HCV are underpinned by stigma that spawns from fear and a lack of education. As a result, engaging the public and actively reducing stigma towards HCV plays a critical role in promoting testing, treatment, and prevention. Further, the research highlighted the need for interventions that actively engage with First Nations at the individual level in order to foster trust in the healthcare system. By including this third level of intervention, policy options can leverage a bottom-up approach to testing that supports both short-term increases in testing and treatment, and more long-term improvements to prevention.

# 9. Policy Options at Each Level of Intervention

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The following subsections provide an overview of the recommended policy and alternative policy options at each of the three levels of intervention.

## 9.1 POLICY OPTIONS FOR INTERVENTION LEVEL I - PROVINCIAL POLICY

### **9.1.1 Recommended Policy Option: FNHA encourages the adoption of a formal HCV strategy by the provincial government**

In addressing the provincial policy level of intervention, the recommended policy option proposes that FNHA, in partnership with HCV advocacy groups, Indigenous communities, and Indigenous Elders, encourage the provincial government to prioritize HCV eradication through the adoption of a formal strategy that promotes testing, treatment, and prevention for First Nations peoples in B.C. This strategy seeks to leverage the collective power of service providers, advocacy groups and health authorities to unite their efforts. Based on the research, it is clear that HCV-related services in B.C. would benefit from an overarching directive that guides the implementation of HCV supports. Further, the adoption of a formal strategy with objectives and timelines would provide all relevant actors with prioritized actions and deliverables, as well as put HCV at the forefront of services.

### **9.1.2 Analysis**

Guided by key findings in the research, this option seeks to address the two overarching criteria established in section seven: Increased testing and treatment of those First Nations living with HCV, and the degree to which Indigenous perspectives on health are incorporated. As this option is a high-level approach that is intended to have government adopt a formal eradication strategy, it is projected to effectively address the first criteria through the prioritization and promotion of prevention, testing, and treatment of HCV, as B.C.'s current patchwork of systems does not adequately do so. A provincial strategy would also promote HCV eradication within remote and rural First Nations communities by opening lines of communication between health providers, creating incentives to improve HCV testing, treatment, and prevention options, and eliminating some of the barriers to care. This proposed provincial strategy would also help to unify advocacy groups and leverage their collective expertise in addressing systemic barriers.

Though this option is projected to meet the two key criteria, its high-level approach does not adequately address the immediate concerns of those living with HCV. It is anticipated that this approach will require increased collaboration between FNHA, First Nations communities, and service providers, which will take time to accomplish. As such, this policy option is intended to be implemented alongside more immediate interventions at the other two levels of intervention.

### **9.1.3 Alternative Options Considered**

Throughout the policy development phase, a number of options to create a unified approach to HCV eradication were considered. For example, that FNHA work with provincial health authorities to incorporate Indigenous perspectives into the training of all healthcare providers, lobbying for changes in healthcare practitioners' scope, modify physician and specialist remuneration models and province-wide changes to testing guidelines. While these options all sought to meet the key criteria, they were limited in their ability to signal a wide-scale shift in the province's commitment to addressing HCV and the impact this has on long-term eradication goals. Further, the interview results highlighted the need for the streamlining of HCV care and services, which would be best addressed through a collaborative provincial strategy.

## **9.2 POLICY OPTIONS FOR INTERVENTION LEVEL II - SERVICE PROVIDERS**

### **9.2.1 Recommended Policy Option: Expanded use of dried blood spot-testing through mobile clinics**

Informed by advances in testing options and successful practices in other jurisdictions, this intervention at the service provider level proposes the expanded use of dried blood spot-testing through the use of mobile clinics. As demonstrated by Saskatchewan's successful implementation, mobile clinics serve to "meet people where they are at," a recurring principle identified throughout many interviews.

This option would see service providers travel to communities, both urban and rural, on a rotating basis to administer community-wide testing and/or treatment. Additionally, these clinics would offer harm reduction resources and counsel. Beyond making treatment physically accessible through the use of mobile clinics, this option includes provisions that communities lead the initiative and encourage widespread testing as a means of reducing stigma and ensuring active participation.

### **9.2.2 Analysis**

This option's ability to increase the testing and treatment of HCV for First Nations in B.C. is rooted in its accessibility and community-led implementation. By accounting for both rural and urban First Nations populations, mobile testing clinics help to increase testing for diverse populations across the province, many of whom are unaware of their status. Additionally, this option is intended to reduce stigma and normalize testing, similar to the blanket-testing approach used by the Cherokee Nation. Mobile clinics seek to conduct widespread community testing instead of having individuals opt-in based on risk behaviours, thereby reducing the stigma attached to testing itself. Further, the simplicity of dried blood spot-testing increases testing efficiency as it does not require any credentials (other than minimal training) to administer.

In looking to how this option incorporates Indigenous perspectives on health and wellness, it is proposed that community-led testing days be organized with guidance from Indigenous leaders within the community. Additionally, clinics should be staffed by providers who self-identify as Indigenous, or those familiar with Indigenous perspectives on health and wellness. The mobile clinics should also consult heavily with the community and its Elders in the lead-up to and following testing days.

### **9.2.3 Alternative Options Considered**

The development of options at the service provider level included a number of alternatives that sought to encourage testing, treatment, and prevention of HCV. Consideration was given to non-traditional testing locations, mail-in testing kits, mandatory cultural safety and humility training for physicians, and the adoption of plain-language communication toolkits for service providers. While each of these options aimed to address specific pieces of HCV, they were limited in their ability to increase the uptake of the interventions or bridge the urban-rural gap identified throughout the literature and interviews. More specifically, non-traditional testing locations presented challenges with regard to confidentiality, while mail-in testing kits didn't provide enough in-community support. Options linked to cultural safety, such as training and plain-language communication may help to improve patient/provider relations, but were not deemed as effective as mobile clinics in promoting HCV testing and treatment in the short-term.

## 9.3 POLICY OPTIONS FOR INTERVENTION LEVEL III - INDIVIDUAL

### **9.3.1 Recommended Policy Option: Indigenous focused public education campaign**

To promote testing, treatment, and prevention of HCV at the individual level, culturally specific information must be shared to reduce stigma. The recommended option seeks to engage the public while ensuring all materials incorporate Indigenous perspectives on health and wellness. To encourage the use of available services, this proposed information campaign would be conceptualized and guided by Indigenous communities. As per our findings, key messaging should promote widespread testing regardless of the perceived likelihood that someone may contract HCV, highlight the availability of newly available treatment options, and share successful testing and treatment stories. In keeping with current FNHA communication strategies, this campaign should be developed in partnership with communities, and reflect Indigenous ways of knowing.

For those communities where educational campaign advertising may not be appropriate, the option includes the development of educational materials that First Nations communities can use alongside traditional ways of storytelling or knowledge sharing.

### **9.3.2 Analysis**

The option is intended to encourage testing while also promoting the availability and effectiveness of new treatments. Given the stigma surrounding HCV, interventions must address public perceptions of both infection and treatment, and promote accurate education on the topic. Looking to jurisdictions that have seen success in their HCV eradication process, many of them work to actively dismantle stigma at the community level by encouraging widespread testing and education. In doing so, the focus is shifted to the success of treatment options instead of risk behaviours. To see success, messaging should therefore highlight the ease and accessibility of testing and treatment, as well as disassociate the infection with negative connotations.

In order for this option to satisfy Indigenous perspectives on health and wellness, it is necessary for the campaign to be conceptualized and delivered in collaboration with Indigenous communities. Messaging developed in partnership with communities, Elders and those with lived experience and focused on Indigenous ways of knowing offers opportunity to promote culturally safe practices. Similar to FNHA's approach to the "my health is Indigenous" campaign, this option seeks to align messaging with community needs and focus on addressing the social determinants of health impacting First Nations in B.C.

### **9.3.3 Alternative Options Considered**

Consideration was given to alternative individual level interventions, such as harm reduction programs like needle distribution, pipe distribution and opioid substitution therapy. While expanding harm reduction services may contribute to a decrease in infections in the short-term, individuals remain at-risk of future infection if they don't have access to adequate information and fear treatment or uncovering infection. As such, the analysis determined that a broader approach to public education would contribute more successfully to the long-term eradication of HCV, though the strengths of harm reductions options have been integrated into implementation strategies discussed in section 10.

## **10. Recommendations and Implementation**

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To ensure that the recommended policy options capture the complexity of HCV infection among First Nations in B.C., FNHA should ensure all three levels of intervention – provincial policy, service providers and individuals – are given due consideration. Because each level of intervention is interconnected and holds equal importance in mitigating HCV infection, there is no particular order to the way in which they are implemented. Therefore, recommended options at the three levels are not in any particular order of implementation as all three levels are of equal importance and complementary.

### **10.1 PROVINCIAL POLICY - ADOPTION OF A PROVINCIAL HCV STRATEGY**

The provincial adoption of a strategy that emphasizes HCV eradication by 2030 is the population level recommendation that will facilitate action. Our team recommends FNHA encourage the provincial government to adopt a formal HCV strategy modeled after the Pan-Canadian STBBI Framework for Action. In doing so, the provincial government will show its commitment to fighting sexually transmitted and blood-borne infections, including HCV, and its disproportionate impact on First Nations populations. To be effective, the adoption of this strategy should be conceptualized with Indigenous perspectives on health and wellness through collaboration with community leaders, those with lived experience, and Elders. As such, it is recommended that FNHA work actively with HCV advocacy and Indigenous health organizations in encouraging the provincial government to adopt a formal HCV eradication strategy.

## 10.2 SERVICE PROVIDERS - EXPANDED USE OF DRIED BLOOD SPOT-TESTING THROUGH MOBILE CLINICS

Service providers are at the forefront of the HCV challenge and require tools that will enable their work towards reducing the burden of HCV, specifically amongst First Nations peoples. At this intervention level, our team recommends an expanded use of dried blood spot-testing delivered through mobile clinics across the province. Dried blood spot-testing allows for a broader set of diseases to be tested for, reducing the stigma attached to HCV and behaviours associated with HCV infection. Mobile clinics will allow for increased accessibility of testing in smaller communities, and improved confidentiality as the providers in the mobile clinics would not be local to the community being served. Importantly, the confidential and accessible care available may also help to reduce stigma around HCV testing and treatment. The mobile clinics should also provide harm reduction supplies and education, such as needle and pipe distribution, mouthpieces, alcohol swabs, information related to opioid substitution therapy or detox, condoms, culturally safe services including access to Elders or smudging, counselling, Narcan, etc. Further, the availability of treatment programs is crucial as follow-up to testing. The implementation of this policy option requires significant resources for the training of service providers, acquiring mobile clinics and ongoing program delivery. However, this also offers opportunity to train community members and develop human capital. The number of mobile clinics and staff supporting each community can be decided upon in collaboration with communities to ensure that their needs are adequately met.

## 10.3 INDIVIDUALS - INDIGENOUS FOCUSED EDUCATION CAMPAIGN

Given the complexity of the challenges underlying HCV infection rates, those with HCV may be unaware of their HCV status, what their diagnosis means, resources available and what steps they need to take to access support. At the level of the individual, our team recommends an information campaign led by FNHA encouraging First Nations communities to know their HCV status and seek treatment. This campaign will ensure that stigma is not part of the image of HCV, and promote testing among all groups of people, regardless of the activities they are engaged in. In support of the campaign, educational materials would be created that address the barriers to testing and treatment, in partnership with communities and Elders. Additionally, these materials can be used in community information sessions to relay the message from FNHA, as well as provide onsite testing to further reduce HCV stigma and encourage everyone to know their status.

# 11. Conclusion

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HCV eradication in First Nations communities across British Columbia is possible. Epidemiological advances have ushered in an era of treatment as prevention that offers hope to individuals, service providers and governments alike. However, jurisdictions where HCV eradication has been made a top priority – especially for populations who face health inequities and discrimination within the healthcare system – have made great strides towards meeting their World Health Organization mandate to eradicate viral hepatitis by 2030.

Although policy in British Columbia has made HCV eradication medically and financially feasible, the social determinants of health of First Nations populations must become the focus of intervention and policy. As confirmed by the research, First Nations populations fear stigma and compromised confidentiality; lack culturally appropriate, safe and relevant interventions as care and treatment; and face barriers in access to testing and/or treatment.

As much of the research indicates, successful Indigenous interventions make use of holistic approaches to healthcare and wellness. Recommendations and interventions that aim to support the health outcomes of First Nations through testing, treatment, and prevention of HCV must be conceptualized with Indigenous perspectives such as Two-Eyed Seeing (which allows for the successes of Western medicine to be blended with the strengths of Indigenous ways of knowing and healing) to create positive changes. Frameworks which blend Indigenous perspectives on wellness must be incorporated into all stages of testing, treatment, and prevention to see success. Government policy must outline the priorities and actionable objectives of the eradication of HCV to unite current efforts and lay the groundwork for minimizing stigma and promoting educational outcomes. Two-Eyed Seeing Service providers who take the time to build rapport and make room for Indigenous ways of knowing significantly increase the chance of stronger health outcomes in the context of HCV and potentially beyond. Long-term success hinges on foundations built in partnership with First Nations.

Finally, meeting those who are infected with HCV and those who engage in behaviours with increased risk of HCV infection where they are at is essential when considering options for testing, treatment, and prevention of HCV. As many are unaware of their status and face barriers such as discrimination or mobility in accessing the healthcare system, mobile and blanket testing activities allow for healthcare providers to identify new cases in a low-barrier setting, offer referrals for treatment, provide education, reduce stigma and extend an invitation to uptake treatment in a future testing visit. As the research confirmed, the demographics of those who are, or are likely to be, infected with HCV vary greatly and as such testing cannot be limited to a specific segment of the population.

Each of the policies recommended in this report have been an attempt to holistically tackle health inequities in First Nations communities in B.C. in the context of HCV. Further work must be done to weave in Indigenous conceptualizations into the implementation plan and community acceptance and engagement.

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# 13. Appendix

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## 13.1 INTERVIEW GUIDE

### Interviewer's checklist

- Introduce yourself, notetaker and project
- Review consent script
- Confirm length of interview and if interviewee has any questions

### Section 1 - Background

Q - What role does your organization play in supporting those living with HCV?

Q - Can you tell me about your role and how long you've been working with individuals living with HCV?

Q- How do you see the social determinants of health affecting the rates of HCV amongst the populations you work with?

### Section 2 - Colonialism & Healthcare

Q- In your view, do you feel there are any reasons why Indigenous groups in BC are disproportionately impacted by HCV?

Q- Which key social determinants of health would you identify through your experience as being most closely related to HCV infection amongst indigenous groups?

Q- How could the current healthcare system work better to support Indigenous peoples living with HCV?

Q- What are key barriers within the current healthcare system that prevent effective testing/treatment/prevention of HCV for Indigenous populations?

Q- In the context of HCV testing/treatment/prevention, what is your conceptualization or definition of 'cultural safety'?

### Section 3 - Co-Infection

Q - Based on your experience, why do you think HCV/HIV co-infection is so prevalent in BC?

Q- Further, how do you feel that we can reduce the incidence of co-infection within 'at-risk' communities? ('at risk' can mean drug users, folks who have been incarcerated, people who engage in risky sexual behaviour, etc)

Q- Do you feel that stigma and/or misinformation around HCV plays a role in the transmission of HCV amongst vulnerable populations? What about failed opportunities for adequate treatment of HCV amongst infected populations?

#### **Section 4 - Urban vs Rural/Geographic Equity Lens**

Q - In your view, what are some of the biggest barriers in HCV testing/treatment for rural communities in BC?

Q - In your opinion, are there any existing or imagined solutions to these barriers?

Q - How well would telehealth services work in remote, Indigenous communities? Why do you think that?

Q- In your view, what are some of the biggest barriers in HCV testing, treatment, and prevention for incarcerated individuals?

Q - In your opinion, are there any existing or imagined solutions to these barriers?

#### **Section 5 - Indigenous Healthcare/Wellness**

Q - In terms of integrating Indigenous models of health and wellness, are there specific examples that you view as being more successful than others? What supported the success of these models/programs?

Q- How can Indigenous models of health and wellness be translated into HCV testing, treatment, and prevention?

#### **Section 6 - Western Models**

Q - Are there gaps in health care providers understanding on HCV risk, testing, care and treatment options? What about their knowledge surrounding the PharmaCare process for drug coverage and parameters for eligibility?

Q- How could our current health system work to better support healthcare providers to deliver culturally safe forms of medical care for Indigenous populations?

#### **Section 7 - Harm Reduction**

Q - In your view, how, if at all, may harm reduction models (such as needle exchange programs) play a role in reducing HCV transmission?

Q- There is a lot of literature about how individuals who are/have been incarcerated have a higher chance of contracting HCV. In your opinion, how could these institutions work to reduce such high rates of transmission?

Q- Further, some experts have suggested that stigma, a lack of health education, and an abstinence approach to harm reduction have increased the chances of people contracting HCV while incarcerated. What are your thoughts on this?

#### **Section 8 - BC & HCV**

Q- BC has one of the highest rates of HCV infection in the country. In your opinion, what are some of the barriers BC faces in reducing the incidence rate?

#### **Section 9 - Conclusion**

Q- Is there anything else you would like to add to support our understanding of a made-in-BC framework for HCV testing, treatment, and prevention for Indigenous populations?

## 13.2 CONSENT SCRIPT

### **Participant Consent Form**

Researchers: Mahsa Athari, Chantal Esperanza, Jenn McDermid, Sarah Tremblay, Jenna Quelch

Project Advisors: Elena Kanigan, Sandy Lee, Doug McArthur

Project Contact: Sarah Tremblay, sarah\_tremblay@sfu.ca or 236-999-3409

Date: January 2019

Dear participant,

We invite you to take part in a research study titled Community Led and Culturally Safe: Options to Promote Hepatitis C Testing, Treatment, and Prevention for First Nations in BC.

The research is overseen by SFU's School of Public Policy with guidance from the First Nations Health Authority. Through this letter, we are providing you with information about the research and inviting you to participate. Ethics approval was provided by the university. Before deciding to participate, you may direct questions to anyone on the research team with whom you feel comfortable speaking to about the project.

### **What is the purpose of the research?**

The research project will help to provide FNHA with critical insight into the challenges and opportunities of a made-in-BC HCV testing, treatment, and prevention strategy that reflects and supports First Nations perspectives on health and wellness. The project will assess and evaluate HCV policies, best practices within BC's health authority structure and their impacts and/or risks on First Nations populations.

Research, learnings, and outcomes will be rooted in FNHA's Directives and its visual representation of the First Nations perspective on health and wellness. Further, the project will take a decolonizing approach to care that considers the recommendations made by the Truth and Reconciliation Commission, as well as the United Nations Declaration on the Rights of Indigenous Peoples.

### **Why were you invited?**

You are being invited to take part in this research because we feel that your experience and expertise in the field of HCV research and/or your position as an Indigenous knowledge holder can contribute to our understanding of hepatitis c and its disproportionate impacts on First Nations peoples in British Columbia. We hope that with your assistance, we can contribute towards building a community-led and made-in-BC model of HCV intervention that is appropriate and suited to BC's Indigenous communities.

### **What is your role?**

This study will involve your participation in an in-depth interview that focuses on the challenges and opportunities of a made-in-BC HCV testing, treatment, and prevention strategy that reflects and supports the First Nations perspective of wellness. The study

team will conduct each interview in pairs and will work collaboratively to learn from the perspective of experts in the field. As a participant, you will be involved in helping to inform the FNHA about how to best approach HCV care amongst BC's Indigenous population.

### **What information will be collected?**

As an expert in the HCV field and/or as an Indigenous knowledge holder, we hope that you may choose to share your ideas, experiences and personal opinions during the interviews. Each interviewee will be asked a similar set of questions that can be previewed ahead of time upon request. During the interview, your comments will be recorded. All information will be kept anonymous and confidential, unless you choose to share your personal details.

### **How will the data be stored?**

Each interview will be audio recorded and the recordings will be stored and password protected on the researchers' computers. Only the SFU research team will have access to your audio recordings, transcripts, and personal information for data analysis. Nothing about you will be shared beyond the research team without your consent. Once the study report is finalized, all of your information from the interview will be deleted.

Further, all the information you supply during the interview will be held in confidence and your name or identifying information will not appear in any report or publication of the research without your consent.

### **Confidentiality**

The SFU Public Policy research team will keep your information confidential throughout the project, only using it according to the terms you agree to.

### **How will your information be used?**

The information you provide during the interview will provide FNHA with a comparative assessment of HCV short- and long-term best practices and current state policy barriers, with the intent of guiding the development of policy and a made-in-B.C. framework for HCV testing for First Nations populations in B.C.

As legacies of colonialism including intergenerational trauma and structural and systemic inequities impact the accessibility of prevention, testing and treatment of HCV for many Indigenous peoples, the research project will consider the barriers to healthcare faced by marginalized groups in B.C., as well as the limitations of interventions to employ culturally relevant, strengths-based, safe, and holistic frameworks.

### **Project risks and benefits:**

There are no known risks involved in participating in this study. However, some participants may experience an emotional response to some of the issues being discussed. Should you experience any uneasiness while participating in conversations, you can immediately end your participation in the study.

The knowledge shared, including your wisdom, experiences, ideas and opinions will help to:

Improve care for individuals living with HCV

Promote culturally-informed and culturally-safe care

Identify traditional knowledge and approaches to living with HCV

Identify what Western medical knowledge of HCV care supports living well with HCV

Improve understanding of different perspectives around HCV care

### **Participation is voluntary**

Your participation in this research is entirely voluntary and it is your choice whether to participate or not. There is no honorarium for participating, however the research team is flexible in meeting participants at their preferred time.

### **Concerns or Complaints**

If you have any concerns or complaints about your rights as an interviewee and/or your experiences while participating in this study, you may contact Doug McArthur (our project mentor and instructor at the School of Public Policy) at: [doug\\_mcarthur@sfu.ca](mailto:doug_mcarthur@sfu.ca)

Please read the next section carefully and sign this consent form once you have read it through. The interviewers will go through the consent process in more depth with all participants if needed. Your consent can be withdrawn at any time before or after the interview, until the report is published.

### **Consent to participate:**

I agree to participate in this study only as I indicate below (with a  $\sqrt$  or X).

### **Consent Checklist:**

Do you understand that you have been asked to be in a research study?

Have you read (or been read) and received a copy of the attached Consent Form?

Do you understand the benefits and risks involved in taking part in this study?

Have you had an opportunity to ask questions and discuss this study?

Do you understand that you are free to withdraw from the study at any time, without having to give a reason?

Has the issue of confidentiality been explained to you?

Do you understand who will have access to your responses?

### **For the purposes of this study, I provide permission:**

For my name to be identified

For my name to be credited in all quotes

### **I would like:**

To verify the accuracy of my quotes before the project is finalized

To be informed of the use of my quotes in all study presentations and publications

To receive a copy of the final report

## 13.3 TRUTH AND RECONCILIATION CANADA'S CALLS TO ACTION

### Truth and Reconciliation Calls to Action: Health

18. We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.

19. We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services.

20. In order to address the jurisdictional disputes concerning Aboriginal people who do not reside on reserves, we call upon the federal government to recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal peoples.

21. We call upon the federal government to provide sustainable funding for existing and new Aboriginal healing centres to address the physical, mental, emotional, and spiritual harms caused by residential schools, and to ensure that the funding of healing centres in Nunavut and the Northwest Territories is a priority.

22. We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients.

23. We call upon all levels of government to:

- Increase the number of Aboriginal professionals working in the health-care field.
- Ensure the retention of Aboriginal health-care providers in Aboriginal communities.
- Provide cultural competency training for all healthcare professionals.

24. We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism.