

Backgrounder:

Context for CATIE's National Deliberative Dialogue on Integrated Hepatitis C Programming and Services

January 2015

Introduction

The rapidly changing landscape in hepatitis C has the potential to significantly transform our national frontline response. New national hepatitis C screening and diagnostic guidelines will probably call for increased testing and screening; new research shows that sexual transmission of hepatitis C via blood contact may be increasing among some gay men and other men who have sex with men (MSM), which may impact our prevention messaging for that population; new national harm reduction best practices have the potential to improve hepatitis C prevention among people who use drugs; and greater availability of more effective, better tolerated treatments will challenge our clinical capacity to treat people living with hepatitis C and support them to remain hepatitis C free when cured.

CATIE proposes to host a National Deliberative Dialogue on Integrated Approaches to Hepatitis C Programming and Services to tackle some of the challenges raised by this changing landscape. Integrated approaches are designed to be comprehensive and client-centred.

This backgrounder provides context for, and outlines the key goals of, the deliberative dialogue.

Current state of hepatitis C in Canada

The Public Health Agency of Canada (PHAC) estimated that 0,96 % of Canadians were antibody positive for hepatitis C in 2011, which represents about 332,500 people.⁽¹⁾ Anti-hepatitis C prevalence includes all people who tested positive for hepatitis C virus antibodies, including individuals who clear the virus spontaneously. Groups identified by PHAC who are most impacted by hepatitis C include current and former injection drug users, inmates, nursing home residents, homeless people who do not inject drugs and people born outside of Canada.¹(1) PHAC also estimates that 35% of people who are anti-hepatitis C positive are foreign born.⁽¹⁾

Despite these numbers, epidemiological data are incomplete in Canada. The analysis of the hepatitis C burden using PHAC's current system of categorizing populations does not provide a comprehensive picture of the burden among Aboriginal peoples. However, we do know that Aboriginal peoples are overrepresented among people who inject drugs.⁽²⁾ This suggests that rates of hepatitis C in these populations may be disproportionately high.

What do we know about hepatitis C care in Canada?

The hepatitis C treatment cascade, sometimes called the continuum of care, may be one useful way to assess how well our current hepatitis C care practices work. This model has been useful in recent years for identifying gaps in the HIV continuum of care and for highlighting where linkages can be improved to reach the desired outcome of undetectable viral load for HIV-positive individuals.⁽³⁻⁷⁾

¹ These are categories set out by the Public Health Agency of Canada.

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The application of a similar treatment cascade model to hepatitis C was first developed for the United States in 2014. It is estimated that of the people living with chronic hepatitis C in the United States, only 50% are aware of their status, only 43% have accessed care, only 27% have a confirmed RNA positive test, only 16% have been prescribed treatment and only 9% have achieved a cure or sustained virological response.(8)

A complete snapshot of the hepatitis C continuum of care does not exist. We do know that hepatitis C prevention services such as the distribution of harm reduction supplies may serve as a gateway to other hepatitis C services, including testing, treatment and support. Despite the crucial role prevention services may play, there are few national-level data on how accessible hepatitis C prevention services are in Canada.

We know more about the other components of the hepatitis C treatment cascade. PHAC estimates that of the 332,500 people who are positive for anti-hepatitis C antibodies, 56% were aware of their status in 2011.(1) Additional estimates for testing rates and data on the rest of the cascade can be found in surveillance systems such as PHAC's I-Track, which involves people who use injection drugs. Such surveillance systems can provide some indication of the treatment cascade in Canada. I-Track shows, for example, that between 2010 and 2012, 91% of people who inject drugs self-reported having ever been tested for hepatitis C.(2)

I-Track suggests that treatment uptake in Canada among people who inject drugs is very low. Among I-Track participants who reported being currently infected with hepatitis C, only 48% reported being under the care of a doctor,(2) only 10% had ever been prescribed hepatitis C treatment (2) and only 2.4% were currently on treatment.(2)

There are also some data on treatment more broadly in Canada. A review of prescriptions for hepatitis C treatment filled since 2010 suggests that fewer than 2,000 people have been treated annually for hepatitis C since then.(9)

The slow progression of hepatitis C and the high prevalence of the disease among people born between 1945 and 1975 means current treatment rates will need to increase to reduce the incidence of complications associated with hepatitis C infections, including cirrhosis and liver cancer. Research suggests that the incidence of these complications will rise significantly in the next 20 years. Rates of compensated and decompensated cirrhosis and of liver cancer are expected to peak in the 2030s.(10) Compared with 2013 rates, it is estimated there may be an 89% increase in cases of compensated cirrhosis, an 80% increase in cases of decompensated cirrhosis and a 205% increase in cases of liver cancer by 2035.(10)

Community response to hepatitis C

We are now beginning to see a more coordinated community response as a result of the lack of adequate services for people at risk for and living with hepatitis C. At the local level, there are some hepatitis C-focused organizations dedicated to providing education on hepatitis C, increasing awareness of the condition or offering support for people at risk for, or with lived experience of, hepatitis C. Complementing the services offered by hospital-based and specialty clinics, many population-specific community-based organizations are integrating a hepatitis C response into their services, including AIDS service organizations, harm reduction organizations and some Aboriginal health organizations.

National organizations like the Canadian Liver Foundation, the Canadian Association for the Study of the Liver (CASL) and the Canadian Association of Hepatology Nurses are speaking out about the need for increased support for hepatitis C treatment and care. Action Hepatitis Canada, a national advocacy network of organizations responding to hepatitis B and C, aims to advocate for a stronger response to hepatitis C provincially and nationally.

Changing landscape of hepatitis C services

The rapidly changing landscape in hepatitis C has the potential to significantly transform our response. Four new developments may contribute to this transformation:

- new national hepatitis C screening and diagnostic guidelines
- new research that shows that sexual transmission of hepatitis C via blood contact is increasing among some MSM
- new national harm reduction best practices
- new treatments that are better tolerated and more effective

New national screening and diagnostic guidelines

PHAC is in the process of developing hepatitis C screening and diagnostic guidelines for healthcare providers. There is a good chance these guidelines will call for increased screening and testing for hepatitis C. Such guidelines may influence provinces to expand their hepatitis C screening capabilities, which will increase the number of people living with hepatitis C who are aware of their status.

Though service delivery is provincially mandated, new national-level screening and testing recommendations may encourage provinces to increase testing rates by helping primary care providers to understand how hepatitis C is transmitted, who may be at increased risk, and when to counsel patients to test. Guidelines may also highlight the two-step process that is necessary for hepatitis C diagnosis, which many primary care providers may not currently understand.

Although there are currently no national-level guidelines, other stakeholders have made specific recommendations for hepatitis C screening and diagnosis. In 2011, the Canadian Collaboration for Immigrant and Refugee Health recommended that all immigrants and refugees from regions where the prevalence of hepatitis C is greater than 3% be screened for hepatitis C.(11) In 2012, the CASL hepatitis C management guidelines recommended that case finding be increased.(12)

The United States Centers for Disease Control and Prevention (CDC) issued a recommendation in 2012 that all people born between 1945 and 1965 be tested at least once for hepatitis C.(13) This birth-cohort screening was to be in addition to continued screening of identified at-risk populations. The Canadian Liver Foundation followed suit in 2013, recommending that all Canadians born between 1945 and 1975 be tested for hepatitis C.(14)

In 2014, a group of New Brunswick physicians released a provincial-level consensus statement on screening recommendations that called for one-time screening of all people born between 1945 and 1975 and annual screening of those at high risk of acquiring hepatitis C, including persons who use injection drugs.(15)

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New understanding of the sexual transmission of hepatitis C among MSM

Although hepatitis C is not classified as a sexually transmitted infection, recent research has shown that the sexual transmission of hepatitis C is possible among gay men and other MSM. Since the 2000s, increasing evidence from studies conducted in high-income countries has shown that hepatitis C may be transmitted sexually among HIV-positive MSM when blood is present.(16–20) There is limited research that suggests that hepatitis C may be transmitted sexually among HIV-negative MSM in the same way.(21,22)

Although some studies have found higher rates of injection drug use among MSM co-infected with HIV and hepatitis C, which may explain some co-infections in this group, other studies have documented sexual risk as the sole risk for transmission.(16,18,22,23) For example, a study from England found that 83% of hepatitis C infections in HIV-positive MSM could not be explained by either injection drug use or blood transfusion but could be explained by rough sexual practices that cause bleeding.(17)

The new understanding that hepatitis C can be transmitted during sex through blood contact may change prevention services, such as risk reduction counselling and safer sex messaging for some MSM and for any couples where blood may be present during sex.

New national best practices for harm reduction

For the first time in Canada, we have national-level evidence-informed recommendations on how to provide consistent, high-quality harm reduction services to people who use drugs. These consensus recommendations provide local harm reduction programs with reliable information on how best to provide services that reduce the harms associated with substance use, including the onward transmission of hepatitis C and HIV.

In 2013, the Working Group on Best Practice for Harm Reduction Programs in Canada, a cross-Canada, multi-stakeholder team, released *Best Practice Recommendations for Canadian Harm Reduction Programs that Provide Service to People who Use Drugs and are at Risk of HIV, HCV and Other Harms: [Part 1](#)*.

Although earlier recommendations were released by some provinces, these new recommendations are the first to be developed for programs nationally. Part 2 of the best practice recommendations, which focuses on program models, testing and vaccination, first aid, referrals and counselling, and relationships with law enforcement and other organizations, is forthcoming in 2015.

Although it is important to have national-level recommendations on best practices in harm reduction, the release of such guidelines does not guarantee that they will be followed. Harm reduction services need to have maximum coverage, intensity and duration to have a significant impact on the transmission of hepatitis C and HIV among people who use drugs.

New hepatitis C treatments

Recent and continuing advances in hepatitis C treatment options allow a chronic disease to be cured in more than 90% of patients with three months of therapy for the first time in the history of modern medicine.(24) Historically, hepatitis C treatment has consisted of pegylated interferon (peg-interferon) and ribavirin, which cause difficult-to-manage side effects. Treatment has lasted for up to a year and has had low cure rates for some groups.

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Advances in hepatitis C treatment options allow a chronic disease to be cured in more than 90% of patients with three months of therapy.

Between 2012 and 2014, Health Canada approved new hepatitis C treatments, including some of the first interferon-free treatments as well as medications that are taken with peg-interferon and ribavirin. The new treatments that are taken as triple therapies with peg-interferon and ribavirin have higher cure rates, although the side effects caused by peg-interferon and ribavirin remain. Treatment times are, however, shorter. Even better, the interferon-free treatments have fewer side effects, very high cure rates in clinical trials and treatment lengths as short as eight weeks.

In the future, multiple interferon-free options will probably be available in Canada. Some of these new treatments are effective for people who have traditionally not done well on hepatitis C treatment, including people with cirrhosis, people who were previously treated, people who have had liver transplants and people co-infected with HIV. Treatment lengths may be as short as six weeks. This will probably have implications for how hepatitis C treatment is delivered.

New treatments will eventually be approved on provincial drug formularies with eligibility criteria, as current treatments are. It is not known whether the eligibility criteria for new treatments will be the same as those for current treatments or whether they will be different because new treatments are very costly, and it is likely that the criteria will vary from province to province. Questions about how these new treatments will be rolled out and who will be prioritized for treatment have yet to be answered. Quebec and British Columbia have both approved some of the new treatments and have issued specific guidelines for their use.

An integrated hepatitis C framework

An integrated hepatitis C framework seeks to improve engagement with, access to and seamless linkage to the full continuum of services required to reduce transmission of the hepatitis C virus and improve health outcomes for people with lived experience of hepatitis C. An integrated hepatitis C framework recognizes that hepatitis C prevention, screening and testing, treatment, and support services are mutually reinforcing elements of a comprehensive and effective response to hepatitis C. It can be used to develop new and enhance existing services to make linkages across programs more effective and efficient.

From a service user perspective, integration provides simplified access to services, comprehensive and tailored support, faster response times, improved user experience and improved health outcomes.(25) An integrated framework also seeks to enhance service user engagement with the continuum of services, particularly with prevention, testing and linkage to care.(26)

The U.S. CDC has outlined useful forms of integration that improve health outcomes and put the service user at the centre of hepatitis, HIV, sexually transmitted infection (STI) and tuberculosis care: *program collaboration* and *service integration*.(27)

Program collaboration is a form of integration where two or more programs develop “a mutually beneficial and well-defined relationship” to achieve common goals.(27) 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 and navigation across the continuum of care to offer complementary client-centred services. For an example of program collaboration, see

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[Chronic Health Navigation Program](#), a program that uses a team of navigators to link service users to and engage clients in prevention, testing, treatment and support services.

Service integration, the second type of integration, is a service delivery method that provides service users with seamless access to programs through one registration system and often co-locates resources under one roof.(27) This one-stop-shop approach aims to make it easier for service users to access services by providing a single point of entry.(27) For an example of service integration, see [Sanguen Health Centre](#), a clinic that provides comprehensive hepatitis C prevention, testing, treatment and support services.

The experiences of the service user are central to an integrated framework. Currently, healthcare delivery can be fragmented, which makes it difficult for service users to access the services they need. For example, hepatitis C treatment may be based in clinics or specialist offices, while support services may only be offered in community-based settings. This fragmentation is not intuitive from the service user's perspective and can create an unnecessarily complex network of programs and services that need to be navigated. This is particularly so for marginalized populations with limited connections to healthcare. Fragmentation can also create missed opportunities to provide needed resources and can lead to service user disengagement from care.

Proposed National Deliberative Dialogue on Integrated Hepatitis C Programming and Services

CATIE is hosting a *National Deliberative Dialogue on Integrated Hepatitis C Programming and Services* to explore how continuum of care models (prevention, testing, treatment and support) that build on the strengths of existing health services can be responsive to the unique needs of service users. In particular, we will explore the hepatitis C continuum of care models for specific populations, identifying promising directions in hepatitis C programming, services and policy.

Anticipated outcomes:

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

A national strategic directions document will synthesize key areas discussed, including priority directions and population-specific programming models, capture key understandings and tension points, and help inform good practices and new directions in client-centered public health, clinical services and programs. These directions will inform some of CATIE's ongoing knowledge exchange work in hepatitis C programming and shape the hepatitis C-focused areas of our national forum, *Making it Work: From Planning to Practice*, October 15-16, 2015.

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The process:

The *deliberative dialogue* will facilitate a process of:

- *thinking together* to reflect on how enhanced hepatitis C efforts might best address the unique needs of populations at risk for, and with lived experience of, hepatitis C
- exploring promising directions for integrated approaches within existing health services, such as HIV-specific services, clinical care, harm reduction, mental health, immigrant/newcomer health and sexual health

Ensuring an inclusive dialogue: We have selected 40 people to attend, including public health workers, clinicians, researchers, community members, and policy-makers, to reflect regional diversity and encourage a representative and inclusive discussion.

Ensuring a common understanding: CATIE is providing participants with the following materials so all participants come to the meeting with a common understanding of integrated hepatitis C programming and services:

- Agenda-at-a-glance with confirmed speakers
- Backgrounder: *Context for CATIE's National Deliberative Dialogue on Integrated Hepatitis C Programming and Services*. This backgrounder has been written in consultation with our partners. It provides context for, and outlines the key goals of, the deliberative dialogue.
- On-line hepatitis C presentations (Watching the presentations takes 90-120 minutes):
 - Surveillance and Epidemiology of Hepatitis C in Canada
 - Best practice Recommendations for Canadian Harm Reduction Programs that Provide Service to People who Use Drugs and are at risk for HIV, HCV, and Other Harms: Part 1 –
 - Hepatitis C in Migrants: An Underappreciated Group at Increased Risk
 - Sexual Transmission of Hepatitis C among Men who Have Sex with Men: A Brief Introduction
 - Hep C: New Therapies and Implications
 - Breaking Down the Barriers to Hepatitis C Virus Treatment among People who use Drugs (PWID): A Review of the 1st Set of International Recommendations

Why CATIE?

CATIE is Canada's source for up-to-date, unbiased information about HIV and hepatitis C. We connect people living with HIV or hepatitis C, at-risk communities, healthcare providers and community organizations with knowledge, resources and expertise to reduce transmission and improve quality of life.

As Canada's national hepatitis C and HIV knowledge broker, we have a long history of facilitating dialogue about issues relevant to our movement. We grew out of the early activist agenda of AIDS ACTION NOW!, which focused on the treatment needs of people living with HIV and highlighted government inaction on HIV research and policy.

In 2008, we integrated HIV prevention into our treatment mandate, understanding that a comprehensive approach to both would reduce the impact of HIV in our communities. In 2008, building on the lessons learned from HIV, we received hepatitis C funding and in 2010 expanded our mandate to include hepatitis C, acknowledging that hepatitis C and HIV affect similar communities and that an integrated response is more effective.

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In recent years, we have convened a number of national meetings with key stakeholders to discuss and share effective models of integration.

- In 2010, CATIE's first deliberative dialogue convened 40 stakeholders to discuss the expansion and integration of HIV prevention services for gay men into a broader context of sexual health.
- In 2012, CATIE's second deliberative dialogue convened 40 stakeholders to discuss the critical issues related to integrated HIV treatment and prevention approaches.
- In 2013, the CATIE Forum New Science, New Directions in HIV and HCV focused on the implementation of integration in frontline programs.

The 2015 deliberative dialogue will focus the discussion more deeply on the impact of integrated programs and service models on hepatitis C care.

The future of Canada's hepatitis C response: Questions for consideration

1. What do hepatitis C continuum of care models (prevention, testing, treatment and support) look like?
 - a. What do different approaches to service integration look like?
 - b. What do different approaches to program collaboration look like?
2. What makes integrated program models successful?
 - a. What are the key components?
 - b. How can program models be tailored to the needs of specific populations affected by HCV?
 - c. What can we learn from the experience of the HIV sector?
3. What are the key components of successful program models that are responsive to each of the populations considered?
 - a. In what ways can hepatitis C programming be integrated into existing population-specific organizations and programs?
 - b. In what ways can population-specific services be integrated into hepatitis C programming?
4. What are the priority directions to move these models forward?
 - a. How can barriers to an integrated hepatitis C care continuum be overcome?
 - i. At the service user level?
 - ii. At the provider level?
 - iii. At the structural level?
5. How will the increased use of more effective, better tolerated and shorter treatments impact practice?
 - a. How will the roles of healthcare providers be affected?
 - b. What will be the ongoing role of community-based organizations?
 - c. How can we increase opportunities for community and clinicians to work together?

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