

WINDOWS OF OPPORTUNITY

Integrated Hepatitis C Programming
Approaches for Priority Populations

National Deliberative Dialogue on Integrated
Hepatitis C Programming and Services

Meeting Report | 2015



Canada's source for
HIV and hepatitis C
information

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1. Executive summary – Our window of opportunity

The landscape in hepatitis C is changing. New hepatitis C treatments have dramatically increased cure rates, shortened treatment durations and have few side effects. The first national best practice recommendations for harm reduction have been produced, and there is a growing evidence base to inform the development of new age-cohort and risk-based national guidelines for hepatitis C screening and diagnosis. There is also updated epidemiological data on priority populations and new research findings on the sexual transmission of hepatitis C among men who have sex with men. Together, these changes have the potential to significantly transform and improve the national frontline response in hepatitis C prevention, testing, treatment and care for communities and individuals affected and at risk. There is now the possibility of eliminating hepatitis C as a public health threat.

For this goal to become a reality, not only must the new treatments be made accessible to all, but health programs, organizations and systems must be able to properly serve the populations most affected. This includes diagnosing individuals with hepatitis C, providing treatment and care, and preventing further spread of the virus. The burden of hepatitis C is largely carried by populations underserved by the mainstream health system, including people who use injection drugs, people who are in prison, Indigenous populations, street-involved youth, and immigrants and newcomers¹ from endemic countries. Older adults have a higher prevalence of chronic hepatitis C than younger people, and they are often dealing with co-morbidities and issues related to aging. The challenge and the opportunity is to develop a health system that responds to the unique realities of populations affected by hepatitis C through a commitment to health equity.

CATIE hosted a *National Deliberative Dialogue* on Integrated Hepatitis C Programming and Services to explore frontline hepatitis C continuum of care models (prevention, testing, treatment and support) for priority populations and to identify promising directions in hepatitis C programming, policy and knowledge exchange.

The *National Deliberative Dialogue* highlighted the fact that programs are most relevant and responsive when those most affected shape and tailor programming. Across Canada, service providers and service users are responding to community needs by developing integrated hepatitis C models of care that incorporate a range of broader support services within specific cultural and community contexts. Organizations that promote and foster programs designed and delivered by those most affected are able to be responsive to community needs and provide effective hepatitis C programming. To address the root causes of the epidemic and eliminate hepatitis C as a public health threat, it will be important to maintain and expand the breadth and depth of community-led programs even as treatment times become shorter and easier to manage.

Many integrated hepatitis C models of care have been developed by motivated, intrinsically-driven individuals and organizations, largely working upstream within funding, political and social structures

¹ Refugees are an important sub-group to be considered within the newcomer population.

that are not necessarily conducive to the development of creative health equity models. In order for there to be a broader and more effective national response, beyond these outlying and unique integrated hepatitis C models, service providers and service users must mobilize for health sector reforms as well as broader socio-political reforms including the decriminalization of drug use, the development of a national hepatitis C strategy and the promotion of anti-oppression and anti-racism policies. Initiatives that strengthen community systems, including advocacy, cross-movement building and community development, are key factors for success. It is critical that the community mobilize to ensure that the best testing, treatment and care options are available to all, regardless of fibrosis level or social, political, economic, racial and cultural location.

The programming, organizational and structural recommendations within this document can begin to inform a collective response to the hepatitis C epidemic. Each stakeholder has a unique role to play moving forward and the recommendations provide a starting place for more detailed strategizing and action planning which can take place within regions, organizations and communities. As the national knowledge broker in hepatitis C prevention, testing, treatment and care, CATIE will use these recommendations to inform our knowledge exchange work over the next few years. The deliberative dialogue discussions identified that CATIE can continue to play a role in convening these action planning discussions when and where useful, as well as undertake community systems strengthening initiatives and knowledge transfer and exchange activities as outlined in Section 3.3. CATIE will continue to engage, consult and follow the guidance of those most affected by hepatitis C as well as a breadth of other stakeholders in defining CATIE's role and responsibilities in the collective work to eliminate hepatitis C.

At a glance

Recommendations: Programming, organizational and structural recommendations.
(For a full list and details, see Section 3.2)

Programming recommendations

- 1: Develop community-specific and culturally safe programming
- 2: Ensure opportunities for clients to engage in programming as soon as they are ready
- 3: Prioritize relationship building and develop trust and credibility with service users
- 4: Ensure a commitment to harm reduction approaches in all aspects of integrated programming
- 5: Develop trauma-informed and reconciliation-based approaches to crisis and conflict resolution
- 6: Despite shortened treatment durations, ensure programs incorporate the full continuum of care
- 7: Facilitate seamless access to services beyond the traditional continuum of hepatitis C services
- 8: Provide non-traditional incentives to service users
- 9: Enhance meaningful service user engagement
- 10: Invest in peer programming
- 11: Enhance outreach and testing efforts with an emphasis on underserved and marginalized populations
- 12: Identify, document and research hepatitis C programming approaches in the new era of hepatitis C treatment

Organizational recommendations

- 1: Ground inter-agency and cross-sectoral partnerships for hepatitis C programming in a common vision and goals
- 2: Create organizational partnerships and structures to foster a client-centred multidisciplinary team-based approach for hepatitis C services
- 3: Develop structures of community governance and embed health equity into the organizational values and mission
- 4: Invest in community systems strengthening
- 5: Explore alternative funding that allows for internal resource distribution and incentive structures that promote integration and health equity
- 6: Strive for a salary-based compensation structure and invest resources in fairly compensating peers and other non-traditional healthcare providers
- 7: Engage a broad set of stakeholders in organizational changes
- 8: Address the social determinants of health through cross-sectoral partnerships
- 9: Address racism, stigma and discrimination through equity-oriented hiring, anti-oppression training, shifting internal power structures and public education

Structural recommendations

- 1: Develop a national action plan for addressing hepatitis C with differentiated approaches designed by and for each priority population
- 2: Ensure that optimal hepatitis C testing, monitoring and treatment options are available and accessible
- 3: Enhance surveillance and the epidemiological evidence base for specific populations
- 4: Ensure hepatitis C integration into broader strategies for sexually transmitted and blood-borne infections at the local, provincial and national levels
- 5: Facilitate the development and implementation of primary care and nurse-led approaches to hepatitis C
- 6: Develop national harm reduction policies including harm reduction in prisons and investment in hepatitis programs inside prisons
- 7: Develop funding models that support salary-based compensation and promote provision of resources to non-traditional healthcare providers such as Indigenous healers, Elders and peers
- 8: Link funding eligibility and evaluation metrics to health equity outcomes
- 9: Invest in health system reforms geared toward health equity including mandating equity-oriented hiring practices, anti-racism and anti-oppression training and transfer of power to service users in shaping care
- 10: Invest in strategies that address the social determinants of health, including anti-poverty initiatives and develop policies to address racism, stigma and discrimination in society
- 11: Invest in community systems strengthening initiatives, including advocacy and cross-movement building

2. Introduction

The burden of hepatitis C is carried by populations that are underserved by mainstream health services, including people who use injection drugs, people who are in prison, Indigenous populations, street-involved youth, HIV positive men who have sex with men and immigrants and newcomers. Adults born between 1945 and 1975 have a higher prevalence of chronic hepatitis C than any other age cohort and many of them are also managing co-morbidities and issues related to aging.² Integrated hepatitis C models have been designed to create more accessible and appropriate services for vulnerable and underserved populations. These models link and provide seamless transition between the various health services to prevent hepatitis C transmission and to test, treat and support individuals who have or are at risk of contracting hepatitis C.

CATIE hosted a *National Deliberative Dialogue* on Integrated Hepatitis C Programming and Services to identify how integrated models are responding to the unique needs of service users and to identify key factors for success. While program integration in itself goes a long way toward creating more accessible and appropriate services for underserved populations, additional health equity approaches designed to address barriers to care and the social determinants of health are also needed. This report is a thematic synthesis of the key areas discussed, including factors for success and recommendations at the programming, organizational and structural levels. Recommendations for specific populations are discussed throughout the report and summarized in Section 3.4.

This report highlights how integrated hepatitis C programs are being designed and delivered and identifies the factors that are essential for responsive and good practice in hepatitis C services. The key concepts side bar on the next page details terms that are core to all of the hepatitis C models discussed.

2.1 Dialogue objectives, process and method of analysis

CATIE organized a national knowledge exchange meeting on February 11–12, 2015, to tackle some of the challenges raised by the changing hepatitis C landscape and to discuss how integrated hepatitis C approaches can be designed to be comprehensive and service user centred. The current state of hepatitis C services and the context of the deliberative dialogue are described in a CATIE backgrounder report.

The dialogue was designed to bring together people working on the ‘frontlines’ of the response to hepatitis C to discuss good practices in program development and to identify key factors for success that could inform further program development across Canada. Innovative programs around the country are providing hepatitis C services for priority populations across the continuum of care. In order to replicate, adapt and scale up these programs, the dialogue aimed to uncover essential learning from these programs as well as explore critical next steps in the development of a broad and effective national response.

² Challacombe, L. The Epidemiology of Hepatitis C in Canada, CATIE Fact Sheets, 2015, available from: <http://www.catie.ca/en/fact-sheets/epidemiology/epidemiology-hepatitis-c-canada>

Objectives

The deliberative dialogue had four primary objectives:

- to inform priority directions for population-specific hepatitis C programming, services and policy that put service users at the centre of an integrated framework;
- to provide guidance to new programs across Canada on hepatitis C continuum of care models for specific populations;
- to facilitate multi-region, cross-sectoral collaboration, knowledge sharing and networking among hepatitis C programming leaders; and
- to inform a national strategic directions document.

The dialogue focused on hepatitis C continuum of care models and the patient journey through a health equity lens. In particular, the focus was on integrated hepatitis C programming models for priority populations facing the most inequitable risks and burden of ill health related to hepatitis C. Four priority populations were chosen as the focus of discussion: Indigenous peoples, people who use injection drugs, immigrants and newcomers, and older adults.

Dialogue participants discussed the challenges and lessons learned from frontline efforts. The goal was to identify key factors for success in existing integrated programming models in order to determine promising directions in hepatitis C programming, policy and knowledge exchange.

Process

Several strategies were used to help ensure the event was successful:

1. *The process: Direction and engagement*
2. *The process: Ensuring an inclusive dialogue*
3. *The process: Ensuring a common understanding*
4. *The deliberative dialogue agenda and structure: Going from a point of view to a view of points*

KEY CONCEPTS

Health equity

Health equity refers to the achievement of equal opportunities for good health for all. Health inequities are health differences between population groups that are systemic, avoidable and unfair. Evidence shows that people from certain population groups experience disparities in their health status, access to services and the quality of care they receive. Factors such as gender identity, race, sexual orientation, immigration status, income and education influence a person's access to timely, appropriate and high-quality care. Health disparities across population groups are the results of individual, structural, and systemic oppression of these groups by society. In order to achieve health equity, healthcare approaches must acknowledge this oppression and work to address these social ills.

Social determinants of health

The social determinants of health are the social and economic conditions that influence the health of individuals, communities and jurisdictions. An individual's biological make-up, medical treatments and/or lifestyle choices are not the only factors that shape their health outcomes. Social and economic factors such as having a livable income, stable and safe housing, healthy food, cultural connections, and a personal sense of belonging that includes meaningful engagement in society also play a powerful role in shaping one's ability to stay healthy. Social determinants of health can also affect one's ability to access the healthcare system or to receive good treatment once in care.

Priority populations and hepatitis C infection in Canada

Hepatitis C disproportionately affects particular populations in Canada, namely people who use injection drugs, people who are in prison, Indigenous peoples,³ street-involved youth, immigrants and newcomers to Canada from high-prevalence countries, older adults⁴ and HIV-positive men who have sex with men. There is overlap among many of these populations. It is important to understand why particular groups have a high prevalence or high incidence of infection because this informs the development of prevention, testing, treatment and care strategies tailored to the needs of these populations.

³ Indigenous is used herein as an inclusive term for individuals and communities including First Nations, Inuit and Métis.

⁴ The term older adults is used to represent the age cohort born between 1945 and 1975.

Before the dialogue, CATIE used a variety of methods to ensure there was extensive input into the development of the event and to enhance engagement at the event. CATIE also worked closely with five population-specific experts to develop overview presentations that summarized key challenges faced by the priority populations. CATIE wanted to ensure that the dialogue was inclusive and that it would facilitate reflection and recognition of multiple perspectives on integrated programming models. With these goals in mind, individuals were selected to attend on the basis of their expertise and experience developing and implementing innovative integrated programming for diverse populations across Canada. The participant selection process was also meant to ensure regional diversity and representation from a range of people involved in the response to hepatitis C, including frontline workers, public health workers, researchers, policy makers and people living with and affected by hepatitis C. CATIE also sought to ensure that there was a balance in the number of participants working with each of the priority populations.⁵

The final agenda was structured to maximize facilitated discussion among participants (Appendix III) so that they could share experiences, insights, concerns and challenges, and so that they could identify overall national and/or population-level directives to move integrated hepatitis C continuum of care models forward regionally. Participants were provided with various reading materials, including a backgrounder developed by CATIE and six prerecorded online presentations by external experts (Appendix II, list of pre-dialogue materials) to ensure participants attended the meeting with a common understanding of the rapidly changing hepatitis C landscape and of integrated programming.

The meeting started with an overview presentation on the hepatitis C continuum of care, followed by short presentations on various integrated hepatitis C models from across the country. The presentations were followed by a large group discussion about similarities and differences between the various models.

The second day focused on population-level discussions. It started with five population-level presentations that summarized how hepatitis C affects each of the priority populations and identified challenges in programming. The rest of the day consisted of small and large group facilitated population-level discussions to identify population-specific priority directions.

Method of analysis

Notes and recordings from the deliberative dialogue were analyzed to identify common factors that contributed to the success of the various models and population-specific programs presented (reported in Section 3.0.) Notes and recordings from the population-specific strategy discussions were organized and summarized to identify population-specific priority directions (reported in Section 3.4.)

⁵ There were 42 participants who were not CATIE employees, including eight from Ontario, four from Quebec, eight from British Columbia, six from the Prairies, five from the Atlantic region, two from the territories, eight national representatives and one international speaker from the U.S (Appendix I, List of meeting participants and advisors).

3. Outcomes: Common factors of success across and within population-specific programs

Programs throughout the country are providing hepatitis C services for priority populations across the continuum of care. Although there are differences between and within them, they share a number of common factors and foundational approaches that contribute to their successes, outlined in this section in general, and in Section 3.4 for specific populations.

All of the programs and models discussed at the deliberative dialogue deliver services along the full continuum of care. These continuum of care models are also known as integrated models.

This section illustrates how programs are operationalizing integration and details good practices in hepatitis C services at the programming, organizational and structural/systemic levels.

Specifically, this section includes the following:

- i) an overview of the principles of integration
- ii) a description of the main techniques and methods being used to operationalize integration in hepatitis C programs
- iii) a discussion of essential factors of success and priority recommendations in hepatitis C programming at the programming, organizational and structural/systemic levels
- iv) a description of the resources and tools required to develop and scale up effective integrated hepatitis C programs.

3.1 Models of integration

Different approaches for operationalizing integration were discussed at the deliberative dialogue. Two broad approaches to integration were identified: *service integration* and *program collaboration*. Each is described below, as are the overarching principles of integration underscored by the models presented.

3.1.1 General principles and approaches to integration

Fragmented health services create barriers to access, quality care and positive health outcomes, especially for marginalized or vulnerable populations. An integrated approach addresses fragmentation and enables development of a wholistic⁶ and coordinated service delivery model.

An integrated approach recognizes that hepatitis C prevention, testing, treatment and care services (including ongoing care services after completion of hepatitis C treatment) are mutually reinforcing aspects of a comprehensive and effective response to hepatitis C.

Although integrated program models are operationalized in a variety of ways to address the needs of specific communities and geographies, integrated programs tend to share two principles:

- They are client centred.
- They are committed to health equity.

Generally, there are two broad approaches to integration: *service integration* and *program collaboration*.⁷ Most models combine elements of both approaches.

- *Service integration* provides service users with seamless access to programs through a one-stop-shop approach. This approach aims to make it easier for service users to access services by providing a single point of entry. Most service integration models include some degree of health navigation, case management and referrals.
- *Program collaboration* is based on partnerships and collaboration across existing programs and services. Program collaboration can reduce duplication of services and increase participation in service delivery from a variety of programs and organizations. It may be most useful in settings with limited resources, where community organizations develop strong linkages with other community-based and medical programs and services to provide navigation across the continuum of care.

Integrated hepatitis C program models are client centred: a demand-driven model of care

Integrated hepatitis C programs are designed to meet the needs of clients first and foremost. The demands and needs of clients are the foundation upon which such programs are built.

In an integrated model, service users are not required to navigate a complicated and fragmented healthcare system on their own to access the information and services they require. An integrated hepatitis C model is designed to facilitate access to the full continuum of prevention, testing, treatment and care services and ensure that service users are supported throughout their journey. An integrated model facilitates linkage and engagement; each service acts as a gateway to other services.

Many integrated models recognize that addressing hepatitis C can be about more than clearing the virus; it can also be about empowerment, validation, and building bridges to other long-term health and life goals.

⁶ Wholistic is the preferred spelling, reflecting the whole person and physical, spiritual and emotional wholeness.

⁷ Belani H, Chorba T, Fletcher F, et al. *Integrated prevention services for HIV infection, viral hepatitis, sexually transmitted diseases and tuberculosis for people who use drugs illicitly: Summary guidance from CDC and the U.S Department of Health and Human Services, recommendations and reports*. Nov. 2012/ 61 (RR05); 1–40. Available from: <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr6105a1.htm>

Integrated hepatitis C models are committed to health equity: serving the underserved

While fragmented health services are not user-friendly for anyone, they can be especially difficult to navigate for marginalized or vulnerable populations. Fragmented services require the service user to take a primary role in communications between health providers, which is difficult for clients who do not speak English as a first language or who face other communication barriers. For marginalized individuals who use injection drugs and other people who may face stigma and discrimination by healthcare providers, it can be daunting to deal with multiple service providers and face judgement in a variety of settings.

Integrated hepatitis C program models are designed to reduce the numbers of individuals who fall through the cracks of a fragmented system. Given the two-stage diagnostic process and slowly progressing nature of hepatitis C infection, it is common for clients to be lost to care. This is especially problematic in terms of health equity because those who fall through the cracks tend to be the most marginalized or vulnerable. In providing seamless, coordinated and wholistic health services, integrated models can enable clients with multiple and complex needs to access health systems more easily without having to build relationships and communicate with multiple service providers.

3.1.2 Types of organizations with integrated models across Canada

In Canada, there is no one model of program integration in hepatitis C. The range of organizations and services available and the way in which hepatitis C services are provided differ across and even within provinces and territories.

Some regions, mainly low-density areas, do not have differentiated hepatitis C services. To a large extent services are already “integrated” in these regions; the challenge is to build the capacity of existing services to include hepatitis C. In other regions, mainly high-density areas, services are differentiated and the challenge is integration. In some places clients may have to migrate to another province or territory to receive care and support.

There is an even greater variation in models serving Indigenous populations because of complex jurisdictional landscape issues and inconsistencies in terms of policies and self-government agreements across the country.

Integrated models of care are being created/adapted by various types of organizations in a range of settings

A number of ***community health centres*** (where clinical and community services are coordinated and housed together) have integrated hepatitis C into their core work with specific populations. Many of these community health centres serve high-need marginalized communities and provide a comprehensive range of primary care services including access to a multidisciplinary hepatitis C team. Examples of community health centres that have integrated hepatitis C into their core work include: South Riverdale Community Health Centre in Toronto; Calgary Urban Project Society in Calgary; and Vancouver Coastal Health’s Pender Clinic.

A number of ***AIDS service organizations*** have expanded their focus beyond HIV in response to the changing needs of their client base. This pattern is particularly relevant to AIDS service organizations that serve communities where drug use and co-infection with HIV and hepatitis C are prevalent, including Centre Sida Amitié in St-Jérôme, Quebec; Elevate Northwestern Ontario (formerly AIDS Thunder Bay); Nine Circles Community Health Centre in Winnipeg; and ASK Wellness Centre in Kamloops, British Columbia.

In some regions, ***public health*** agencies are taking the lead with integrated hepatitis C programming. The Yukon is an example of a low-density region using a fully integrated hepatitis C testing, treatment, care and support model that is centralized within public health. The hepatitis C program is embedded within the larger program for sexually transmitted and blood-borne infections. Hepatitis C testing, treatment and care are

fully integrated into public health. A public health nurse works with a specialist to ensure that all people who are tested are connected to treatment and care.

Some ***hepatitis C clinical programs*** have developed integrated program models to work more effectively with clients who face barriers to care, including the telemedicine program at the Ottawa Hospital and Sanguen Health Centre in Guelph and Waterloo, Ontario.

There are a number of ***Indigenous-led models*** both on- and off-Reserve, including models under the jurisdiction of Indigenous health authorities, including Ahtahkakoop Health Centre on a Reserve in Saskatchewan.

There are ***organizations and integrated models operated by and for people who use injection drugs***, as well as organizations and programs led by people with lived experience of hepatitis C. For example, L'Association pour la Defense des Droits et l'Inclusion des Personnes qui Consomment des Drogues Quebec (ADDICQ) is a peer-driven provincial network of people who use drugs in Quebec advocating for improved health services, including hepatitis C services.

Many of these integrated hepatitis C programs are ***nurse-led***. A lead nurse works to connect clients with a range of primary and specialty care services along the continuum of care and develops programming based on the needs of clients. Nurse-led integrated hepatitis C programs include The Hepatitis C Program at Pender Community Health Centre in Vancouver and The Hepatitis C Education and Support Program run out of the North End Community Health Centre in Halifax.

Although the deliberative dialogue did not include specific focus on prison-related programming, there are some hepatitis C programs ***inside federal and provincial prisons*** and for people who have been released.⁸ ***Peer health groups operated by people who are incarcerated*** are offering hepatitis C education and connecting people with health services. Some public health institutions, community health centres, AIDS service organizations, Indigenous organizations and prisoner justice organizations are also providing hepatitis C programs inside prisons.⁹

Settlement centres, newcomer organizations, community centres and community development organizations are beginning to engage in hepatitis C awareness-raising activities and are starting to incorporate hepatitis C initiatives into their work.

3.1.3 Techniques and methods for operationalizing integration

Integrated hepatitis C programming is operationalized in a variety of ways. There are a number of approaches to integrating prevention, testing, treatment and care, and many provide seamless transition between services. The methods described below are examples of program collaboration approaches; other methods are service integration approaches, and still others are combinations of both.

Health system navigators

Health navigators help clients overcome barriers to care by providing one-to-one support, education, guidance, accompaniment, referrals and advocacy for individuals along their health journey. They help to bridge services and support clients as they weave their way through systems with greater ease. The goal of health navigators is to build the capacity of clients to manage their own care and to make informed decisions about their health. Health navigation falls under the broader program collaboration approach. Health navigators can be peers or other individuals with the communication, advocacy and relationship-building

⁸ Betteridge G, Dias G. *Hard times: HIV and hepatitis C prevention programming for prisoners in Canada. Canadian HIV/AIDS Legal Network and Prisoners' HIV/AIDS Support Action Network (PASAN.)* 2007. Available from: http://www.pasan.org/Toolkits/Hard_Time.pdf

⁹ Ibid.

skills to support clients. ASK Wellness Centre's Chronic Health Navigation Program is an example of how health navigators provide integrated hepatitis C services to clients.¹⁰

Services coordination

Services coordination is a model that follows a program collaboration approach through which separate, independent organizations link their services through intentional communications strategies and shared case management.¹¹ It is supported by various virtual and telephone-based technologies, along with shared scheduling and clear referral systems. This model can be most useful in providing speciality care in geographically remote areas. Technologies such as “Doc in the box,” with which service providers and clients at a primary care setting can connect with specialists through online technologies, enable independent service providers to collaborate and promote team communications across physical distances. The Ottawa Hospital and Regional Hepatitis Program's Telemedicine Program is an example of a services coordination model – it provides care and treatment to people remotely through the Ontario Telemedicine Network.

Centralized services

Through a centralized services approach, primary care and/or specialty care providers and a range of other health and social service providers all work together in a central location. Coordination and transition between services is aided by proximity of services.¹² Service providers can be physically present within a specialty clinic or specialty services can be offered within a primary care setting, such as a community health centre. Primary care and specialty care services can also be situated within non-health-related organizations, including settlement centres and community centres. Through this approach, services may remain independent, or they may follow a shared care model through which collaboration occurs because of the proximity of and relationships between providers, and because there is an organizational commitment to collaboration. The Calgary Urban Project Society's hepatitis C clinic in Alberta is one example of a centralized services approach. The clinic is located within a community health centre that also offers a range of other services to clients.

Decentralized services

A decentralized services model involves a specialized outreach team providing on-site services in a range of settings and also linking clients with a more comprehensive hub of services within a home organization. Many decentralized service approaches are led by a nurse who is connected to a home institution. The North End Community Health Centre, Hepatitis C Education and Support Program in Halifax, Nova Scotia, is an example of a decentralized services approach: it is housed in the North End Community Health Centre, but its core team spends 90% of its time in outreach settings.

Combined approach

A combined approach brings program collaboration and services integration together to some degree. It involves several service providers coming together to develop an integrated program with a unified mandate and service-delivery approach. Service providers bring a range of services into one location (service integration) and create a program mandate and shared vision/mission (program collaboration) amongst program collaborators who may be located in different settings. For example, the Toronto Hepatitis C Program is a partnership between South Riverdale Community Health Centre, Regent Park Community Health Centre and Sherbourne Health Centre. The program provides integrated, inter-professional services which enables clients to access all of the services they require from one program.

¹⁰ CATIE. Chronic Health Navigation Program. Programming Connection. 2014. Available from: <http://www.catie.ca/en/pc/program/chronic-health-nav>

¹¹ Flexhaugh M, Noyes S, Phillips R. *Integrated models of primary care and mental health and substance use care in the community: Literature review and guiding document*. British Columbia Ministry of Health. August 2012. Available from: <http://www.health.gov.bc.ca/library/publications/year/2012/integrated-models-lit-review.pdf>

¹² Ibid.

3.2 Recommended common factors of success

Although there are differences across and within programs for the priority populations discussed at the deliberative dialogue, the following recommendations are based on success factors that programs share, including practices related to integrating services and to providing relevant and responsive health equity oriented programming.

The recommendations are grouped into three categories: programming, organizational, and structural. Programs do not exist in isolation; they operate within organizations and systems that either support or impede effective program development and delivery. In terms of replicating, scaling up and continuing to improve the response to hepatitis C, the following programming, organizational, and structural factors may be critical to success.

3.2.1 Programming recommendations

The following recommendations highlight the program-level approaches and mechanisms that are factors of success in the development of integrated models of care that are accessible, relevant and effective at addressing hepatitis C.

01 Programming recommendation #1: Develop community-specific and culturally safe programming

Successful integrated program models are culturally relevant and safe. While the term cultural safety¹³ was first used by and for Indigenous peoples, the concept and its practical approach may apply to all cultures and communities. Moving the standard of care beyond that of cultural competence to that of ensuring cultural safety is a programmatic factor for success. Cultural safety transforms power imbalances in society and it advances progress toward self-determination and de-colonization.

“Not only is indigeneity a risk factor, but it is also part of the solution.”
— Meeting participant

Culturally safe programming begins with a recognition that Indigenous peoples and people from other cultural/ethnic/spiritual communities are accessing the services provided. Programs that invest in Indigenous-led models of care can produce culturally safe programming. Hiring and retaining an Indigenous workforce is critical. Indigenous peoples in Canada have developed a variety of culturally safe programs.

“One of the things that concerns me is that ‘those’ populations are Aboriginal people. When you are speaking of and about ‘your’ populations it would be respectful to acknowledge that you do have Aboriginal people on your caseloads. That is the start of a dialogue with Aboriginal people in all of our communities.”
— Meeting participant

02 Programming recommendation #2: Ensure opportunities for clients to engage in programming as soon as they are ready

When a client is ready to begin addressing their hepatitis C infection, it is important that programs respond and not turn individuals away. Although treatment may not be possible immediately, programs that have pre- and post-treatment elements can engage clients immediately and over time, which limits lost opportunities for engagement and treatment.

¹³ Brascoupe S, Waters, C. Cultural safety: Exploring the applicability of the concept of cultural safety to Aboriginal health and community wellness. *Journal of Aboriginal Health*. 2009;7 (1): 6–40. Available from: http://www.naho.ca/jah/english/jah05_02/V5_I2_Cultural_01.pdf

“Instead of just focusing on if someone is sick enough for hep C treatment, is there a window of opportunity that we need to take advantage of now, because now they are ready. Triage based on window of opportunity instead of how advanced the disease is.”
— Meeting participant

Immediate engagement is particularly important when working with marginalized or vulnerable service users for whom treatment and care readiness may be directly linked to specific moments-in-time: when lifestyle, emotional readiness, relative stability, and other factors line up. When triaging and prioritizing services, it is essential to consider “windows of opportunity” or critical moments-in-time when a service user may be particularly well-positioned (i.e., personally ready) for treatment and care. For example, there is a “window of opportunity” to discuss hepatitis C testing and treatment when an individual begins to engage with a methadone maintenance program. In this example, hepatitis C treatment can be part of a broader stabilization plan; “treatment becomes part of engagement and stabilization, not the other way around where stabilization is required for treatment” (as one meeting participant explained).

03 Programming recommendation #3: Prioritize relationship building and develop trust and credibility with service users

A key success factor of integrated hepatitis C programs is the trust established with service users. People who face consistent hostility and discrimination from the mainstream are naturally reticent to trust healthcare and service providers. It is critical to provide non-judgemental and respectful services, to follow through on commitments, to offer flexible and appropriate hours and timely follow-up, and to deliver services with patience and flexibility. The term “being where someone is at” embodies an approach that is attentive to the priorities and realities of an individual, and it promotes trust and relationship building by making individuals feel understood and respected.

“What works is building trust. If you always deliver what you say, trust will follow. This is a population that is given mixed messages and constantly not delivered upon. It’s impressive when you do. It’s shocking.” — Meeting participant

Programs that offer a familial atmosphere and that foster genuine relationships between service providers and clients garner stronger engagement and adherence to treatment and programming. For example, at the Centre Sida Amitié, patients are given a diploma at the end of their treatment and report a sense of family connection, using terms like aunt, uncle and cousin to describe service providers and clients.

“The physician is like a grandfather, the nurses are like aunts and others are like cousins. It’s hard to let go of the relationship.” — Meeting participant

04 Programming recommendation #4: Ensure a commitment to harm reduction approaches in all aspects of integrated programming

A harm reduction approach across the full continuum of hepatitis C care is critical to effectively offering services to people who use injection drugs. Harm reduction programs can include safe consumption sites, safe equipment distribution, safe-use education, overdose prevention interventions, and anti-stigma initiatives. Services like these reduce potential harms associated with drug use and provide a gateway to testing and other health-related services that can lead to treatment and care.

Criminalization of drug use makes people who use drugs more susceptible to adverse health issues and makes it difficult for people who use drugs to access mainstream health care services. A harm reduction approach includes providing services designed to create safe spaces and make health care more accessible. An integrated model should employ a harm reduction approach in its prevention, testing, treatment and care (including post-treatment care) programming.

SIDE NOTE

Centre Sida Amitié, St-Jérôme, Quebec

A clinic that feels like a family: a low-threshold harm reduction approach

A harm reduction approach to treatment ensures that treatment is accessible to clients whether or not they have stable housing or are sober. Centre Sida Amitié, in St-Jérôme, Quebec, is a low-threshold organization for people who are street involved and use substances. The organizational commitment to harm reduction has facilitated successfully engaging service users, many of whom are transient youth who have successfully completed hepatitis C treatment regimens. Program staff have a relationship with service users, recognizing that in many cases, staff are the only significant relationships in service users' lives.

05

Programming recommendation #5: Develop trauma-informed and reconciliation-based approaches to crisis and conflict resolution

A key success factor of integrated hepatitis C programs is their ability to anticipate and appropriately address conflict and crisis. Individuals who are living with, affected by, or at risk of hepatitis C may also be faced with managing a range of stressors, social exclusions and unmet needs on a daily basis. It is normal for misunderstandings and conflict to arise occasionally, considering the burden of stress and perhaps trauma some people may be dealing with. Programs that protect space within which misunderstandings and conflict may occur, and which have supportive conflict resolution mechanisms in place, particularly for individuals experiencing crisis, are more successful in terms of reach, retention and outcomes. The same success is not realized when individuals who are experiencing conflict or crisis are turned away.

“I’ve never fired a patient. It’s always just, so this can’t happen right now but you can come back to me tomorrow. Life is so

stressful. Coping strategies are diverse. We are all humans.” — Meeting participant

Banning or excluding individuals from services because of conflict or behaviours is re-traumatizing and fuels issues of health inequity for highly underserved populations. Trauma-informed methods of engagement can prevent conflict and inform reconciliation approaches. It is important to train staff in reconciliation, transformative justice, conflict resolution and trauma-informed approaches. Hiring staff that have strong capacity for and skills in relationship-building, empathy, and trust-oriented practices is also critical.

06

Programming recommendation #6: Despite shortened treatment durations, ensure programs incorporate the full continuum of care

With shorter treatment times and better tolerated treatments, the role of supportive care in the context of hepatitis C is changing but certainly not going away. While individuals may no longer need to attend health centres for treatment and managing side effects is less of an issue than in the past, there will be a heightened need to support individuals' treatment adherence. There will also be a continued need for prevention strategies, as well as post-clearance healthcare and support, including liver care and mental health support, and ongoing services as needed. Indeed, although it may become easier to clear the virus, the challenge will be supporting individuals to remain clear of the virus and providing post-clearance health support.

“We are not going to treat our way out of the epidemic. We talk about eradication, but we’re not going to be able to do it with just treatment so prevention strategies have to be scaled up side by side.” — Meeting participant

Hepatitis C treatment is a gateway to engage individuals in services for other health-related and basic needs. Individuals from priority populations are likely to have other health-related and basic needs that are also important in terms of hepatitis C treatment outcomes, healthy living with hepatitis C and care.

07 Programming recommendation #7: Facilitate seamless access to services beyond the traditional hepatitis C continuum of care services

A key success factor for integrated hepatitis C services is seamless access to services and supports that are not hepatitis C specific. Individuals from priority populations may have other, more pressing health-related and basic needs, including (but not necessarily limited to) housing, income support, healthy food, peer support, psychosocial supports, legal support, employment assistance, and language training. It is important to pay particular attention to the breadth of non-traditional health services and supports that are essential to a comprehensive hepatitis C program model.

“Who wants to go and see a doctor if you haven’t showered in a week?” — Meeting participant

08 Programming recommendation #8: Provide non-traditional incentives to service users

“Incentives save lives. You might not have to use incentives forever, but incentives can be a really good thing. It is not always something you hand over, it can be kindness, respect and gestures.” — Meeting participant

Non-traditional incentives can make programs more appropriately suited to clients’ realities and needs. Any individual who engages in a healthcare program does so because he or she is incentivized to do so; often the incentive is to become healthier. For many individuals, long-term health is a less-pressing priority than are issues such as child care, employment, food security, and/or access to drugs and equipment. Individuals grapple with competing priorities and, often, the asymptomatic nature and slow progression of hepatitis C means that clearing the virus is not a primary concern for individuals with multiple, more immediate needs. Non-traditional incentives beyond the simple health benefits can make programs more appropriate and suited to client needs and realities. Non-traditional incentives such as laundry facilities, snacks, gift cards, food boxes, honoraria and child care can make programs accessible and suited to the varied and more immediate needs of individuals.

“We need to find ways to meaningfully engage the people most affected and sometimes compensation is a part of that. I hope this continues to be a part of the dialogue. I worry that this might be a piece that falls off the cliff.” — Meeting participant

09 Programming recommendation #9: Enhance meaningful service user engagement

Integrated hepatitis C program models are culturally situated and client-centred. Engaging service users in the planning, delivery and evaluation of programs and services is a key success factor in ensuring that they are relevant to the individuals for whom they are intended, and that they reflect the communities within which they are offered/provided. For example, having patient advisory boards that guide research, evaluation and program development is a useful strategy. The key to meaningful engagement of service users (peers) is transfer of real power and ownership and fundamental respect for the value of lived experience and its resulting individual expertise.

“It’s worth believing in the by and for approach and sitting down with people as equals at the table and not simply taking individuals as nice personalities who look good in a report. Because yes, we include people, but in the end we didn’t listen.” — Meeting participant

There is much to be learned from HIV principles such as the *Greater Involvement of People Living with HIV (GIPA)* and *Meaningful Engagement of People Living with HIV (MEPA)*, as well as from the disability rights principle *Nothing About Us Without Us*.

10 Programming recommendation #10: Invest in peer programming

“We would be absolutely nowhere without our peer programs and people with lived experience. It’s worth the work.” — Meeting participant

“Most of us don’t like being called peers. I myself am a community support worker. I receive the same training as other workers. The only difference is that I have walked the walk and they haven’t. We are treated as equals in our workspace so there is no problem. Our model works really well.” — Meeting participant

To design and deliver relevant, culturally safe and effective programming, it is important that individuals from priority populations are meaningfully engaged in the processes. The success of particular elements of programming hinges especially heavily on the input and guidance of people with lived experience. For example, having peers design and lead outreach strategies has proven extremely effective in terms of reaching and serving highly marginalized and underserved populations. Individuals who have experience and trust within particular communities can identify where, how and when to reach out. Indigenous patient navigators have been critical in bridging service users with the healthcare system in Indigenous communities.

“I believe that the capacity to respond to this is actually within newcomer and immigrant communities because the clients have social work and medical degrees.”
— Meeting participant

11 Programming recommendation #11: Enhance outreach and testing efforts with emphasis on underserved and marginalized populations

Enhanced outreach and testing efforts are key to success in reaching and bringing people into care. Though there is no simple solution, a first step is to introduce a more robust role for hepatitis C screening into primary care, as well as enhanced targeted testing.

Hiring and engaging people who have relevant lived experience to design and deliver outreach and testing strategies for underserved and marginalized populations is an important approach. Individuals who identify with and have trust within particular communities are well positioned to plan where, how and when to reach out. For example, the Punjabi Community Health Services, a community health centre serving South Asian communities, engages retired “aunties” as peer navigators to connect the broader community to its health and social services.

12 Programming recommendation #12: Identify, document and research hepatitis C programming approaches in the new era of hepatitis C treatment

To continue improving hepatitis C programming, it is essential to identify, document and share new promising approaches and good practices that are in development in this new era of hepatitis C treatments. It is also important to leverage research opportunities to develop evidence-based policies, programs and interventions. In terms of fostering innovation, partnerships with researchers can be a strategy to support interventions that are unlikely to be funded by mainstream sources, at least initially prior to sufficient evidence to support funding.

3.2.2 Organizational recommendations

The following recommendations detail the organizational-level approaches and mechanisms that are key success factors in the development of integrated models of care that are accessible, relevant and effective in addressing hepatitis C.

01 Organizational recommendation #1: Ground inter-agency and cross-sectoral partnerships for hepatitis C programming in a common vision and goals

A key success factor in achieving integration and collaboration between agencies is the development of a shared vision and goals. Organizations that come together and develop a common vision and methods for evaluating success have greater incentive and structural support to work cohesively toward a common end-point or goal. The Toronto hepatitis C program provides a good example of how various agencies developed a unifying vision and common accountability mechanisms.

Developing shared goals is useful for partnerships between specialist and primary care organizations, and it is important for partnerships between multiple sectors and stakeholders, including those focused on correctional services. Collaboration and partnership with correctional services and organizations involved in post-release programs/reintegration is essential to serving the prisons population — a priority population that is currently underserved.

02 Organizational recommendation #2: Create organizational partnerships and structures to foster a client-centred multidisciplinary team-based approach for hepatitis C services

A key success factor in achieving comprehensive, client-centred hepatitis C services is ensuring seamless access to multidisciplinary care. Working with a comprehensive range of service providers from a variety of disciplines and specialties is important but not sufficient to develop integrated and cohesive team-based models. It can also be useful to intentionally structure an interdisciplinary team-based approach through organizational partnerships or by having staff from different sectors work from a shared case model. It can also be helpful to offer learning exchanges and other internal team activities to increase the sense of a shared culture and shared work.

The Toronto hepatitis C program model is based on an interdisciplinary team-based approach to hepatitis C. Case managers are assigned integrated caseloads and manage multidisciplinary staff teams.

03 Organizational recommendation #3: Develop structures of community governance and embed health equity into the organizational values and vision

An essential element of success in developing integrated, client-centred models of hepatitis C care is organizational capacity for flexibility and responsiveness to community needs. Organizations often develop programs and approaches based on needs within communities, but community-level needs and realities often shift over time. As such, having organizational capacity to adjust priorities and approaches to remain relevant and effective is critical.

Processes that ongoing evaluation of organizational relevance and effectiveness embed change and responsiveness within organizational structures and allow for responsive programming. Having an organizational mission that is underpinned by health equity allows organizations to be flexible and to change over time in an effort to align with community needs and strengths. Similarly, being community-based and community-governed through community-led boards and advisory committees fosters responsiveness to community needs.

04

Organizational recommendation #4: Invest in community systems strengthening¹⁴

“Both urban and non-urban settings have a reliance on goodwill instead of good systems to make things happen and the commitment of a few to move things forward. We don’t have a systems approach. We rely on this history of charitable approach because of the communities we are talking about and because they are not seen as deserving. That is the fight that we have collectively.” — Meeting participant

Organizations and individuals engaging in integrated, client-centred and health equity oriented hepatitis C care do so, primarily, from a place of goodwill rather than because they are supported and enabled to do so within health systems. It is precarious and unsustainable to depend on the exceptional commitment of a few outliers who are willing to work in an under-resourced, under-supported fashion. It is also difficult to scale up these approaches and replicate models that fundamentally require an exceptional commitment without structural/systemic support.

“All of the models that were presented had individuals with a lot of passion ready to push the edges. In talking about models and transferability we need to recognize that some models only work because of the overdedicated commitment of the people who are pushing the boundaries.” — Meeting participant

SIDE NOTE

ASK Wellness Centre

**An organization highly responsive to changing community needs:
Redefining the continuum of care**

The ASK Wellness Centre in Kamloops, BC, formerly an AIDS service organization, is an example of an integrated organizational model that addresses the broader determinants of health. Expanding its services and mandate to address the changing needs of its service users, this agency is now a hub for people with mental health and substance use issues, who are often homeless. The organization no longer focuses on blood-borne infections in isolation but, rather, serves anyone who needs housing and/or mental health services. Housing, employment and education are now part of ASK’s continuum of care. Hepatitis C (and HIV) prevention, testing and treatment services are addressed as needed, but they are no longer the entry points for services.

05

Organizational recommendation #5: Explore alternative funding that allows for internal resource distribution and incentive structures that promote integration and health equity

One of the benefits of developing integrated and comprehensive models of hepatitis C care is that it provides an opportunity to apply for funding from sources that do not traditionally fund health services, including funders that supports housing, employment, arts, culture, etc. As described by a meeting participant, “The benefits of integration include diversification of funding strategies. You can seek funding from a diversity of kinds of funders and be resilient to funding changes.”

Funding from the pharmaceutical industry is one option for expanding fiscal resources and realizing some freedom for creativity in terms of payment structure and internal resource allocation. However, careful consideration should be given to ethical issues inherent in accepting funding from pharmaceutical companies and other industries for which core

¹⁴ Community systems strengthening is an approach that promotes the development of informed, capable and coordinated communities and community-based organizations, groups and structures and enables community-based organizations to be equal and effective partners in shaping health outcomes.

impact and approach may be counter to equity and justice. It is important for organizations to understand the implications of working with industry and to ensure that internal strategies intentionally focus on them.

Public funding presents its own set of challenges and ethical dilemmas. Often public funds come with specific expenditure limitations defined by very narrow parameters. Accepting public funding may limit an organization's ability to engage in political advocacy around issues of health equity. As expressed by one meeting participant, "We are truly in crisis because it's the public funders that we rely on to do this work that attach the strings to us like marionettes and force us to think about integration in a wholistic way when they haven't evolved to the notion of wholistic the way we have. Funding is dependent on our disease-based models and we call it a population-based approach."

A key factor of success is investment(s) in changing the underlying systemic problems within health systems that de-incentivize working with marginalized populations and de-incentivize creating integrated, client-centred models of care. This requires that organizations invest in the capacity to unpack systemic problems and develop strategies for change: it requires organizations to become experts in community systems strengthening.¹⁵ Staff may not have the skills required for systems analysis and/or systemic change. Investing in these skills and abilities and partnering with organizations where these skills exist is essential to the development of a sustainable, resilient and cohesive response to the hepatitis C epidemic.

06 Organizational recommendation #6: Strive for a salary-based compensation structure and invest resources in fairly compensating peers and other non-traditional healthcare providers

A key factor for success at the organizational level is investing resources to adequately compensate and incentivize service providers and teams to spend the necessary time to ensure a coordinated and comprehensive approach to client-centred care. While there have been innovations to develop strategies and models to address hepatitis C that are integrated, comprehensive, multidisciplinary, trauma informed, culturally safe and health equity oriented, traditional healthcare funding models have not necessarily adapted to reflect these shifts. As such, some of the more traditional funding structures limit the ability to develop integrated, multidisciplinary and client-driven or client-centred care. For example, the traditional fee-for-service model limits the amount of time healthcare providers can spend with their clients or spend developing partnerships with other community service organizations. A salary model of payment can be more suited to client-centred programming in these cases.

Traditional funding structures might include limited resources with which peers and/or non-traditional healthcare providers such as Indigenous healers and Elders are compensated. It is important to invest resources to appropriately compensate these individuals to support a truly multidisciplinary team.

07 Organizational recommendation #7: Engage a broad range of stakeholders in realizing organizational changes

Significant organizational changes may be realized by adopting an integrated, health equity and client-centred approach to hepatitis C care. For some community health organizations, population bases may remain the same, but specific partners and integration processes might be new. For AIDS service organizations that are integrating hepatitis C into their programs and services, priority populations might shift and levels of integrated care might also be novel. Each organization will be presented with specific changes, whether in its population base, its staffing, its approach to program/service delivery, or its goals. A broad stakeholder engagement process that invites service users, people with lived experience, staff and management to share anxieties, to explore the opportunities around change, and to develop a unified plan is critical to change management strategies and to develop responsive programming for hepatitis C.

¹⁵ The Global Fund to Fight Aids, Tuberculosis and Malaria. *Community systems strengthening framework*. Revised edition. 2014.

SIDE NOTE

Hepatitis C integration into AIDS service organizations (ASOs)

When it comes to integrating hepatitis C into ASOs' program/service delivery, space is required to explore and address many anxieties and challenges that might arise through a stakeholder engagement process. As expressed by a meeting participant, "Something we need to acknowledge is the fear within the ASOs of what's going to happen. With Hep C, the sheer numbers overwhelm those living with HIV. What's going to happen? Are we going to lose focus on HIV? Is HIV going to suffer? How will we honour the differences in the people. There are a lot of commonalities and co-infection but these are two different clienteles - especially if you are looking at cure. If we have a cure, we are looking at graduation and slowly weaning people off services, whereas with HIV it is a lifelong commitment to services. I want everyone to be aware of the building anxiety when we are looking at redesigning and bringing programs forward." These kinds of questions can be explored in a stakeholder engagement process and it is also important to share solutions across ASOs.

08

Organizational recommendation #8: Address social determinants of health through cross-sectoral partnerships

"Pills will treat hepatitis C but will not treat the social determinants of the risk factors. This is where the entire issue of reinfection is coming up. Based on these models, until and unless we provide supportive care and scale up harm reduction and addictions services, we won't be able to turn the tide of hepatitis C especially amongst people who use injection drugs (PWID) or people who are in the group where transmission is happening actively. That is where integration of services is an important piece of the puzzle."

— Meeting participant

An integrated model that is service user centred acknowledges broader social determinants of health in an individual's life. Through program collaboration and cross-sectoral partnerships with other services, many integrated models are assisting service users to access broader social services and supports they might need, including housing, employment, income stability, and access to healthy food, settlement, legal, cultural and other services identified by clients.

"The one thing that was really important for us was to build some cultural competency within our staff and to look at what our partnerships were within our service delivery model. Many of the private sector landlords that we were working with were evicting First Nations tenants because their families were staying with them. We spoke to the landlords about what family means and worked with clients to advocate for their needs and rights."

— Meeting participant

09

Organizational recommendation #9: Address racism, stigma and discrimination through equity-oriented hiring, anti-oppression training, shifting internal power structures and public education

An anti-racist and anti-oppression organizational approach is essential in creating appropriate services for those most affected by hepatitis C, as well as ultimately addressing the root causes of health inequity. It is important to hire a diverse workforce representative of the community being served and/or to partner with organizations operated by and for those most affected. It may also be important to provide anti-oppression and anti-racism training for staff, and to shift internal power relations and structures so that service users and marginalized individuals who face personal and systemic racism are given decision-making power within the organization.

“The level of racism in our community is a massive barrier to care.”
— Meeting participant

It is also important to invest in efforts that challenge and shift racism, discrimination and oppression outside of the organization and within the community more broadly. Essential to shifting broader systemic root causes of inequity is engaging in public education, political advocacy and cross-movement building around decriminalization, decolonization and equity-oriented initiatives.

3.2.3 Structural recommendations

The following recommendations detail structural approaches and mechanisms that foster integration and enable the development of responsive models of care that are accessible, relevant and effective in addressing hepatitis C.

01

Structural recommendation #1: Develop a national action plan for addressing hepatitis C with differentiated approaches designed by and for each priority population

A key structural factor to successfully address hepatitis C nationally is evidence-based public health policy. It is critical to have national and provincial strategies that include clear targets and financial commitments to address hepatitis C. To design effective and relevant strategies to address hepatitis C in priority populations, individuals from these populations must play a central role in designing, delivering and evaluating

SIDE NOTE

Addressing interpersonal and systemic racism against Indigenous peoples

In the context of addressing interpersonal and systemic racism against Indigenous peoples, it is important for organizations to place particular emphasis on learning about and responding to the realities of colonization, intergenerational trauma from the residential school system, cultural genocide and systemic abuse. Indigenous-led initiatives and strategies to address hepatitis C are essential. For organizations that are not Indigenous-led, this might mean partnering with, investing in, advocating for, and following the guidance of Indigenous-led organizations and strategies.¹⁶

¹⁶ Health Council of Canada. *Empathy, dignity and respect: Creating cultural safety for Aboriginal urban health care*. Toronto. Health Council of Canada. 2012.

population-specific approaches. Priority populations, including people who use injection drugs, people who are in prison, Indigenous peoples, street-involved youth, immigrants and newcomers to Canada from high-prevalence countries, older adults and HIV-positive men who have sex with men, must be invited to develop and deliver national and local strategies to address hepatitis C. For example, Indigenous-led and Indigenous-specific interventions are essential in terms of reaching and offering effective care to Indigenous peoples.

02 Structural recommendation #2: Ensure that optimal testing, monitoring, and treatment options are available and accessible to everyone living with, affected by, and at-risk of hepatitis C

The best testing, monitoring, and treatment options must be widely accessible to all individuals regardless of their geographic location, socio-economic status, or stage of liver damage or disease.

Treatment eligibility must be based upon clients' readiness and desire for treatment, not 'traditional' clinical or financial eligibility requirements.

Investment in the development of more streamlined, low-cost and accessible diagnostic tools and disease-monitoring technologies should be prioritized. Rapid hepatitis C antibody tests are available, but access to rapid testing remains a major challenge. Point-of-care testing for hepatitis C is available in the United States but is not currently available in Canada. A Fibroscan is a non-invasive and quick disease monitoring technology, but its availability is extremely limited.

03 Structural recommendation #3: Enhance surveillance and the epidemiological evidence-base for priority populations

Enhanced surveillance and epidemiological evidence is critical to better understanding the impact of hepatitis C in priority populations, and to developing policies, programs, and interventions that are based on the best evidence available at the time.

04 Structural recommendation #4: Ensure integration of hepatitis C into broader strategies for sexually transmitted and blood-borne infections at local, provincial and national levels

A commitment to incorporate hepatitis C into broader strategies and funding structures for sexually transmitted and blood-borne infections is critical. Some provincial HIV strategies developed for people who use injection drugs have not included hepatitis C services in efforts to scale up testing and treatment. This omission represents a significant missed opportunity.

05 Structural recommendation #5: Facilitate the development and implementation of primary care and nurse-led approaches to hepatitis C

A key structural factor in providing quality care to under-served communities and populations is having care integrated into primary care settings and investing in nurse-led models. Building the capacity of primary care providers and nurses to provide hepatitis C services is key to delivering integrated services in low-density areas. Limited access to speciality care is an issue not only in low-density settings, but also in some cities. It is important to develop professional guidelines and educational opportunities for primary care providers to engage in hepatitis C testing, treatment and care. Facilitating and prioritizing hepatitis C training opportunities for nurses and investing in nurse-led models of treatment and care is also useful. An important On-Reserve example is the model established in Ahtahkakoop, Saskatchewan. As part of this Indigenous-led and collaborative model, an Indigenous nurse manager from outside of the community comes to the health centre regularly and links clients with a physician through a technology called 'Doc in the box'

where a specialist is immediately linked to a client through online technologies. The nurse manager also brings a Fibrosan to enable rapid testing.

06 Structural recommendation #6: Develop national harm reduction policies including harm reduction in prisons and invest in hepatitis C programs inside prisons

Harm reduction must be central to the national hepatitis C strategy. A commitment to harm reduction is an evidence-based health-centred approach for people who inject drugs.

There is a huge gap in strategies and interventions for the prison population. It is essential for governments (all levels) and prison authorities to acknowledge that people use injection drugs in prison. In response to this reality, it is critical that governments and prison authorities support harm reduction interventions, including distribution of safe drug-use and tattooing equipment.

07 Structural recommendation #7: Develop funding models that support salary-based compensation and promote provision of resources to non-traditional healthcare providers

Current funding models are not well-suited to developing integrated, client-centred and health equity oriented hepatitis C care. Fee-for-service models and limited resources for peers and non-traditional staff, including Indigenous healers and Elders, limit capacity to provide culturally safe, client-centred care. Providing funding for salary-based models and ensuring availability of resources for peers and non-traditional healthcare providers, including Indigenous healers and Elders, is critical.

08 Structural recommendation #8: Link funding eligibility and evaluation metrics to health equity outcomes

It is important to link funding eligibility and evaluation metrics to health equity outcomes. Developing targeted testing, treatment, and health outcomes for priority populations, rather than targets for whole populations, will incentivize the development of services geared toward priority populations.

09 Structural recommendation #9: Invest in health system reforms geared toward health equity including mandating equity-oriented hiring practices, anti-racism and anti-oppression training and transfer of power to service users in shaping care

“Why aren’t people getting good care? Our system doesn’t demand that you provide good quality primary care and services to people who use drugs.” — Meeting participant

SIDE NOTE

Many Indigenous communities are leading the way in developing or adopting innovative ways to provide speciality care in low-density settings. One example is the use of the ‘Doc in the box’ technology, which has allowed local family physicians to provide treatment support to patients on small Reserves in northern Saskatchewan. A nurse manager comes to the health centre in northern Saskatchewan regularly and immediately links clients to a specialist through online technologies. This online technology allows clients in northern Saskatchewan to be linked with a specialist in real-time during their appointment.

It is essential that, through health policy, health systems be restructured to be accessible and effective for people who are marginalized, oppressed, and excluded in society. It is important to develop policies that ensure diverse healthcare workforces with strong representation from marginalized populations. For example, development of policies that mandate the implementation of health advisory boards governed by people who are systematically underserved by health systems is one way to ensure that health institutions and professionals are held accountable to those who are systematically underserved.

10 **Structural recommendation #10: Invest in strategies that address social determinants of health, including anti-poverty initiatives and develop policies to address racism, stigma and discrimination in society**

Having a health system that properly serves those who are marginalized and excluded in society is an important step, but is ultimately just a bandaid solution to the larger, more fundamental problems of social exclusion and marginalization.

It is essential to invest in policies and programs that improve the social and economic living conditions of oppressed and marginalized populations. Investing in housing, employment, education, harm reduction, and community-building initiatives creates safe and healthy communities. Investing in prisons, policing and other punishment-oriented institutions serves to re-traumatize individuals and reinforce social exclusion, marginalization, personal safety issues, and poor health.

Historic and continued societal oppression in the form of racism, colonialism, homophobia and transphobia are roots of social exclusion and marginalization. It is important for governments at all levels, and for local authorities to partner with groups and individuals with lived experience of discrimination to invest in public education campaigns and to develop policies that require schools, healthcare centres and workplaces to adopt decolonized, anti-oppressive and anti-racist strategies. In addition to educational elements, strategies must include power-sharing and re-structuring initiatives that shift power to individuals and populations with lived experience of racialization and discrimination.

11 **Structural recommendation #11: Invest in initiatives, including advocacy and cross-movement building**

There is an urgency to establish collaborative partnerships for effective advocacy and systems change efforts. Action Hepatitis Canada has begun to provide leadership in hepatitis C advocacy at the national level. There is also a need to revisit existing initiatives, including the Public Health Agency of Canada's Hepatitis C Strategic Framework for Action (2009). Funding for access to treatment could become a 'wedge' issue, with various groups competing for preferential treatment, but it is important to unify and mobilize for access to treatment and care together.

It is also critical to invest in cross-movement building with non-hepatitis C specific groups. These cross-

movement building and partnership initiatives require dedicated funding and resources.

3.3 Knowledge exchange resources and tools to build capacity for change

The following knowledge exchange tools were identified as priority needs to enable implementation of the programming, organizational and structural recommendations listed above and which will inform CATIE's knowledge exchange activities moving forward.

Increase knowledge exchange of existing integrated, responsive hepatitis C program models

Although there are many promising and innovative integrated hepatitis C frontline program models across the country, there are no systematic ways to share these programs, or to evaluate promising practices. There is a need to build on significant local innovation among frontline service providers and communities across the country by prioritizing the following knowledge exchange activities:

- ***Identify and map out existing program models and document them to share lessons learned and promising practices.*** In particular, there is a need to identify and document how harm reduction programs are adapting their program models to provide continued support and care in the context of new, more effective, and shorter treatment regimens. The Indigenous-focused discussions highlighted the need for a mapping exercise to document existing urban and rural models across the country, both on- and off-Reserve, and to create linkages across programs to foster learning and support.
- ***Build a national network of individuals and organizations working with immigrants and newcomers to Canada or interested in developing models geared toward this priority population.*** Immigrants and newcomers to Canada have far fewer services than other populations, and a national network might boost development of programs for them.
- ***Develop good practice recommendations to help build local capacity among providers working in low-resource primary care and social service settings.***
- ***Develop good practice recommendations and training opportunities focused on how to develop effective peer-based models and other models led by those most affected.***
- ***Develop good practice recommendations on how to partner with existing organizations operated by and for those most affected (Indigenous peoples, people who use injection drugs, etc.).***

Invest in education and capacity-building for healthcare providers

There is an urgent need to build capacity in hepatitis C. This includes developing and delivering education modules and other training strategies designed to build capacity in primary care and social service settings. It is particularly critical to develop tools and resources for clinicians and service users to increase their awareness and knowledge about hepatitis C testing. Alongside learning tools directly related to hepatitis C, there is also a need to increase education and capacity of healthcare providers to work with a diversity of populations and follow an anti-oppressive, trauma-informed, harm reduction and culturally safe approach to care.

Enhance health and hepatitis C literacy amongst service providers from varying sectors and amongst the Canadian public

There is a need to prioritize health and hepatitis C literacy amongst non-health specific service providers and amongst the Canadian public more broadly. There remains much misinformation on hepatitis C and other sexually transmitted and blood-borne infections and on prevention and treatment options. One of the benefits of new hepatitis C treatments is that people may be incentivized to test. However, many people continue to believe that interferon, with its challenging side effects, is the main treatment for hepatitis C, and this is a

potential deterrent to testing and treatment consideration.

Enhance health equity literacy amongst policy-makers, service providers and the Canadian public

There is a need to develop clearer and more consistent understanding of the language around and function of health equity and social determinants of health and hepatitis C. Specifically, there is a need to:

- Establish a clear understanding of the concepts and dynamics of health equity and social determinants of health.
- Develop a clear understanding of social determinants of hepatitis C and a cohesive analysis of how the hepatitis C epidemic is connected to issues of health equity.
- Establish tools for incorporating health equity into practise and develop mechanisms for sharing case studies and good practices.

Enhance community systems strengthening literacy and capacity amongst populations most affected, service providers and policy-makers

There is a need to develop a clear understanding of the community systems strengthening framework and to build capacity to engage in community systems strengthening initiatives. Specifically, there is a need to:

- Establish a clear understanding of the concept and dynamics of community systems strengthening.
- Develop tools for local and regional health systems mapping and analyses.
- Develop tools and best practices for advocacy, movement-building and broad stakeholder mobilization.
- Develop mechanisms for sharing case studies of effective community systems strengthening initiatives, including lessons learned from the HIV movement.

3.4 Population-specific priority directions

Although the hepatitis C programs across and within the priority populations discussed at the deliberative dialogue had several features in common, important population-specific realities and priorities were also identified. As outlined in the structural recommendations, it is critical that the national response to hepatitis C include differentiated approaches designed by and for each priority population. The population-specific presentations and discussions at the deliberative dialogue provided an opportunity to identify preliminary priority directions for Indigenous peoples, people who use injection drugs, immigrants and newcomers to Canada, as well as older adults. These are described below.

3.4.1 Priority directions to address hepatitis C amongst Indigenous peoples

It is critical to appreciate the tremendous cultural, linguistic, and socio-economic diversity across and within Indigenous communities, with over half of the Indigenous population located in urban centres, and with much migration between urban and non-urban locations. There is immense variation in Indigenous models of integrated programming because of complex jurisdictional landscape issues and inconsistencies in terms of policies and self-government agreements across the country. There are on- and off-Reserve programs; programs in urban, rural and remote locations; programs under federal and provincial/territorial jurisdictions; multiple health providers; multiple health standards; and multiple funders.

Vision for a hepatitis C model of care for Indigenous peoples

Local and cultural contextualization of any model is critical, but the following elements support a common vision for an effective and relevant hepatitis C model of care for Indigenous peoples.

Structures must be developed and led by First Nations, Inuit, and Métis peoples to eliminate the disproportionate burden of hepatitis C within Indigenous populations by establishing health targets for this population that surpass those for the overall Canadian population. Such a specific focus on and investment in health outcomes for priority populations is known as equity-plus¹⁷ in the provision of prevention, testing, care, treatment and support services to achieve zero.¹⁸

- Indigenous-led and multidisciplinary approaches:
 - are rooted in Indigenous determinants of health (including colonial racism and social exclusion);
 - entail diverse and shared care models with primary, mobile, community-based, eHealth and appropriate specialist support; and
 - prioritize Indigenous workforces, including health brokers and navigators (who are Indigenous but not necessarily from the community in question).
- Multifaceted and equitable approaches:
 - involve the provision of integrated care and are structured to enable practitioners to spend the time needed to appropriately address particularly complex needs of many Indigenous clients;
 - involve integrated prevention, testing, treatment and care for sexually transmitted and blood-borne infections, which is provided either through service integration or program collaboration;
 - include appropriate post-test education and linkage to care; and
 - facilitate and make available access to hepatitis C treatment based on client readiness rather than clinical eligibility criteria markers (degree of fibrosis, number of courses of therapy) or financial criteria.

¹⁷ Equity plus is a term used to describe the goal of having target health outcomes for priority populations that not only equal those for the overall population but surpass them. This would require a focus on and specific investment in the health outcomes of priority populations.

¹⁸ Achieving zero is a term referring to the aim of eliminating the overrepresentation of Indigenous peoples and other underserved populations in all health disparity data.

- Wholistic and culturally safe approaches:
 - involve wholistic and culturally safe programming, with culture broadly defined to include gender, lived experience and traditional cultural beliefs;
 - incorporate Indigenous processes and Indigenous ways of knowing and healing; and
 - provide trauma-informed care that addresses historic, collective and inter-generational trauma.
- Geographically flexible and adaptable approaches:
 - respond to and make connections between highly mobile rural and urban populations.
- Cross-sectoral collaborative approaches:
 - involve formal ties and connections with other sectors (e.g., connections with correctional services are needed given overrepresentation of Indigenous people among incarcerated populations).

Recommendations for addressing hepatitis C within Indigenous communities

- Establish a national Indigenous mapping exercise to gather data on Indigenous models, including rural, remote, on- and off-Reserve, urban and mobile models. These models must be shared and used as guides for creating responsive programs.
- Create a national Indigenous hepatitis C strategy to provide a framework for action for Indigenous leadership and communities, as well as healthcare providers and governments.
- Invest in programs and services that are wholistic and culturally safe at both individual and organizational levels.
- Invest in programs that are founded in Indigenous processes and Indigenous ways of knowing and healing.

Tools, resources and supports

- A tool will be needed to map services across the country.
- Mobile testing or pop-up clinics will be needed to increase uptake of testing. Appropriate post-testing education and linkage to care should be made available.
- Formal ties and connections with provincial/territorial and federal correctional services should be established.
- Models for peer support programs should be shared.
- National and international health authorities will need to collect and interpret Indigenous-specific data and pursue an equity plus¹⁹ approach that includes establishing target numbers of Indigenous people being tested, treated and accessing services, instead of simply setting overall target numbers for the general population, which may miss population-specific differences.
- Health education resources should be made available in multiple Indigenous languages.

3.4.2 Priority directions to address hepatitis C amongst people who use injection drugs¹⁹

Injection drug use occurs across ages, genders, races, cultures, socio-economic classes and rural and urban settings. People who use injection drugs are diverse, and models for hepatitis C will need to adapt to the particular community they serve. Harm reduction services vary across provincial, territorial and federal jurisdictions and models will need to adapt to services, programs and infrastructures specific to each location.

¹⁹ There were 2 break-out groups discussing priority directions for people who use drugs at the deliberative dialogue. This section summarizes and integrates the findings from both of these groups.

Vision for a hepatitis C model of care for people who use injection drugs

Local and cultural contextualization of any model is critical, but the following elements support a common vision for an effective and relevant hepatitis C model of care for people who use injection drugs. Community-based primary care models are central to the vision. Community-based primary care models should address the whole person and should include the following elements:

- Models of care should be ongoing so that patients can remain in care indefinitely (i.e., it's not just about hepatitis C treatment, but, about all aspects of care for an individual who is using injection drugs). One of the goals is for people who use injection drugs to develop an ongoing relationship with primary care, which might include engaging in after-treatment, engaging in support groups, leading support groups and becoming a staff member, and participating in ongoing testing.
- Community-based organizations are a part of the model and directly connected with the clinic.
- Alternative funding allows for salary-based models of compensation as opposed to fee-for-service compensation.
- The model should be driven by peers and people with lived experience. It might include:
 - peer-designed and peer-led programs;
 - patient/client advisory boards;
 - peer-led research and evaluation;
 - partnerships with peer-led organizations;
 - peer health navigators;
 - ongoing learning and training about best practices in peer work;
 - a strong knowledge-building component (it might serve as a hub to provide curricula and training);
 - a team-based approach to knowledge building and sharing; and
 - knowledge and training that addresses the misconceptions that healthcare providers have regarding people who use injection drugs.
- The model should provide client-driven care in which clients lead and guide the service team.
- Community/street outreach is embedded in the model:
 - Peer/community workers guide outreach services.
 - The catchment area can be broadened, including rural and remote areas.
 - Outreach can be used to expand testing.
 - There must be sufficient capacity in the primary care model to accept referrals from the outreach team for people who test positive.
 - Strong relationships must be built between outreach workers and clinical care providers, with an emphasis on consistent messaging, continuous communication and a smooth referral process.
 - Outreach can be conducted within prisons, and partnerships can be established with peer groups both within and outside of prison environments.
- The model should explicitly follow principles of harm reduction:
 - The environment should be free of stigma and judgement. People who are using injection drugs are welcome to be in the space; they are designing and delivering programs; they are part of the staff team.
 - Safe equipment is available on-site with education around using safely.
 - Safe equipment and a harm reduction approach are used when working in prisons.²¹

- A multidisciplinary team approach is employed:
 - Key roles include addiction specialists, mental health counsellors, community and outreach workers, family physicians and hepatitis C treatment specialists.
- Nurse-led hepatitis C treatment models and nurse leadership is central:
 - Nurses should be enabled and supported to take lead roles coordinating various kinds of care and supports required by individuals with hepatitis C. This makes it possible to centre care outside of specialty clinics, which can be inaccessible and more rigid in structure.
- Community systems strengthening initiatives are important parts of the model:
 - Investments should be made in building the skills, partnerships and abilities of clients and staff to analyze root causes of health inequity and to mobilize for systems-level changes.
 - People with lived experience should lead the response.
 - Action Hepatitis Canada is a key organization, along with Indigenous organizations and organizations run by and for people who use injection drugs.

Recommendations to address hepatitis C amongst people who use injection drugs

- Ensure that hepatitis C treatment is free and accessible for everyone who expresses readiness.
- Invest in peer-based programming along with harm reduction programming in all settings.
- Invest heavily in prevention through drug equipment distribution, education, testing and treatment with high-risk individuals.
- Create a specific section within the national hepatitis C strategy designed by and for people who use injection drugs.

Tools, resources and supports

- Training opportunities and resources on peer-led models should be developed (consider existing models, including the peer leadership development model in HIV by Ontario AIDS Network and Pacific AIDS Network).
- People who use injection drugs should be supported to develop anti-stigma and good practice resources for use by people who work closely with people who use injection drugs.
- Resources should be developed to build community systems strengthening capacity and leadership, especially by and for people living with hepatitis C.
- Epidemiological data related to this priority population should be collected.
- Bold and meaningful partnerships should be pursued with provincial/territorial and federal correctional services as well as peer health organizations operated by people who are incarcerated. Existing models of hepatitis C care within prisons can be used for guidance.
- Partnerships should be developed with researchers to leverage ability to pilot innovative and potentially controversial programming.

²¹ Betteridge G, Dias G. *Hard times: HIV and hepatitis C prevention programming for prisoners in Canada. Canadian HIV/AIDS Legal Network and Prisoners' HIV/AIDS Support Action Network (PASAN.)* 2007. Available from: http://www.pasan.org/Toolkits/Hard_Time.pdf

3.4.3 Priority directions to address hepatitis C amongst immigrants and newcomers to Canada from high-prevalence countries

While immigrants and newcomers to Canada are healthier than their Canadian counterparts when they arrive (the healthy immigrant effect ²²), some research has shown that the longer a person resides in Canada, the more their health status declines. Studies have found that immigrants and newcomers to Canada report poorer health outcomes over time because of many factors, including poverty, stress, and structural barriers to accessing health services and receiving culturally appropriate care. Immigrants and newcomers access healthcare services less than people born in Canada, and this is especially true of refugees and individuals who do not have status or proper immigration documents. Medical education often cannot keep pace with the changing population demographics of the country. These factors create unique challenges that must be addressed.

Stigma associated with hepatitis is not as prevalent among many immigrant and newcomer population groups as it is among people born in Canada because hepatitis C and hepatitis B are primarily transmitted through medical systems in many immigrant and newcomer countries of origin. In many immigrant communities, hepatitis C is considered a chronic disease.

Vision for an integrated model of care for immigrants and new Canadians

Local and cultural contextualization of any model is critical, but the following elements support a common vision for an effective and relevant hepatitis C model of care for immigrants and newcomers to Canada.

- Immigrant community hubs should serve as focal points for hepatitis C programming and services. These hubs include agencies specialized in settlement, social and primary health services for newcomers, including refugees and individuals without the proper immigration documents. They can be integrated into a one-stop-shop model and can make more formalized connections to specialist services beyond their immediate scopes.
- Multidisciplinary and family-based models of immigrant health should be founded upon:
 - family-centred health care that wraps around the service user's needs in an integrated and comprehensive way;
 - the availability of staff and services that can address accessibility issues of treatment affordability as well as provide on-site interpretation and translation services; and
 - partnerships with programs and services for related supports such as settlement, language, child care, literacy and employment training that address broader social conditions and needs of newcomers in a comprehensive manner.
- Cross-cultural/cultural safety capabilities and interpretation services should be improved in hospitals and other mainstream health centres and speciality clinics. This includes appreciating non-Western models of healthcare, and communicating on the basis of values and beliefs of clients. It is also important to employ a workforce that represents the diversity within the newcomer populations.
- Alternative funding models should be instituted for specialist services, including salaried compensation rather than fee-for-service compensation, which gives healthcare providers the flexibility to take the time to provide culturally appropriate care.
- Strategies should be established for non-insured service users, including refugees and individuals without proper immigration documents. This could involve sector-wide arrangements with hospitals, common data collection and resource-sharing mechanisms.

²² Gushulak B, Pottie K, Roberts J, et al. Migration and health in Canada: Health in the global village. *CMAJ*. 2011 Sep;183(12):E952-E958

Recommendations to address hepatitis C amongst immigrants and new Canadians: tools, resources and supports

- Prioritize investment in community hubs in large urban centres with significant newcomer populations.
- Include hepatitis C information referrals and testing as part of standard newcomer settlement and orientation packages offered at settlement agencies.
- Prioritize this population within provincial and national hepatitis C strategies (move beyond a focus on the incidence of the disease). Train healthcare providers in cultural safety, cross-cultural communication and non-Western paradigms of care.
- Hire a diverse workforce that is representative of the diversity in Canadian communities.

3.4.4 Priority directions to address hepatitis C amongst older adults

Hepatitis C and older adults

Older adults represent an extremely heterogeneous population, so efforts to develop programming must incorporate a diversity of approaches and strategies.

Vision for an integrated model of care for older adults

Local and cultural contextualization of any model is critical, but the following elements support a common vision for an effective and relevant hepatitis C model of care for older adults.

Everyone who lives with hepatitis C should:

- know that they are living with hepatitis C;
- have choices with respect to their care, treatment and support; and
- have barrier-free access to appropriate care, treatment and support.

Recommendations for older adults: tools, resources and supports

- Prioritize a publicly funded awareness-raising campaign specifically for older adults and their service providers, which educates them generally, but also more specifically underscores the importance of urgency (testing and diagnosis), care and treatment and social support.
- Ensure barrier-free access to testing and care through innovative approaches to care, counselling and social support (not limited to or restricted by pharmacological interventions).
- Focus on the age of the virus instead of simply on the age of the individual.
- Foster broader awareness of treatment options, and ensure that models prioritize mental health and wellness over purely pharmacological interventions specific to hepatitis.
- Develop peer support and support groups for older adults.
- Increase mainstream media awareness to de-stigmatize and normalize hepatitis C.
- Increase the profile of people with lived experience who are willing to act as public champions and to share their stories.
- Develop a national hepatitis C strategy with approaches specific to older adults.

4. Limitations of the deliberative dialogue

Participants acknowledged several important limitations of the deliberative dialogue.

Though the intention of the deliberative dialogue was to discuss different approaches to integrated hepatitis C care for priority populations, there was insufficient time to discuss all models and/or all priority populations. In particular, no Indigenous-led models were formally presented, only models led by non-Indigenous peoples working with Indigenous populations. Indigenous-led models were shared by meeting participants in the discussion sections, but not in the formal presentation sections.

In addition, no models for people in prison were presented, and there was no representation from groups or organizations working inside prisons.



5. Acknowledgements

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Appendix I

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Appendix II

Meeting agenda

National Deliberative Dialogue on Integrated Hepatitis C (HCV) Programming and Services

Wednesday, February 11, 2015

Delta Toronto • Kensington Ballroom, Southcore Financial Centre, 75 Lower Simcoe St, Toronto, ON

The first day of the *Deliberative Dialogue* will focus on different approaches to integrated HCV programs and services. Brief presentations will highlight program collaboration and service integration models that meet the comprehensive needs of people at risk for, and with lived experience of, HCV. In the afternoon, we will focus on how putting the needs of people living with HCV at the centre of service delivery can help us think differently about what integrated program models might look like. Brief presentations on customized HCV treatment programs will set the stage for our discussions.

Time	
7:45-8:30	Registration and Breakfast
8:30-9:00	Welcome, Introductions and Overview of CATIE's Role Laurie Edmiston, Executive Director, CATIE Marc-André LeBlanc, Meeting Facilitator Welcome to the traditional territory Dr. Malcolm King, a member of the Mississaugas of the New Credit First Nation, and Scientific Director, CIHR Institute of Aboriginal Peoples' Health, Opening of the meeting Ed Bennett, Community Readiness Project Supervisor, CAAN
9:15-10:00	The HCV Continuum of Care: Overcoming Barriers to Successful Engagement Shruti H. Mehta, PhD MPH, Professor, Johns Hopkins Bloomberg School of Public Health
10:00-10:15	Break
10:15-11:15	Integrated Community Health Approaches in Urban Settings: Examining Different Models Five 10-minute presentations followed by large-group discussion. <ul style="list-style-type: none">• Halifax: Jacqueline Atkinson, HCV Program Lead, RN, North End Community Centre• Toronto: Jason Altenberg, Director of Programs and Services, South Riverdale Community Health Centre• Winnipeg: Carla Pindera, Manager of Clinical Programs, Nine Circles Community Health Centre• Calgary: Lynda Watson Waddington, Hepatitis C Nurse Clinician, Calgary Urban Project Society (CUPS)• St-Jérôme: Hugo Bissonnet, Directeur Général, Centre Sida Amitié

11:15-12:15	<p>Facilitated Discussion Participants will discuss the development and implementation of integrated HCV approaches, and discuss the strengths, challenges and opportunities presented by the various approaches.</p>
12:15-1:15	<p>Lunch</p>
1:15-2:05	<p>Integrated Community Health Approaches in Low Density Areas</p> <p>Four 10-minute presentations followed by large-group discussion.</p> <ul style="list-style-type: none"> • Kamloops/Merritt, British Columbia: Bob Hughes, Executive Director, ASK Wellness Society • Yukon: H��l��ne B��langer, RN, BScN, Infectious Diseases and HCV Treatment Nurse, Yukon Communicable Diseases Control • Saskatoon, Saskatchewan: Lesley Gallagher, HCV Nurse Clinician, Saskatoon Infectious Disease Care Network • Thunder Bay, Ontario: Holly Gauvin, Executive Director, Elevate NWO (formerly AIDS Thunder Bay)
2:35-2:45	<p>Facilitated Discussion Participants will discuss the development and implementation of integrated HCV approaches, and discuss the strengths, challenges and opportunities presented by the various approaches.</p>
3:00-3:15	<p>Break</p>
3:15-4:00	<p>Expanding a Traditional HCV Treatment Model to Meet the Comprehensive Needs of People Living with HCV.</p> <p>Two 15-minute presentations followed by large-group discussion.</p> <ul style="list-style-type: none"> • An Integrated Clinic Model: Dr. Chris Steingart, Executive Director, Sanguen Health Centre • Integrated HCV Treatment: Telemedicine and Community Liaison Program: Dr. Curtis Cooper MD, FRCPC, Director, The Ottawa Hospital and Regional Viral Hepatitis Program
4:00-5:00	<p>Facilitated Discussion Participants will discuss expanding traditional treatment models to meet the comprehensive needs of people living with HCV, the implications of new HCV treatments in their programming, and lessons learned from different approaches.</p>
5:00-5:15	<p>Wrap-up for Day 1 Marc-Andr�� LeBlanc</p>
	<p>Welcome Reception at the Hotel</p>

Appendix II

Meeting agenda

National Deliberative Dialogue on Integrated Hepatitis C (HCV) Programming and Services

Thursday, February 12, 2015

Delta Toronto • Kensington Ballroom, Southcore Financial Centre, 75 Lower Simcoe St, Toronto, ON

The second day of the *Deliberative Dialogue* will focus on population-level approaches to HCV services. A panel of brief presentations will synthesize population-specific priorities and challenges. Participants will engage in small-group discussions focused on identifying strengths, opportunities and priority recommendations to move integrated HCV programs forward with specific populations. An interactive and iterative process will allow each group to provide feedback and build on each other's thinking, culminating in final population-level recommendations.

Time	
8:00-8:30	Breakfast
8:30-9:00	Reflection on Day 1 and Orientation to Day 2 Laurie Edmiston, Executive Director, CATIE Marc-André LeBlanc, Meeting Facilitator
9:00 - 10:00	Addressing Different Realities and Priorities: A Population-Level Discussion Five 10-minute presentations followed by large-group discussion. <ul style="list-style-type: none">- <u>Older Adults</u>: Daryl Luster, President, Pacific Hepatitis C Network- <u>First Nations, Inuit and Métis Peoples</u>: Alexandra King, MD, FRCPC, Nipissing First Nation, GIM w/ HIV & Hep C focus, Vancouver Infectious Diseases Centre; PhD Student, Simon Fraser University- <u>Immigrant and Refugee Communities</u>: Baldev Mutta, Chief Executive Officer, Punjabi Community Health Services- <u>People who Use Drugs</u>: Karine Hudon, Direction générale, Association québécoise pour la promotion de la santé des personnes utilisatrices de drogues (AQPSUD)- <u>People who Use Drugs</u>: Terra Tynes, Community Support Worker, Toronto Community Hep C Program
10:00-10:30	Facilitated Discussion Participants will use their own expertise and the information from the presentations to discuss common (overlapping and intersecting) themes across populations.
10:30-10:45	Break

10:45-12:15	<p>Small Population-Level Discussion</p> <p>Participants are assigned to small break-out groups based on the five identified populations. They will discuss how program models can be tailored to meet the needs of their assigned population, and to envision the key components of a successful program model for it. They will be asked to develop key recommendations/priorities for their assigned population.</p>
12:15-1:15	<p>Lunch</p>
1:15-1:45	<p>Report Backs from the Small Group Discussions</p> <p>Each break-out group will present the key components they have identified; including key recommendations/priorities to enhance HCV program delivery. Later in the day, groups will receive feedback on their vision through a facilitated discussion.</p>
1:45-2:35	<p>Facilitated Discussion</p> <p>Participants will discuss how key components highlighted by other groups intersect and overlap with their groups, discuss differences between populations and provide feedback on each group's recommendations/priorities.</p>
2:35-2:45	<p>Group photo in hotel lobby</p>
2:45-3:00	<p>Break</p>
3:00-4:00	<p>Small Population-Level Discussion</p> <p>Participants will reflect on the large group discussions and the feedback provided by other groups, and finalize their recommendations/priorities to move integrated HCV programs forward.</p>
4:00-4:45	<p>Pulling it All Together: Next Steps, Wrap-up, Evaluation <i>Marc-André LeBlanc, Meeting Facilitator</i> <i>Laurie Edmiston, Executive Director, CATIE</i></p>

Appendix III

List of pre-meeting background materials

- CATIE. Backgrounder: Context for CATIE's *National Deliberative Dialogue* on Integrated Hepatitis C Programming and Services, January 2015.
- List of pre-recorded webinars:²³
 - 1) Hepatitis C: New Therapies and Implications, January 8, 2015
 - 2) Sexual Transmission of Hepatitis C Among Men who have Sex with Men, January 12, 2015
 - 3) Breaking Down the Barriers to Hepatitis C Virus Treatment Among People Who Use Drugs (PWID): A Review of the 1st Set of International Recommendations
 - 4) Best Practice Recommendations for Canadian Harm Reduction Programs that Provide Service to People Who Use Drugs and are at Risk for HIV, Hepatitis C, and other Harms
 - 5) Hepatitis C in Migrants: An Underappreciated Group at Increased Risk , January 19, 2015
 - 6) Surveillance and Epidemiology of Hepatitis C in Canada, January 20, 2015

²³ The pre-recorded webinars are available from: <http://www.catie.ca/en/changing-landscape-hepatitis-c>

Appendix IV

Evaluation Results

Evaluation forms were distributed to attendees. The response rate was high at 81% (34/42).

The event was relevant to all attendees. Relevance was assessed through the following indicators:

- 100% of participants agreed or strongly agreed that the deliberative dialogue was appropriate for them.
- 100% of participants agreed or strongly agreed that they will use/apply the knowledge gained through this deliberative dialogue in their work.
- 100% of participants agreed or strongly agreed that the deliberative dialogue was relevant to the work of their organization.

The deliberative dialogue met its overall objectives.

Increased knowledge:

- 97% of participants agreed or strongly agreed that the deliberative dialogue increased their knowledge of new directions in hepatitis C programming.
- 100% of participants agreed or strongly agreed that they would recommend that CATIE continue to offer this type of event.

Increased capacity to respond:

- 100% of participants agreed or strongly agreed that the deliberative dialogue increased their capacity to respond to hepatitis C.

Provided an opportunity to network:

- 100% of participants agreed or strongly agreed that the deliberative dialogue provided an opportunity to network with others.
- 97% of participants agreed or strongly agreed that the deliberative dialogue was effective at facilitating multi-region, cross-sectoral collaboration, knowledge sharing and networking among hepatitis C programming leaders.

Provided an opportunity to explore issues and identify priorities:

- 100% of participants agreed or strongly agreed that the deliberative dialogue was effective at informing priority directions for population-specific hepatitis C programming, services and policy that put service users at the centre of an integrated framework.
- 97% of participants agreed or strongly agreed that the deliberative dialogue was effective at providing guidance to programs across Canada on hepatitis C continuum of care models for specific populations.

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